

Article

Age, Autonomy, and Authority of Knowledge: Discursive Constructions of Youth Decision-Making Capacity and Parental Support in Transgender Minors' Accounts of Healthcare Access Journal of Adolescent Research I-29 © The Author(s) 2022 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/07435584221115351 journals.sagepub.com/home/jar

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Abstract

While access to care is known to improve health outcomes for transgender youth, these youth often face challenges in accessing care related to decision-making capacity and the legal limitations regarding age of consent. In this study, we utilize discourse analytic methods to identify how notions of age, autonomy, and authority of knowledge influence transgender youths'

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ability to make agentic decisions about their bodies and health, and better understand the power dynamics present in youths' relations with parents and providers. We conducted 11 one-on-one interviews with transgender youth between the ages of 13 to 17 and one focus group with high schoolage trans youth (n=8) in the Seattle-Tacoma area of Washington state. We identified two sets of discourses: (1) discourses of autonomy, which included self-determination, confidentiality, and authority of knowledge and (2) discourses of support, which included role ambiguity, trust/mistrust, and good and bad parents. Findings from this study highlight power dynamics present in trans youths' relations with parents and providers.

Keywords

transgender youth, consent, shared decision-making, access to care

Introduction

Transgender (henceforth, trans) adolescents in the U.S. today face intersecting forms of societal marginalization, discrimination, and stigmatization and are disproportionately impacted by disparate health outcomes and barriers in accessing care (Day et al., 2017; Gridley et al., 2016; Johns et al., 2019; Hughto et al., 2015; Johnson & Amella, 2014; Wilson et al., 2016). While access to care is known to improve health outcomes for these youth (Gridley et al., 2016; Tellier, 2019), trans youth often face challenges in accessing appropriate and affirming care that are related to decision-making capacity and legal limitations regarding age of consent (Clark & Virani, 2021). Trans health providers differ in their views about whether young people, who typically cannot give consent until the age of 18, are capable of making autonomous decisions about trans health interventions (e.g., puberty blockers, hormones, and surgeries). Parents of trans youth are also likely to have a range of reactions in response their child's transgender identity. Parental reactions—which range from feeling a sense of loss, viewing their child's gender-nonconformity as a phase, viewing the youth's gender identity as a symptom of a resolvable psychological issue, and psychologically or physically abusing the youth (Grossman et al., 2005; Katz-Wise et al., 2017; Riley et al., 2011; Tishelman et al., 2015)—heavily influence parental perspectives. Parents' self-identity may also influence decisions they make about which health interventions are needed and important in their children's care (Feudtner et al., 2018).

Within the provision of pediatric healthcare, generally, are tensions regarding a child's best interests, decision-making capacity, legal authority, and the limits of parental decision making (Clark & Virani, 2021). Except in the setting of abuse or neglect, parents are granted authoritative decisional power on behalf of legal minors to provide consent for health-related services because of their legal responsibility and the assumption that they will act in the best interests of their child (Kuther, 2003). While this notion of a child's best interest is socially constructed and conceptually vague, the "best interest" standard has become the legal and ethical standard for determining when state intervention is warranted in the care of children (Diekema, 2004). In contrast, Diekema's (2004) harm principle provides an alternative ethical framework to consider whether parental refusal of treatment merits state intervention and suggests that "the characteristic of parental decision-making that justifies interference is not that it is contrary to the child's best interest, but rather that the decision poses some harm to the child" (p. 250). Despite evidence of the harms of withholding treatments (e.g., suicidality, harassment, and use of non-prescription hormones), ethical concerns remain related to the determination of trans youths' best interests and their capacity and legal authority to both access and consent to medical intervention (Clark et al., 2020; Clark & Virani, 2021).

In practice, a young person's ability to consent to healthcare services is essentially triadic, with youth under 18, providers, and parents all involved in health decision-making processes. This practice is broadly defined as shared decision-making (SDM) and in the case of older children and adolescents (i.e., children 9 years and older) should include the assent of the patient, which gives consideration to each pediatric patient's capacity, or developmental maturation, for participating in decision-making (Katz & Webb, 2016; Kon & Morrison, 2018). While the American Academy of Pediatrics (AAP) endorses SDM as a central tenet of family-centered care, the degree of powersharing among youth and adults is variable and influenced by parental attitudes about children's ability to make autonomous decisions regarding their bodies and health, provider attitudes regarding the value of youths' perspectives when making medical decisions, providers' communicative skills to facilitate such conversations, and the degree to which youth feel safe and empowered to advocate for themselves in health care contexts (Katz & Webb, 2016). Additionally, the recent wave of anti-transgender legislation, which is more prevalent in some regions of the U.S. compared to others, is likely to influence how SDM is operationalized in the care of trans minors.

Furthermore, SDM presents unique challenges for adolescents who seek healthcare for issues that are frequently stigmatized and may evoke negative consequences if disclosed to parents (e.g., sexual and reproductive health services, substance use treatment and counseling, and psychiatric care), with some minors choosing to go without care rather than seek parental permission (Brawner & Sutton, 2018; Kuther, 2003). In most states, adolescents aged 13 to 18 are granted the authoritative decisional power to consent for healthcare-related to these specific concerns (Broome & Stieglitz, 1992). Giving legal minors the ability to consent autonomously in these circumstances is based on the belief that it ensures unconditional access to care for adolescents who might otherwise be impeded or dissuaded from seeking healthcare services (Brody & Waldron, 2000). However, no such provisions exist that address the unique needs of legal minors who seek healthcare for issues related to gender identity. In recent years, multiple legal scholars have advocated for capacity-based consent for treatment among transgender minors (Carroll, 2009; Ikuta, 2016; Romero & Reingold, 2013; Shield, 2007), yet limited research has explored decision-making processes and the construction of what constitutes "capacity" in the setting of transgender medicine, particularly when trans minors lack parental support.

