A Qualitative Study of Primary Care Physicians' Approaches to Caring for Adult Adopted Patients

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VISUAL ABSTRACT

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ABSTRACT

PURPOSE Adoption has lifelong health implications for 7.8 million adopted people and their families in the United States. The majority of adoptees have limited family medical history (LFMH). Primary care physicians (PCPs) rarely receive training about adoptees including their mental health needs and increased suicide risk. The growing availability and popularity of direct-to-consumer genetic testing kits amplifies the need for PCPs to be prepared to address genetic testing for adoptees with LFMH. This study explores PCP training and approaches to adult adopted patients with LFMH.

METHODS We used critical adoption studies as a theoretical framework for this study to understand how adoptive identity might shape clinical experiences. We recruited PCPs from Minnesota and Rhode Island via purposive, criteria-based, reputational sampling. We conducted hour-long semistructured qualitative interviews incorporating hypothetical clinical vignettes. Transcripts were coded via template organizing method and analyzed via Immersion-Crystallization.

RESULTS We interviewed 23 PCPs. They reported receiving little training or resources on adult adoptees with LFMH and showed substantial knowledge gaps regarding mental health and genetic testing for this population. Many failed to adjust history-taking and primary care approaches, which they recognized as potentially resulting in inaccuracies, inappropriate clinical care, and microaggressions while inadvertently triggering anxiety, shame, and distrust among patients. A mismatch between adopted patients' and physicians' understandings of family medical history could strain the therapeutic relationship. Nearly all interviewees viewed additional training to care for adult adoptees with LFMH as beneficial.

CONCLUSION Future research should expand education and training for PCPs on adult adoptees with LFMH.

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INTRODUCTION

Adoption has lifelong health implications for adopted people and their families.[1-3] In the United States, more than 7.8 million people are adopted.[4] The majority have limited access to their family medical history. Whereas there are many reasons patients might have limited family medical history (LFMH), legal and financial barriers can prevent adoptees from accessing their family medical histories.[5-7] Limited family medical history and an increased likelihood of adverse childhood experiences can challenge primary care physicians' (PCPs') ability to provide quality health care for adult adoptees.[8-13] For example, adoptees are 3.7 times more likely to report attempted suicide than their nonadopted siblings.[14] Pediatric research and clinical resources exist for adopted children with LFMH[15-18] but are lacking for adults. Although adoption bears lifelong implications for mental health,[8,9,14,19-25] identity formation,[26,27] medical management,[28-30] and reproductive decision making,[31-34] medical literature on caring for these patients is sparse.

Direct-to-consumer genetic testing has exploded in popularity in recent years.[4,35] Advertisements promise adoptees with LFMH answers to lifelong unknowns including parentage (and possible reunion), racial and ethnic identity, and health information they are otherwise unlikely to access.[4,35-37] Adopted patients want to discuss genetic testing with PCPs and are pursuing testing independently.[4,33,38,39] Consumers can purchase kits online without prescriptions or medical interpretation, amplifying the need for clinicians to address genetic testing, particularly for adult adopted patients with LFMH.

Patient narratives from adult adoptees with LFMH illustrate clinical encounters that trigger medical anxiety, shame, guilt, and distrust.[28,30,40] Yet, little research exists examining the training and perspectives of PCPs caring for adult adopted patients with LFMH.[30] This phenomenologic study explores how PCPs approach caring for these patients.

METHODS

Theoretical Framework

This project was informed by critical adoption studies (CAS), an interdisciplinary field rooted in feminist, queer, and critical race theories and defined by its interrogation of adoption and power, including how adoption knowledge is produced and how adoption intersects with multiple structural inequities.[41,42] Critical adoption studies examine adoption on both the macro and micro levels including how adoption professionals and clinicians engage with adoptees, adoptive families, and biological families.[41] We used CAS as a theoretical framework to understand how adoption might be a formative component of intersectional identity for patients,[30] develop interview questions, and guide data analysis.