Present Study

This analysis was conducted as part of a broader qualitative study, the purpose of which was to understand how trans youth under the age of 18 discursively manage their access to healthcare. In the primary analysis, we examined youths' accounts of navigating healthcare with the goals of (1) identifying the types of discourses youth encountered within healthcare about who they are and (2) better understanding how youth strategically employed language and narratives to navigate institutional systems and socio-structural processes in order to get their healthcare needs met. In the present analysis we utilize discourse analytic methods to identify how notions of age, autonomy, and authority of knowledge influence trans youths' ability to make agentic decisions about their bodies and health, and better understand the power dynamics present in youths' relations with parents and providers. Within the healthcare context, capacity is defined as "the degree to which [a patient] has the ability to understand a proposed therapy or procedure, including its risks, benefits, and alternatives; to communicate relevant questions; and to arrive at a decision consistent with [their] values" (Cummings & Mercurio, 2010, p. 252). As such, we focused on understanding how operationalizing consent in practice—what it stands for, who gets to execute it, and at which age—might impact youths' ability to access care, as well as identifying discursive constructions of decision-making capacity as they are applied specifically to trans minors. For example, how does one's ability, or lack of ability, to legally consent for health services and interventions impact trans minors' decisional

power to influence health-related decisions effectively made by adults? We gave particular attention to how consent was constructed in parent-child and patient-provider interactions and asked how youth, parents, and providers were constructed as knowledgeable and capable in SDM processes, including via informal conversations youth had with parents, particularly when youth were questioned about being sure of themselves.

Method

Analytic Framework

Discourse analytic theory and methods were used to guide the conduct and analysis of this study. Discourse analysis (DA) arises from within linguistic studies, literary criticism, and semiotic, performative theories of language (Starks & Trinidad, 2007). A discursive approach to research explores language as a "form of action" (Wilkinson & Kitzinger, 2000) and seeks to understand how individuals and institutions use language to create and enact identities and activities (Starks & Trinidad, 2007). DA is operationalized and conceptualized differently by different disciplines, and there is no one agreedupon approach or set of analytic steps considered uniform to discourse analysis. While linguistics focuses on the function and structure of words and phrases, critical social theory takes a different approach and looks at language as a social practice. It takes into consideration the context of language use and seeks to reveal and challenge existing power structures (McCloskey, 2008). Discourse analytic methods are often used to examine structural inequalities in healthcare, communication in healthcare contexts, health policy, and power dynamics in health service provision.

In the style of critical social theory, we adopted a Foucauldian definition of discourse in which the word discourse refers to "practices that systematically form the objects of which they speak" (Foucault, 1972, p. 49). Foucault's core concerns were discourse, power, and how social identities—what he termed "subject positions"—are constructed. Foucault's work was directed at entire systems of thought or "knowledge systems" (Hacking, 2004; e.g., medicine, religion, psychology, and law) and was concerned with the dynamics through which individuals become—or are forced to become—institutionally recognizable types of subjects (e.g., capable decision-makers). A discourse in Foucauldian terms is a body of knowledge that both constrains and enables what, in any given historical moment, we can write, speak, think, or ask about a given social object or practice (McHoul & Grace, 2015). A Foucauldian approach to discourse analysis examines the institutional and societal discourses that enable and constrain individual action at a particular

moment in time (Willig, 2008). Thus our focus was on understanding how the discourses we identify operate in use—for example, in SDM processes and within family structures—to facilitate or foreclose trans minors' opportunities to access healthcare in the ways that they wanted to.

Participants

We conducted 11 one-on-one interviews with trans youth between the ages of 13 and 17 and one focus group with high school-age trans youth (n=8) in the Seattle-Tacoma area of Washington state. Six parents of trans youth also participated in interviews with their children and discussed their experiences interacting with the health care system on behalf of their child. Flyers with information about this study and how to contact the researchers were posted electronically via online social media and social support groups. Printed materials were distributed at local organizations that serve youth (both LGBTQ+ specific and not) and at LGBTQ+ youth advocacy and community organizing events.

Ethical Considerations and Waiver of Parental Permission

Ethical approval was obtained from the University of Washington Institutional Review Board. A waiver of parental permission was obtained that permitted the enrollment of youth under age 18, both with and without parental involvement or consent. Requiring parental consent for participation in this study could promote a selection bias in favor of youth with supportive parents and could exclude youth who may not feel comfortable asking parents' permission or talking about their gender identities in the presence of parents (Flores et al., 2018; Taylor, 2008).

Youth interview participants who participated without a parent or guardian were advised to consult with a youth advocate. The youth advocate was a doctoral candidate in the Department of Epidemiology at the University of Washington School of Public Health with over 10 years of experience supporting and advocating for queer and trans youth. The youth advocate's role was to ensure that youth understood their rights as research participants and neutralize power dynamics between the interviewer and youth participants (Panfil et al., 2017). Of the seven youth interview participants who chose to participate without parental permission, three elected to have the youth advocate present. One youth requested her presence during the consent process but not during the interview, and two youth requested her presence during the consent process and interview. The youth advocate was present during the entirety of the focus group. All youth participants who participated with

parental permission were given the youth advocate's contact information during the consent process and encouraged to contact her with any questions or concerns. Consent was obtained from participants before the start of the focus group and each of the one-on-one interviews.