Sample and Recruitment

We used purposive, criteria-based, reputational sampling for this study.[43] We distributed calls for participants to resident and attending physicians via e-mail lists for family medicine, internal medicine, and internal medicine-pediatrics residency programs affiliated with the Warren Alpert Medical School (Rhode Island) and the University of Minnesota Medical School (Minnesota) as well as the Rhode Island Medical Society, local chapters of the American Academy of Family Physicians, and the American College of Physicians. Calls were not disseminated to Minnesota medical societies, given their requirements for author residency. Participants must have completed medical school in the United States, be fluent in English, and be in residency or practicing primary care. After their interviews, participants were asked to recommend other PCPs with specific characteristics (medical specialty, years practicing, practice setting, patient panel demographics) to obtain sample breadth. Participants were invited to enter a raffle for a $100 Amazon gift card. This qualitative study received exempt approval by the Institutional Review Board of Brown University.

Instrument Development

Our interview guide incorporated concepts from CAS and a literature review on the knowledge, training, beliefs, and clinical approach of PCPs treating lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) patients,[44-46] mental health concerns,[47] and regarding genetic testing counseling[48] (Supplemental Appendix). The interview guide was refined with feedback by several stakeholders. The LGBTQ patient literature was relevant because these patients have important similarities to adult adoptees with LFMH; some of these similarities include experiencing variable recognition by health care providers (eg, coming out[30]), heterogeneous self-identification in a minority group, and a greater risk of attempted suicide,[49] with lifelong implications for care. Question topics were also developed from a review of published patient narratives,[28,40,50-52] studies,[8,14,53] and materials published by adoptee community organizations.[50]

Given this patient population's small number and broad dispersal, we expected that few PCPs would have treated large numbers of adult adoptees and might hesitate to participate in the study. Rather than exclude most PCPs with limited experience treating adoptees, PCPs were asked to imagine their treatment approach by responding to hypothetical clinical vignettes. This framing invited data collection about a small, understudied patient population while allowing PCPs to discuss any prior patient experiences. Open-ended questions and clinical vignettes explored PCPs' beliefs, training, knowledge, clinical approach, and self-reported competency about family medical history, adoption, mental health, and genetic testing.

Data Collection

We conducted semistructured individual interviews lasting approximately 60 minutes from July 2022 through January 2023 via Zoom (Zoom Video Communications, Inc) by author J.H.W., a female medical student and an adoptee with qualitative interview experience. She obtained consent electronically at the beginning of each interview. Zoom interview recordings automatically generated transcripts, which she reviewed manually and corrected errors. Deidentified transcripts were assigned a randomly generated number code and imported into NVivo qualitative coding software (Lumivero).

Data Analysis

We used an iterative multistage data analysis approach, which allowed for the detection of data saturation as it was reached. In the first stage, J.H.W. read transcripts via an open inductive coding approach. Next, the authors reviewed and refined the inductive code list to create a codebook with code definitions for use in the template organizing method.[54] The resulting codebook was developed from the initial data analysis and topics raised by the interview guide, existing literature on adoptees, and the CAS theoretical framework. Interview transcripts were coded by J.H.W. in batches of 5 using NVivo software. The codebook was reevaluated with each batch via close reading of transcripts to refine the codebook. Once coding was completed, we used a chunking technique—compiling and examining similarly coded paragraphs together by querying the coded data in NVivo—to facilitate further data analysis.[55] At this stage, we used the Immersion-Crystallization method to analyze the coded data by topic and to identify themes.[54,55] Throughout the process, the authors discussed emerging themes and reexamined the data until a final interpretation was reached.

RESULTS

We interviewed 23 PCPs (12 in Minnesota and 11 in Rhode Island) (Table 1). The majority were academic family medicine physicians who had practiced for several decades. Nearly all reported caring for an adopted patient in their careers, though most believed they constituted a very small subset (~5%) of their patients. Most PCPs described themselves as having personal connections to this patient population; 17 reported being close to someone adopted and 20 to someone with LFMH (Table 2). Interviewee comments revealed the following 3 primary themes. Representative quotes from participants are listed in Table 3.

Theme 1: PCPs Report Knowledge Gaps Regarding Adult Adoptees With LFMH and Want Guidance Regarding Appropriate Preventive Screening and Genetic Testing

Most interviewees reported receiving no training or resources about adults with adoption or LFMH. As one interviewee explained, "Until we had a discussion about it, I never even thought of this as something missing in our education. But it is." Most PCPs recognized their knowledge gaps for this population throughout the interviews. A few had received training about adopted children, which they found helpful context for adopted adults.