Data Collection

One-on-one interviews. Data collection occurred between November 2018 and September 2019. The principal investigator conducted in-depth, semi-structured interviews in person. Before interviews, he disclosed his transgender status to all participants and invited them to ask any questions they had about his experience or identity. This practice is consistent with discursive interviewing techniques, which are more informal conversational exchanges than other interviewing techniques and involve interviewers as active participants rather than positioning them as neutral "speaking questionnaires" (Kvale & Brinkmann, 2009, p. 156). Participants were asked about particularly memorable or pivotal healthcare encounters during which they felt that their gender was a factor in the quality of their interaction or central to how meaning was assigned to their particular health concern(s). The principal investigator is a pediatric emergency nurse with over 15 years of experience working with youth and LGBTQ+ populations. Interviews lasted between 60 and 120 minutes, were audio-recorded, deidentified, and transcribed by a professional transcriptionist. Youth participants received a US\$25 gift card for participating.

Focus groups. The focus group included youth who belonged to an existing support and discussion group for transgender and gender-nonconforming youth attending a single high school in the Seattle area. It was conducted in a private space at the hosting organization to ensure confidentiality and participant comfort. In addition to the youth advocate, the discussion group moderator—with whom focus group participants had existing positive relationships in which they are supported in their identities as queer and trans youth—was also present for the focus group discussion. Ground rules for discussion were co-created and agreed upon by participants before the start of the focus group. Following an introductory prompt via which participants were invited to reflect on their experiences with healthcare providers, the primary researcher facilitated interchange among participants to create a permissive environment for expressing personal, shared, and sometimes conflicting viewpoints regarding youths' encounters with healthcare systems. The focus group lasted approximately 90 minutes, was audio-recorded, deidentified, and transcribed

by a professional transcriptionist. Focus group participants received a US\$20 gift card.

Data Analysis

All youth participants were invited to participate as members of the data analysis team. Of the 11 participants who participated in one-on-one interviews, 2 chose to participate as data analysts. Given that discourse analysis focuses on how knowledge and truth are generated, and on the power relations embedded within discourses, we felt that the inclusion of youth in the data analysis and interpretation phases of this study was an important intervention for disrupting traditionally held power dynamics that situate research subjects as objects of study rather than as agentic co-creators of knowledge in the research process, particularly when those research subjects are legal minors. While this study did not adopt a community-based participatory research (CBPR) approach in the traditional sense, our decision to include youth in qualitative data analysis and interpretation is consistent with the tenets of youth-led participatory action research (YPAR), a type of CBPR that engages young people in conducting research to better understand issues and injustices that directly impact them (Ozer, 2016; Wallerstein et al., 2018).

Discourse analyses frequently start with a relatively small amount of data (Johnstone, 2018). It is possible, for example, to use a single person's narrative and compare it with extant texts. On the other hand, larger data sets can be helpful in understanding variations of language-in-use across individuals and settings (Starks & Trinidad, 2007). In the present analysis we were less concerned with the frequency with which particular discourses showed up in the text, and more with why and how they occurred in the data. We analyzed data from 12 total transcripts. These data included 28 speakers and a total of 162,637 words from 353 pages of text. Participants' accounts also included a large amount of shadowed data, meaning instances in which participants spoke of others' experience as well as their own, how their experience resembles or differs from others, and why (Morse, 2000). While Morse's concept of shadowed data is more relevant to phenomenological analyses of experience, we suggest that shadowed data in this instance provided some insight regarding the scope of discourses that trans youth encounter in their conversations with parents and providers.

Prior to the analysis phase of this project the primary researcher hosted three educational sessions for youth participant-researchers and the youth advocate, each of which lasted approximately 2 hours. The goals of these sessions were to situate discourse analysis epistemologically, understand the

types of knowledge it aims to produce and the role that discourse analysts perform in the research process. Prior to the analysis of interview data, analysts collectively participated in practice coding sessions using media texts. Notably, both youth participant-researchers had prior exposure to discourse analysis as it is employed in literary criticism and performative theories of language, particularly queer performativity (Milani, 2019). The analysis team was comprised of the primary researcher and interviewer, the youth advocate, two youth participant-researchers, and a senior researcher with experience conducting discourse analyses. Three members of the analysis team identified as transgender and two as cisgender. All of the data analysts were white.

We utilized Willig's (2008) framework for Foucauldian Discourse Analysis to guide the analytic process. The primary researcher was responsible for organizing the data and coding process. The analysis began with each analyst reading and rereading the transcripts carefully. The text was initially coded by multiple analysts, with each transcript being coded by at least two analysts. Codes were then reexamined and reviewed—read and reread line by line and word for word—in order to ensure that codes reflected the identification of the text that contributes to the discursive object. We then began grouping codes to identify discursive constructions related to participants' narratives (i.e., what they said and how they said it). During this process, the coding and discursive constructions were discussed by authors in-depth on multiple occasions. All voices were considered equally, and discord was viewed as an important opportunity to reflect on how our varying social positions (e.g., as trans individuals, as youth, as healthcare professionals, as researchers, etc.) informed how we differentially coded various segments of data. When disagreement occurred between researchers about coding individual segments of data, youths' analytic perspectives were privileged. The discursive constructions were then analyzed for identifying what Foucault refers to as discourses. At this stage of the analysis, we closely examined the discursive contexts in which the different constructions of the object were being deployed. Discursive constructions were then analyzed for the purpose of identifying broader discourses. The final stage of analysis involved a higher level of abstraction, in which we theorized the meaning of the discourses and the functions they served. At this stage of analysis, we integrated empirical literature to contextualize our findings within broader level discourses in the extant literature (e.g., self-determination). Discussions between the authors were continuous throughout the analytic process, which took place over a series of 3 months and was conducted via a back-and-forth approach rather than a linear manner.