Participants with personal connections to adoption (having an adopted child, family member, or friend) identified these ties as influential to their understanding of adopted patients with LFMH. One PCP and adoptive parent stated, "Anything I know I know because I'm an adoptive parent, not that I received in my training at all. Sometimes I'm amazed when I take my kid to the doctor. The way they ask questions is so clueless. 'Sorry, did you not hear me when I said she was adopted?' I think people are just very oriented toward a certain way that they think about family." Several PCPs explained that their personal ties had also motivated them to seek formal training, typically limited to a single article or lecture rather than ongoing education about adoption and LFMH.

All PCPs interviewed expressed uncertainty regarding best practices and standards of care for adult adoptees with LFMH. Nearly all felt that additional training would be beneficial in addressing knowledge gaps, especially regarding preventive screening, genetic testing, and discussing adoption sensitively. Most identified medical school as the ideal setting to introduce an inclusive conceptualization of family. The

Table 1. Individual Participant Characteristics

Participant	State	Specialty	Setting	Years practicing medicine	Personal connection to:	
					Adoption	Limited family medical history
1	RI	Internal medicine-pediatrics	Academic nonprofit	24	No	Yes, friend
2	RI	Family medicine	Academic nonprofit	27	Yes, immediate family (child)	Yes, immediate family (child)
3	RI	Internal medicine (PCP)	Academic nonprofit	7	No	Yes
4	RI	Family medicine	Academic nonprofit	3	No	No
5	RI	Family medicine	Academic nonprofit	25	No	No
6	RI	Internal medicine (PCP)	Community nonprofit	42	Yes, immediate family (child)	Yes, immediate family (child)
7	RI	Family medicine	Community nonprofit	28	Yes, immediate family (child)	Yes, immediate family (child)
8	RI	Internal medicine (PCP)	Community for profit	23	Yes	Yes
9	RI	Internal medicine (PCP)	Community nonprofit	31	Yes, immediate family (child)	Yes, immediate family (child)
10	RI	Family medicine	Community nonprofit	38	Yes, friend	Yes, friend
11	RI	Internal medicine (PCP)	Community for profit	35	Yes	Yes
12	MN	Family medicine	Community for profit	39	Yes	Yes
13	MN	Family medicine	Community for profit	44	Yes, friend	Yes, friend
14	MN	Family medicine	Community for profit	20	Yes, friend	Yes
15	MN	Family medicine	Community nonprofit	39	Yes, immediate family (child)	Yes, immediate family (child)
16	MN	Family medicine	Community nonprofit	32	Yes, immediate family (child)	Yes, immediate family (child)
17	MN	Family medicine	Academic nonprofit	40	Yes, immediate family	Yes, immediate family
18	MN	Family medicine	Academic nonprofit	37	Yes, immediate family	Yes, immediate family (child)
19	MN	Family medicine	Academic nonprofit	4	No	No
20	MN	Family medicine	Community for profit	14	No	Yes
21	MN	Family medicine	Academic nonprofit	34	Yes	Yes
22	MN	Family medicine	Academic nonprofit	17	Yes, immediate family	Yes, immediate family
23	MN	Family medicine	Community nonprofit	27	Yes, immediate family (child)	Yes, immediate family (child)

MN = Minnesota; PCP = primary care physician; RI = Rhode Island.

few who did not endorse further training cited treating few adopted patients.

Despite knowledge gaps, most PCPs felt comfortable caring for this patient population. Some drew parallels to caring for immigrant and refugee patients, who often have some degree of LFMH, owing to limited access to health care, health literacy, or cultural beliefs regarding illness.[56]

Preventive Screening

Participants reported receiving little guidance regarding preventive screening for adopted patients with LFMH. Several PCPs observed that risk assessment algorithms for screening do not address LFMH, inviting variability. They expressed uncertainty regarding the appropriate time to begin screening and whether to offer additional tests or genetic testing for this population.

Most interviewees reported assigning adult adopted patients with LFMH to "average risk" for preventive screenings. Some reasoned that average risk was appropriate because family medical history is often inaccurate, citing confounders such as limited access to health care, limited health literacy, misattributed paternity, familial estrangement, and poverty.