Results

Participant Characteristics

Participants lived in various locations in Western Washington, including in both urban (n=9) and rural (n=2) settings. Rural versus urban designation was based on self-identification by participants. Participants represented a variety of gender identities including transgender male (n=6), transgender female (n=3), queer/gender non-conforming (n=1), and transmasculine/ FTM (n=1). During one-on-one interviews, participants discussed their experiences navigating various health services, including primary care, urgent care, psychotherapy, gender clinics/specialists, surgery, sexual and reproductive health services, nutrition, emergency medicine, laboratory, pharmacy, and school-based health services. All parents (n=6) who participated in interviews with their children discussed health insurance reimbursement. The majority of interview participants were White (91%; n=10). One participant was multiracial. A total of eight high school age (i.e., 13–17 years) youth participated in the focus group. We did not collect any individual information or identifiers for focus group participants. Focus group participants spoke about a diversity of topics. These included privacy and confidentiality in the healthcare context when youth lacked parental support, neurodiversity and the role of ableism in health service provision for trans youth, age restrictions on youths' ability to access transgender health-related services, and interventions, the use of trans-inclusive language in healthcare contexts, and the impact of gender dysphoria on other health issues.

Discourses of Autonomy

Self-determination. Broadly defined, self-determination refers to the process by which a person controls their own life (Ryan & Deci, 2017). Specific to trans individuals is the concept of gender self-determination, which Zimman (2017, p. 229) argues is made possible by a particular cultural framing of body and self, where "knowledge of the self is cast as something that can be accessed only by the individual in question." Gender self-determination diverges from other frameworks of knowledge of the mind, such as psychoanalysis, and challenges the historical framing of transsexuality, or transgenderism, as a diagnosis (Zimman, 2017).

Youth participants frequently recounted experiences in which they were denied the privilege to self-determine when and how they disclosed their transgender status. Parents, for example, did not always share youths'

particular safety concerns regarding when and how they disclosed their trans status to others—if they wanted to disclose at all. Youth participants spoke of situations in which parents required them to disclose to others before parents were willing to support them in accessing health interventions that facilitate medical gender transition or legal services aimed at changing youths' names and gender markers.

"[My mom's] first response was, 'fine, but you have to start coming out to people if you're doing this.' What I wanted to do was pursue hormones. I wanted to start hormones and not tell anyone and transition later. I wanted to get a few months in and just see where I was at and then go from there. And [my mom] was like, 'no, you have to put your money where your mouth is if you want to do this.' I was like, 'well, no.' But she didn't care, she dragged me to my aunt's house, who lives in the same neighborhood, and she was like, 'we're coming out to auntie right now.' And she did it for me, and I just went. And then she was like, 'cool, that's the first step. Now I will call and see if we can get an appointment [with the doctor].'" (Age 17)

Youth frequently talked about feeling the need to prove their genders to adults (i.e., parents and providers). The need to prove themselves to adults restricted youths' agency over the trajectories their transitions took, particularly concerning the conditions in which they could access health services. Historically the notion of gender transition has stood for a standardized trajectory of sex reassignment, in which individuals pass from psychiatrist to endocrinologist, to surgeon to judge, and where there is an assumption of a normalized endpoint (Carter, 2014; Rubin, 2003). However, since the 1990s, "transition" has been more frequently "deployed to refer to the ways in which people move across socially defined boundaries from an unchosen gender category" (Carter, 2014, p. 235). Below, a participant talks about a therapist's request that she start presenting as "female" before the initiation of hormone therapy.

"[The therapist] was like, 'you have to start presenting at some point if you want to do this. It's better to do it sooner rather than later. It makes your case stronger, and then by the time you're 16, we can start [hormones] immediately.' I was super resistant. I was very hung up and continued to be on the idea of passing and feeling like I have to be cis[gender] passing. I didn't want to transition unless I could be cis-passing. And I didn't want to present unless I could be cis-passing. I was like, 'I don't want to. It's scary. I'm not gonna pass. I don't see why I have to wear dresses for six months before you can give me hormones. Like is it gonna be safe?'" (Age 17)

Youth recalled experiences in which they encountered resistance—specifically because of their age and especially when they lacked parental support—when they requested name and gender changes in healthcare record systems. The ability to change one's name and be referred to with the correct name and pronouns was an issue not only of self-determination but also related to safety and confidentiality.

"I asked to change my name in the system – not even like change it legally. They just change your name so that when I'm in the hallway, I don't get outed [and then] I [don't] have to come up to them when they call my [dead/old] name. So I tried to do that, and [the doctor] was like, you can't do that. I'm like, actually I can. So I talked with my mom, and she called the doctor's office. It was kind of disrespectful that they thought because I was not 18, I don't know what I'm talking about". (Age 13)

Confidentiality. Youth expressed worry about parents learning of their transgender identities via institutions (e.g., school records and/or health records). Many participants were aware that parents might view the authority of institutions as more legitimate than that of their peers and that institutional support for their identities was more likely to provoke parental harassment or policing of their genders.

"Especially in an institutional context, I felt and continue to feel that if [my parents] hear [that I'm trans] from a friend, I can play it off as a different thing but specifically in the context of the university, of healthcare, of these institutional steps. . . I know that it would freak them out a lot that I was doing anything that looked like taking these steps without their participation and consent." (Age 17)

When youth lacked parental support for their identities, their experiences accessing health services were frequently characterized by hypervigilance about health information. This was particularly true when participants interacted with providers in primary care or urgent care clinics and where their health concerns both were and were not related to "transgender health issues" (e.g., chest binding, initiation of medications to facilitate medical gender transition). It was often unclear to both providers and youth what information parents can legally access or request from youths' health records. One participant, for example, sought evaluation for chest pain that he suspected might be related to chest binding. To ensure his transgender status was not inadvertently disclosed to his parents, he provided an alternative reason for his visit.

"I had given this line [about birth control] to the receptionist. I didn't exactly tell the receptionist, 'oh, just a second, I'm lying to my parents, and then I'm going to go into the doctor for a different thing.' I thought I saw [the doctor] put something about binding into the [electronic medical record]. I'm not necessarily in the habit of reading over doctor's shoulders and policing what they're putting down, but I was like, 'hey, did you just put down that I was binding? Because as I mentioned, I'm a closeted trans man whose parents cannot know that I was binding. So could you put down something else?' The doctor was like, 'okay, what else do you want me to put down?' I was like, 'wow, that was a close call.' My main concerns were specifically around my parents finding out that I was binding or like enacting trans-ness."' (Age 17)

The need for confidentiality also limited what youth felt they could share with medical and mental health providers when parents were present in clinical encounters. One participant, for example, recalled a visit with a provider during which her parents were also present in the room.

"It was kind of awkward. I felt like I couldn't be as truthful as I could if it was just — somehow, I wish it was just me and [the doctor]. Because there were some things that I wasn't sure about saying around my parents." (Age 16)

For some youth, the issue of confidentiality was further complicated when parents shared custody of participants, when participants lived in more than one home, and when youth had support from one parent but not from another. Concerns about unsupportive parents learning of youth's transgender status posed significant safety risks to some youth and other members of their families, such as siblings.

"At first when I lived with both of [my parents] back and forth, it sucked because [my mom] couldn't change [my name and gender marker] in the [health record] system because if [my dad] took me to the doctor he would find out and I wouldn't be in a safe position." (Age 13)

The need to withhold their transgender status from parents involved a great deal of deliberation about what settings were safe for youth to be themselves in and were characterized by evolving levels of precarity.

"It was hugely convoluted. In terms of binding, I was sometimes changing on campus, which was an event. I was asking people to use my name who were friends in certain spaces and not in certain other spaces and around certain people and not around certain other people. I was trying to be. . . as out in an institution that doesn't necessarily allow for partial outness as I could be

without actually having the chance of coming to [my mother's] attention. I was almost moved out [of my parents' house]. I was out in half of my classes. I had a folder of papers that had one name on them and a folder of papers that had another name on them. I was trying to do my best to make sure that [my mom] didn't encounter this folder. It was something that I was putting a ton of thought and energy into. Constantly I was like, 'okay, how can I do this? Can I afford to use this name in this space? When do I come out to the scholarship? When do I start moving in this direction knowing that I'm going to be living with my parents over the summer?'" (Age 17)

Authority of knowledge. Participants recounted a variety of experiences in which their authority of knowledge was questioned or discounted, specifically because of their age.

"I had heard generally negative things about trans people's interactions with doctors. I remember when I first started seeing therapists or when I first went to a gender doctor, or when I first saw my primary care provider again after coming out, I was very much on the defensive. You're ready to defend yourself. Especially if you're younger, I feel like you need to be ready to prove that you know enough." (Age 17)

In some cases, parents were willing to support their children's trans identities socially but were not willing to provide consent for initiation of medications aimed at facilitating medical gender transition. When parents expressed concern about their children's authority of knowledge, they often responded by seeking medical or psychiatric evaluation. In many cases, youth were ultimately able to garner parental support for their identities through the authority of knowledge performed by medical and mental health providers.

"When I came out to my parents, the first thing my mom said was, 'Well, we should go – we'll set up an appointment with the pediatrician and see what he says. . .what he thinks.' The idea was to get a recommendation for a therapist. They wanted a therapist to confirm if I was insane or something. They wanted someone to back them up that we should wait, which I'm so lucky that that didn't happen. Because if someone had said we should wait, that would have given my parents the backbone they needed to be like, 'yeah, we're waiting, this is what the therapist and the doctor said. You're 14. You don't know." (Age 17)

Discourses of Support

Role ambiguity. Participants' narratives often challenged dominant constructions of parent-child and patient-provider relationships in which parents and

providers tacitly understand children's needs and in which providers are constructed as benevolent and all-knowing. For many participants, this created a kind of role ambiguity in which they were at once required to be experts but not granted the authority of knowledge or decisional power that adults are granted. Participants recounted experiences in which they were frequently called upon to explain things to providers that cisgender youth generally are not, and they envisioned ideal patient-provider relationships in which this was not the case.

"I think that most trans people – I've heard this from trans people over and over again. I know just as much if not more about what I want than the doctors around me do. They don't know what I want my life to look like. I do. Every single time I've gone to a doctor for something gender related, I've known everything they were going to say to me. Because I've been reading about it since I was 13." (Age 17)

Many participants felt that they could trust other trans people—and collective transgender community knowledge, including information shared through online networks—more than they could trust providers. Provider lack of knowledge and role ambiguity often exacerbated the distress for which participants sought healthcare and past negative experiences with clinical providers caused lasting fear for many youth. To mitigate anticipated distress, participants often prepared for subpar clinical experiences by educating providers about their gender identities in advance of appointments. Even when youth and parents made significant attempts to ensure safe clinical environments, they were frequently met with ignorance about their identities and health needs.

"I had a panic attack before I went to the doctor, and my parents called [the doctor's office] and told them I was trans because I was freaking out about my primary provider deadnaming me. [The nurse] kept misgendering me, and I swear she used like all three different pronouns for me like within a span of 5 minutes." (Age 15)

Participants' narratives of parental involvement and support—or lack thereof—were also characterized by a similar kind of role ambiguity. For many youth, this involved explaining their health needs and experiences to parents. Parents' understandings of their children's health needs were often limited and some parents discounted the severity of distress that participants experienced. Youth participants frequently talked about their parents' views of interventions aimed at facilitating medical gender transition (e.g.,

hormones and surgeries) as fixing a problem. Youth struggled to help their parents understand the complexities of their need for ongoing support, whether or not they were interested in and able to access puberty blockers, hormones, and surgeries.