Table 2. Summarized Participant Characteristics

Participants, No.	23
Years practicing medicine	
Mean	27.4
Minimum	3
Maximum	44
State distribution, No. (%)	
Minnesota	12 (52)
Rhode Island	11 (48)
Specialty, No. (%)	
Family medicine	17 (74)
Internal medicine (PCP)	5 (22)
Internal medicine-pediatrics	1 (4)
Practice setting, No. (%)	
Academic	10 (44)
For profit	6 (26)
Nonprofit	7 (30)
Personal connection to adoption, No. (%)	
Yes	17 (74)[a]
No	6 (26)
Personal connection to LFMH, No. (%)	
Yes	20 (87)
No	3 (13)

LFMH = limited family medical history; PCP = primary care physician.

[a] A total of 8 (35%) were parents who adopted (4 from Rhode Island, 4 from Minnesota), and 3 (13%) were siblings or aunt/uncle of adoptee.

Approximately one-third of PCPs, however, indicated having a lower threshold; screening patients with LFMH at earlier ages or working them up more promptly. As one PCP explained, "Just having the knowledge of a strong family history, we recommend counseling and the consideration of a genetic test. So in the absence of that knowledge I wouldn't be able to do that. I wouldn't think of it. This population won't get any enhanced surveillance if needed." These PCPs reasoned that patients with LFMH were less likely to receive family history–indicated screening, risking delayed diagnosis and more advanced disease. Alternately, some PCPs voiced concerns about earlier testing resulting in unnecessary interventions and anxiety. One interviewee mused, "Do I do early colon cancer screening? How am I approaching this? Every test that we do for patients can take on a life of its own, so there's that balance of not overscreening." Some PCPs remarked that LFMH could become a "risk factor for inadvertent health disparities" via exposure to either too much or too little testing. To some PCPs, this highlighted the need to engage these patients in shared decision making.

Genetic Testing

Participants' expressed knowledge gaps, variable familiarity, and requests for additional clinical guidance were most pronounced regarding genetic testing. Nearly all expressed uncertainty about the accuracy of direct-to-consumer genetic testing kits, health insurance coverage, downstream effects on life insurance, privacy concerns, and how to interpret results for the general population, much less for adoptees with LFMH. Many PCPs wondered if genetic testing—professional or direct-to-consumer kits—might offer benefits for adoptees and other patients with LFMH. Whereas PCPs felt comfortable initiating conversations regarding genetic testing, all indicated they would seek more training and refer these patients to a genetics counselor.

Theme 2: Mental Illness and Trauma Are Underrecognized and Underaddressed

The majority of interviewees reported limited knowledge regarding the effect of adoption on mental health. All commented on the heterogeneity of adopted people, adoption experiences, and the effect of adoption on adoptees. Many shared examples of adoptees from their practices and personal lives for whom the importance of adoptive identity varied significantly.

Many PCPs observed that the term "adoption" encompasses vastly different arrangements including adoption by extended family or a nonrelative, adoption from foster care or a private home mediated by adoption agencies, and adoption by parents of same or differing nationalities, races, or ethnicities. Participants noted that adoptions exist on a continuum of interaction between biological and adoptive families, ranging from no contact and court-sealed records to accessible records and regular contact.

The majority of interviewees recognized some relation between adoption and mental illness and identified preadoption factors, such as in utero or childhood exposure to trauma, substance use, neglect, older age at the time of adoption, and time in foster or institutional care, that might affect an adoptee's health. Some also recognized postadoption challenges including LFMH, complicated family dynamics, and identity formation, especially for transracial adoptions.

Many PCPs discussed adopted patients' potential to experience depression, anxiety, posttraumatic stress disorder,

Table 3. Illustrative Quotes

Themes	Quotes
Theme 1: PCPs report significant knowledge gaps regarding adult adoptees with LFMH and want guidance regarding appropriate preventive screening and genetic testing.	"In terms of formal resources we've had, I don't think there's ever really been any training, any continuing medical education or anything about how to approach [LFMH] with patients." (Participant 9)
	"I can't think of any training that I've had on this topic…I cannot think of a time when we have addressed adoption at all other than as an option for patients who are facing an unplanned pregnancy, and that's a different angle altogether." (Participant 21)
	"I don't think I've had any formal training or lectures or specific things on how to care for people who are adopted. I've learned about people who are adopted both from friends and from my clinical work over time, but not formal training." (Participant 5)
	"Most of [my training] comes from personal experience of raising an adopted child. So every bit was focused on care of the adopted child, not care of the adult who happens to be adopted as a kid. It's nonexistent, particularly for the adults." (Participant 7)
	"What do adult adoptees want from their primary care doctor? How much do I ask, what do I ask?" (Participant 14)
	"The differential is a little broader if you don't have the family medical history. But you don't want to pin everything on it because I've also taken care of patients who were raised by their biological family, and think that they know their family medical history, and there are surprises." (Participant 2)
	"I think it is a little more uncomfortable because you're guessing. Based on the US Preventive Services Task Force guidelines, in some ways it's easier because you don't need to personalize the risk factors. It's a little more difficult sometimes when you don't have the parents to check or ask." (Participant 10)
	"The idea of knowing everything about ourselves is a theoretical flaw…the idea of 'I want all the labs. Test me for everything.' People want more information, and so that extends to genetic testing, whatever 23andMe has done is activating the patient mindset that really pushes for 'Can you do a whole body scan?' Our responsibility as a PCP and one of the hardest parts of our job is figuring out when to stop doing things and trying to say no to people." (Participant 3)
	"Offering genetic testing, how reasonable is that? What is the standard of care? Does that really make a difference?" (Participant 22)
Theme 2: Mental illness and trauma are underrecognized and underaddressed.	"I think it makes people a little sad to not know their health history, their heritage. 'Why did my parents choose an adoption plan?' I think that's a difficult challenge in life to have to go through, even if you had wonderful adoptive parents. Even if they have really good reasons, it's still a challenge both in people I know personally and also in my patients." (Participant 22)
	"When you're adopted, you at some point are going to most likely be dealing with the question of why and abandonment issues, how those would play into anxiety and depression. It could be felt as a traumatic event [depending on how] the age would affect their understanding of it…a newborn baby it's gonna be felt differently. Possibly it's less easily recognized by the adoptee, the patient or the doctor. Let's say somebody was in an orphanage in another country with the experience there and then getting adopted. Did they meet more than one [set of adoptive parents]? Were they not accepted initially? [Did] they come through the foster care system where the parents could have been much more traumatic, some substance abuse, physical or mental neglect, or whatever leading to DCYF being involved, and then eventually going to different foster parents, and then becoming adopted. So there's so many different circumstances, but I think there's a big chance that people will feel at the end, and no matter what the circumstances is, 'How could my mother let me go?'" (Participant 11)
	"There are certain psychological and psychiatric challenges that adoptive adults might be more predisposed to from the experience of having been adopted. For kids, there is concern about attachment and trauma from whatever happened leading to the adoption that could have an impact on a person's health. Where were they between the time that the biological parents gave them up for adoption and the adoption itself? What kind of care did they get there?" (Participant 21)
	"There could have been trauma associated with why the biological parents are not the functional parents. Famine, pestilence, prostitution, all kinds of things that can get in the way. Lots of adoptions from areas that are war torn or famine torn. It would depend on how the adoptive child views their adoption. […If they] remember their first parents, or being in a foster home, and then they're placed in a new situation at age 10 or 12, that could be highly traumatic to the child." (Participant 10)
	"There's this grief that can be expressed in a lot of different ways, whether it's depression or posttraumatic stress disorder, anxiety, or a difficulty forming close bonds with others." (Participant 22)

continues

DCYF = Department of Children, Youth, and Families; LFMH = limited family medical history; PCP = primary care physician.