For many participants, parents did not outright reject their trans children but did not necessarily offer ongoing support either. This required youth to exercise a great deal of maturity and responsibility and to strategically navigate pathways for garnering parental consent for transgender-related health interventions. Youth participants felt ambivalence about being afforded some level of agency to advocate for themselves and also wished their parents might more overtly bolster their efforts to navigate the health care system.

"If I want to seek some transition thing, I will bring it up with my dad first and make sure he's on board. I feel like I can maybe potentially do stuff on the down-low without him knowing, but I would feel nervous about it. I try and make sure he's on board first, and then usually, I end up making the appointments for things. I like being able to have some independence and freedom to take care of things myself, but also I feel like sometimes I ask my dad to do things, and then he doesn't, and then I'm kind of forced to do it myself, which can be frustrating." (Age 15)

Youth frequently felt that they were called upon to assuage their parents' fears about the unknowns of treatment, and youth and parents often did not share the same fears. For some youth, this involved rectifying parents' misperceptions and fears about trans identity with youths' own need to be recognized. Some youth participants were explicitly harassed by parents about their transgender status or subjected to parents' arguments about not being "real" (i.e., "real men" or "real women").

"[My dad] tried to tell me that I would never — what he said was, 'You can't really be a woman. You'll just be trans, and I don't want that for you.' Then he got more specific too. He was really quiet, and he said, 'You can take hormones and dress however you want, but you'll never be able to have a clitoris.' I was like, 'Okay, (a) you're wrong, and (b) I don't understand what you're talking about. Why are you going here?' He doesn't know anything about this at all, and he totally was spitballing. It was really weird. I didn't even know how to respond to that or why he thought that that was a relevant thing to say." (Age 17)

Trust/mistrust. The role ambiguity that youth encountered often led them to feel that they could not trust providers' and/or parents' abilities to provide them with the support and care they needed. Participants talked about wanting to put their trust in adults but also feeling that they needed to protect their

emotional and physical safety. Youth spent significant amounts of time deliberating over how to share their experiences with adults in terms that would be most acceptable to parents and providers, and they felt caught up in a dynamic in which they necessarily relied on providers and/or parents because of their age but were often required to guide adults through conversations about their health and health needs. One youth spoke about how his experience as a transgender person of color complicated his willingness to put trust in medical and mental health providers.

"As a trans person and a person of color, it's the feeling that doctors are going to screw you over. As someone who has had experiences with being misgendered or dead named or being made vastly uncomfortable by doctors, I think that's definitely a big reason why I don't trust them. It's such a weird position to be in, and it makes me uncomfortable. I feel out of place. I felt really uncomfortable with [the doctor], and I think definitely right from the start, someone deadnaming me and misgendering me makes me even more uncomfortable with them." (Age 15)

Another participant spoke about how a previous negative experience—during which he was not provided all the information to make an informed decision about possible interventions for menstrual suppression—led to feelings of hypervigilance about having all the information when making decisions about his body and health in the future.

"I am often very nervous that [providers] will ask something, and I won't know the other alternatives. And I'll [consent] without realizing that is, in fact, bad, and I should not [consent]. . .because I don't have things like the internet at my disposal at the time [to vet my options]." (Age 15)

Fears about knowing all of one's options, as well as doubt about the degree to which participants could trust any given provider or practice, were echoed by several parent participants. When parents felt they were not able to protect their children or ensure safe clinical encounters, parents felt they had failed their children. Finding a "good provider" was framed as both an issue of healthcare consumption as well as an issue of healthcare navigation that required significant personal labor and was not possible for all families.

"I thought I was doing the right thing by identifying this provider that was called 'the gender clinic.' It was known supposedly for following the WPATH guidelines, and it supposedly had this board and was very progressive. I thought I was doing the right thing. There are a lot of privilege issues here. If I were this bamboozled, I can only imagine how youth without a parent to help navigate

this. . .oh my gosh, you know, where are they? How does a healthcare consumer figure out who to trust? Especially youth who don't have supportive parents. I wasn't able to find [my son] a good provider, and I analyze things for a living." (Parent)

Good and bad parents. Frequently, parents neither completely supported nor rejected their children, and the support they were able and willing to offer was dynamic. In many cases, parents' abilities to support their trans children evolved over time. Parent participants often discursively placed themselves and other parents of trans youth along a good-bad parent continuum. Parents who supported their children were seen as exemplary and unique, promoting a binary construction of good versus bad parents. All participants were aware that many transgender individuals experience explicit family rejection throughout their lifetimes and youth often contextualized their parents' degree of support within broader discourses of family rejection among transgender individuals. Several youth participants spoke about their experiences with "bad" parents who actively made efforts to prohibit their children from expressing their gender identities, particularly with regards to embodied change.

"Over the summer, my mom found my binder. I don't know if she even figured out what it was, but she definitely got rid of it and didn't mention it to me. I had to go figure it out myself. I felt like the reaction she would have had is, 'Hand over your binder. I'm getting rid of it. This isn't you. You're not allowed to do this."" (Age 17)

"Bad" parents were also constructed as those that used health issues as weapons, creating barriers to health care access to trans-specific health interventions. In these cases, parents were not constructed as permanently prohibiting their children from accessing certain health interventions but rather bartered with them or presented the youth with ultimatums.

"Some other things that I've seen used by adults as weapons or barriers for access – 'So we can't talk about trans stuff, we can't talk about transition until you put on weight until you stop taking a lot of drugs or until you go see a doctor. Until your mental health is in a good place." (Age 15)

Good parents, on the other hand, were overwhelmingly constructed as parents who explicitly supported their children's decision-making. Their narratives were characterized by a kind of power-sharing. Good parents supported their children's right to gender self-determination and frequently advocated on their children's behalf in medical and mental health contexts.