Table 3. Illustrative Quotes *(continued)*

Themes	Quotes
Subtheme: Adoption can be thought of as trauma, with minor opinions represented.	"That's exceptionally complex. But no matter what or when an individual person has their connection with someone severed, I have come to believe that there is trauma associated with that. There are trauma effects in utero, shortly after birth, regardless of how cognizant the individual is of it. There's no reason that we have to have a frontal lobe for it to be registered. So I really do believe that on some level, there is some trauma associated with that. How an individual absorbs it and how it manifests itself is different, but there is some." (Participant 16)
	"It'd be presumptuous to say that it is automatically trauma that someone other than your biological parents became the primary caregivers in your life. For a lot of people, that is probably one of the best [people] they would identify; those people are incredibly important." (Participant 1)
	"My instinct is to say no, because again I think it goes back to the circumstances around that adoption. If we really think about it, adoption is a beautiful thing, and it's a gift that it exists. If the circumstance around it was not trauma, was not abuse, if there were no adverse trauma adverse events that led up to the adoption, then I would say that, in general, adoption itself shouldn't be considered a trauma." (Participant 20)
Theme 3: PCPs often obtain family medical history imprecisely, risking miscommunication, microaggressions, and the patient-physician relationship.	"It's always anxiety provoking to go to the provider, and then [being] not sure how to answer questions. When they ask about family medical history…it's a moment of not really [being] sure how to answer a question. The assumption that I'm their mom doesn't acknowledge this other part of their story and it's not like saying I'm not their mom. There is a piece of wanting to honor both [moms]." (Participant 23)
	"I would hope that the way we're teaching medical students these days…lots of patients have families of all shapes and sizes and types, and they may not have access to a biological family history, and that's fine. You don't want to browbeat this so that you're making the patient feel bad or like they're different or weird or something that they don't have this information." (Participant 2)
	"Those who are adopted, or who don't have contact with their biological families would be so worried about what information they couldn't give me, and then I would just say, 'You're not alone. There's a lot of people who don't know their biological family's history.'" (Participant 16)

DCYF = Department of Children, Youth, and Families; LFMH = limited family medical history; PCP = primary care physician.

and reactive attachment disorder, as well as challenges with school, relationships, and identity formation. Several interviewees observed that adoptees experience discrimination, owing to adoption's stigmatization as inferior to biological kinship, especially for transracial adoptees who might be highly visible as an adoptee and a racial minority relative to their adoptive parents. One PCP reported several patients moving away because of bullying related to race and adoption.

Slightly more than one-quarter of PCPs did not endorse a relation between adoption and mental illness, although a few stipulated one between adoption and mental health. A few speculated that adopted people could have inherited a genetic predisposition to mental illness, which might have affected their birth parents, contributing to their decision to choose adoption.

Adoption and Trauma

Most PCPs recognized some association between adoption and trauma including preadoption (trauma resulting in removal from the home and subsequent adoption, trauma in foster care), adoption itself as inherently traumatic, or postadoption (stigmatization, identity challenges). All associated more time in foster care with greater exposure to trauma and more severe effects on mental health.

Primary care physicians were divided, however, as to whether adoption itself was inherently traumatic. Two-thirds of interviewees disagreed, believing the younger the adoptee at the time of the adoption, the lower the risk of mental illness. In contrast, one-third of PCPs, all of whom had personal ties to adoption, believed adoption to be an inherently traumatic event. Of these, the majority were adoptive parents, which influenced their beliefs. One PCP and adoptive parent shared, "This surprised me as an adoptive parent…the potential for adoption itself to be a potentially traumatic situation. Having thought of how much a child can understand—even in infancy when they're really young, having their environment changed, something that they were used to [taken] away from them, and then changed abruptly. I think that can be traumatic in ways that I hadn't really understood without having had the personal experience of being an adoptive parent."

Underutilization of Adoption-Specific Mental Health Resources

Although most interviewees recognized that adoption affects adoptee mental health, while responding to a hypothetical clinical vignette, one-half did not initially offer an adoption-specific resource (eg, therapist, support group, website) to adult adopted patients exhibiting signs of clinical depression. Whereas all PCPs stated that they would offer a referral to a therapist, only one-quarter indicated that they would attempt to refer an adopted patient specifically to a therapist experienced with adoption issues. Most were unaware of mental health professionals in their community specializing in adoption issues to whom they could

refer patients. In contrast, several PCPs regarded finding an adoption-competent therapist as unnecessary, believing all therapists have training in adoption. After prompting about adoption-specific resources, approximately one-half of the interviewees suggested peer-support resources (eg, community organizations), but only a few could name specific examples.