"My parents weren't going to be like, 'Oh, we aren't going to help you do this if you don't do it how we want to do it.' I've heard that from other trans people that I know. Like, they need to appease their parents. It's a barter or something. I knew in the end that it would be up to me, and I knew in the end that it was my decision, which I think a lot of trans young people don't get. I think that's a big part of like why I feel like I can talk to [my parents] about things." (Age 17)

Similarly, parent participants constructed their roles as good parents in terms of allowing their children to autonomously make decisions about their bodies and health and facilitating access to care when parental consent was required.

"I never felt that it was my place to dictate what [my children] did with their bodies. I think that's just been our approach. Like about sexuality or other things – once they get to be a certain age. . .when they're a teen, it's not really my business unless they want to share it with me or they want to know what I think." (Parent)

For some parents, the imperative to support their children was not immediately clear, but when confronted with data regarding negative health outcomes among transgender populations, parents' perspectives often shifted. One parent, for example, recounted a challenging time in his child's life in which he feared for his child's safety and wellbeing. This ultimately led to a shift in his mindset about how best to support his child.

"It suddenly became not about me. It was about what [my child] wanted. For me, that was a huge shift in my mindset. I'm not going to barter with him about some surgery. I was at a parent meeting, and we were talking about top surgery, and a parent said to me, 'Well, how do you feel about it?' I said, 'I haven't even really thought about how I feel about it. If [my child] needs this surgery, it's not about [what I think]."' (Parent)

Discussion

Findings from this study highlight power dynamics present in trans youths' relations with parents and providers, particularly related to youths' status as legal minors, that undermine trans youths' autonomy. On the one hand, trans youth were required to be sure of themselves in terms of gender, which made it necessary to perform a strong authority of knowledge. On the other hand, their abilities to make decisions about their bodies and health were often hindered by dominant perceptions of adolescents being too young to make

autonomous decisions about gender and healthcare more generally (i.e., they were constructed as incapable of making decisions about their gender and health). Presently, the gender-affirmative model of healthcare defines "gender health" as "a child's opportunity to live in the gender that feels most real or most comfortable to that child" (Hidalgo et al., 2013). While this may be attainable for some trans children, findings from this study problematize the notion that children are tacitly afforded the opportunity to choose which gender feels most real or most comfortable to them and suggest that a multitude of interpersonal and institutional factors influence youths' abilities to make choices about their genders and health and that the social environment in which youth are situated directly impacts how they manage their identities (Goffnett et al., 2022).

Many participants' options for expressing their genders with freedom from restriction, condemnation, or rejection were constrained in multiple healthcare contexts, specifically because of their lack of proximity to a consenting adult; notably, in this study, a cisgender adult. In many instances, youths' self-knowledge or capacity to make decisions about their bodies and health was not regarded with the same level of certainty with which parents' perspectives are generally regarded in medical decision-making about children's lives. Youth were frequently unable to access interventions which have been discursively framed in recent literature as "life-saving" interventions (e.g., mental health counseling, prescription of puberty blockers, hormones, and in some cases gender-affirming surgeries; Hughes et al., 2021). Yet these conditions were generally not regarded by providers in youths' accounts as harmful. When youth were able to access services without parental involvement, a lack of clarity regarding confidentiality and patient rights characterized their narratives. Laws vary from state to state, and guidelines that address the confidentiality of clinical encounters—such as in health records and explanation of benefits—are lacking as they apply to legal minors. Given that the vast majority of minors rely on parents as the primary source of payment or eligibility for medical care—through public or private insurance—this lack of clarity regarding confidentiality poses significant challenges to maintaining safety and confidentiality. As we found in our study potential threats to safety and confidentiality may produce feelings of stress, uncertainty, and anxiety that impact youths' mental and physical well-being.

While all legal minors are confronted with issues related to their age and decision-making capacity in healthcare contexts, our findings suggest that trans youth are confronted with unique issues specific to the construction of gender non-normativity. In this sense, trans youth are in a unique position—one characterized by a kind of institutional and societal ambivalence in which they are at once invited, if not required, to be certain of themselves in terms

of gender in order to demonstrate capacity—or developmental maturation but not granted the legal authority to make decisions about their bodies without the confirmation or authority of adults. With few exceptions, narratives of parental support were rarely constructed in binary terms and parental refusal of treatment for their children showed up both actively and passively. This suggests that parental acceptance/refusal exists on a spectrum of care and harm and adds to growing research demonstrating that characterizing families of trans youth as either affirming or rejecting is an over-simplification of the family environment (Catapla & McGuire, 2018; Goffnett et al., 2022). A recent qualitative study exploring family support among trans youth, for example, found that while most participants received general support (e.g., housing), gender-specific support was less common (Andrzejewski et al., 2021). Goffnett et al. (2022) have found that support for trans youth often varies amongst family members and that youth sometimes live in homes with both supportive and hostile members. Importantly, community ideologies present in the surrounding environment (e.g., regional politics and microlevel religious ideologies) also impact how family members treat trans youth (Goffnett et al., 2022).

In this study, parents had a variety of reactions to being taught and learning from their children, as well as different perspectives on power-sharing and autonomy related to parent-child dynamics. Parental reactions to their child's transgender status were often not static and evolved in understanding and support over time. These findings are consistent with existing studies that have investigated the transactional process of identity development between trans youth and their caregivers. Katz-Wise et al. (2017), for example, have demonstrated that "caregivers' efforts to make their children adhere to societal norms of gender presentation [are] rarely grounded in an intention to suppress gender identity but rather [are] motivated by a constant struggle to ensure their [children are] protected from judgment, hostile questioning, bullying, and harm" (p. 259).

Our findings reinforce results from other studies demonstrating that even when youth and parents share similar concerns regarding medical treatment, their perspectives about the risk and benefits of treatment are not always congruent (Lawlis et al., 2017). When youth and parents have differing perspectives regarding intervention in the form of puberty blockers, hormones, and/or surgeries, parents' fears of harassment, peer rejection, physical harm, and regret may lead parents to resist their child's ability to access transgender affirming care before reaching the legal age of consent (Janicka & Forcier, 2016; Lawlis et al., 2017). Participants in our study shared their desire to have access to medical and mental health providers who can help parents understand the impact of gender dysphoria, for example, within the broader

landscape of trans youths' lives. Such interventions may help to address some of the role ambiguity that frequently characterized participants' relations with parents and providers.

The construction of parent subjectivities in terms of good versus bad parents may ultimately alienate parents of trans youth who would most benefit from support and ongoing resources. Not all parents have the privilege of time, money, and health care access that frequently characterizes the narratives of parents of trans youth who are constructed as supportive. Unlike individuals from many other stigmatized groups (e.g., those who encounter bias, inequity, and discrimination based on race/ethnicity or socioeconomic status), trans individuals and their biological families do not characteristically possess a shared stigmatized identity (Klein & Golub, 2016). As a result, transgender individuals lack what has been termed "primary group member" support, which is the kind of support that a family member or significant other can provide when they have experienced and overcome similar stigma and discrimination (Simpson, 2018). This may contribute to the role ambiguity we identified among participants' narratives of support, as well as their feelings that parents often lagged behind them in their understanding of transgender-related health issues.

Limitations

There are limitations to this study, which should be considered when interpreting our findings. Participants were predominantly white, and thus the results may not represent the ways in which trans young people's authority of knowledge and decision-making capacity is constructed across racialist discourses embedded within healthcare and other institutional structures (e.g., the law). Notably, Willig's framework does not comprise a full analysis in the Foucauldian sense. In particular, the six stages of Willig's framework do not address Foucault's concern with historicity (i.e., historical actuality) and the evolution of discursive formations over time (i.e., their genealogy). Future discourse analyses seeking to better understand the construction of capacity in trans childhood might analyze constructions of the transgender child as an agentic decision maker throughout history (see, e.g., Gill-Peterson's *Histories of the Transgender Child*) or the construction of the child as a figure more generally (see, e.g., Castaneda's *Figurations*), particularly with regard to the intersections of race and gender.

Participants in our study represent a cross-section of the varied experiences of trans youth under age 18. There is a selection bias in favor of participants who were interested in sharing their accounts of healthcare access. This may not be inclusive of many trans youth who have reasons to believe they

cannot or should not share their stories—particularly those youth most likely to lack parental support who may fear for their safety if participation in a research study could risk unintended disclosure of their transgender status to parents. Additionally, given that participants predominantly lived in urbans areas where they are more likely have access to healthcare, our ability to draw parallels to experiences in other regions—specifically the Midwest and Southern U.S. where trans youth experience higher rates of discriminatory rhetoric and victimization (Kosciw et al., 2016)—is limited. Lastly, the construction of parent subjectivities identified via our analysis was limited to the reports of supportive parents and accounts from youth who interviewed without their parents present.

Implications

Future research is needed that includes the perspectives of parents resistant to their children's trans identities in order to more fully understand the complex family dynamics that many trans youth navigate and that impact their ability to safely access needed health care services. In the future, Diekema's harm principle (Diekema, 2004) may be helpful in making determinations about whether or not parental refusal of treatment for trans youth meets the threshold justifying state intervention. However, given that state intervention may be helpful for some trans adolescents and harmful for others, additional studies that locate the shared decision-making process as their sites of analyses are needed, particularly across state lines and healthcare systems. Researchers have highlighted barriers to performing informed consent among transgender adults, which are likely to be exacerbated in the case of trans minors. In settings lacking protocols and consensus, for example, healthcare providers have been found to "double down" on upholding medical authority and claims to expertise (Armstrong, 2003; Shuster, 2018). Such inconsistencies in the provision of transgender healthcare increase stigma in clinical encounters (Paine, 2018) and interfere with the degree to which collaborative decision-making operates in practice (Dewey, 2015). More research is needed that explores the perspectives of healthcare providers navigating shared decision-making processes with trans youth and their families to better understand how healthcare providers position themselves, how they encounter disagreements about treatment among youth and parents, and how they navigate consent and conversations about goals of care in these contexts.

As debates about the capacity, rights, and legal authority of trans minors to consent to treatment continue, several immediate and tangible practice changes should be adopted to mitigate the potential of harm, especially considering the complex power dynamics that youth in our study encountered in

their interactions with parents and providers: (1) Health record systems should be adapted to include patients' names and pronouns, particularly when patients' correct names differ from their legal names and when default pronouns are assumed based on sex assigned at birth, (2) clear and accessible information should be provided to youth under 18 about the extent to which health information can be kept confidential from parents/guardians, (3) peer support and patient advocates should be incorporated into clinical practice to assist youth and parents in navigating the complexities of healthcare systems, and (4) the availability of psychosocial support to parents of trans children should be increased, particularly when parents and youth have differing perspectives regarding goals of care.

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April Clark is a PhD student in Women's, Gender, and Sexuality Studies at SUNY Stony Brook. Her research explores and critiques contemporary developmental psychology regarding transgender young people, bringing together queer and feminist science studies, and trans of color critique.

Robin Hardwick is an undergraduate student at Reed College majoring in Sociology and minoring in Statistics. They hope to combine quantitative and qualitative research methods to explore how low socioeconomic status, LGBTQ+, and marginalized racial communities differ from expected social structures in ways that contribute positively to their success.

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