Theme 3: PCPs Often Obtain Family Medical History Imprecisely, Risking Miscommunication, Microaggressions, and the Patient-Physician Relationship

Most interviewees viewed family medical history as useful only in specific, limited scenarios and frequently questioned the accuracy of family medical histories. One PCP reflected, "In medical school it was talked about as being so important. Then in actual practice I found it less and less important. Medicine was so different back then, even what people were told that they had wasn't always what they really had. My grandfather was told that he was dying from tuberculosis, but he actually had lung cancer, but my grandmother didn't want him to know."

Nearly all PCPs demonstrated gathering family medical history imprecisely, which some interviewees reflected might contribute to misinformation in patient health records. Most PCPs reported asking patients about "your family," burdening patients to clarify between adoptive and biological families. Several described witnessing these miscommunications firsthand as parents of adopted children with LFMH, yet in their own practices did not adjust how they interviewed patients. As one PCP and adoptive parent shared, "I am guilty of not specifying [biological family]. It's possible I could be getting family medical history from relatives who are not biologically related or not picking up on if a patient doesn't know, and they just say 'no.'"

Most PCPs recognized the potential for family medical history taking to trigger complex emotions, including grief, anger, and ambiguous loss of biological family, in their adopted patients. Some reflected that equating "family" with biology could be dismissive to adoptive and stepfamilies and other important nonbiological relationships. Participants who were also adoptive parents recalled that these discussions raised issues of familial belonging and loyalty, causing distress for their own adopted children at medical appointments.

Participants also commented on the anxiety and frustration expressed by adoptees after being repeatedly asked about family medical history on questionnaires and during rooming and the interview. One explained, "All of our questions come off as a test. It's very worrying to people to not have answers to them. [Family medical history] is a source of anxiety. The fact that I asked it means that it's a piece of information that might have had some relevance that they don't have access to. So it's inevitable. I don't know how else [adoptees with LFMH] would take it."

DISCUSSION

Addressing Knowledge Gaps

Our findings suggest that PCPs receive little education about adopted patients with LFMH throughout their medical training, which is consistent with surveys indicating that adoption and foster care are rarely addressed during medical school.[57,58] The study set a low threshold for defining training on adoption or patients with LFMH received by participants, including both formal and informal, one-time and sustained learning, and institutionally and self-directed learning opportunities (eg, a coresident presenting on adoption and foster care, a workshop, or reading an article on adopted, pediatric patients). The true extent of PCP knowledge gaps regarding adoption is likely greater than was shown in this study, which oversampled PCPs with personal connections to adoption and LFMH, who are more likely to have received additional adoption education and be more motivated.

Adoption has often been viewed solely as a pediatric issue, and the American Academy of Pediatrics is the only medical society to address adoption.[12,17] This is reflected in our findings; although a few interviewees had training on adoption, it was limited to children. Research indicates, however, that adoptive identity often becomes more salient starting in early adulthood,[59] and guidance on adopted adults is scarce, thus failing to address the lifelong effects of adoption.[31]

Nearly all PCPs interviewed desired greater education on this population, particularly regarding inclusive family history taking, mental health, preventive screening, and the potential value of genetic testing, with implications for reproductive decision making. Absent formal training, physicians might draw on media narratives of adoption or personal experiences, creating considerable heterogeneity in PCPs' knowledge base. In psychology and social work, researchers have discussed the importance of deconstructing media narratives about adoption.[31,60] Clinicians with little knowledge of adoption might inadvertently commit microaggressions toward their patients such as perpetuating adoption stereotypes, minimizing adoption complexities, or invalidating adoptees' perspectives.[28,61,62] Primary care physicians with personal ties to adoption might assume that they understand an adopted patient's experience or engage in countertransference. Regardless, limited training contributes to suboptimal care and could harm the patient-physician relationship.

Adult adoptees with LFMH, like other patient populations who experience societal barriers with negative implications for health care, deserve improved clinician training and quality of care. Although adult adoptees with LFMH are a unique population, they share similarities with others from which adoption-competent primary care can be extrapolated.[63] Adoption-competent care includes trauma-informed care addressing ambiguous loss, disenfranchised grief, challenges with identity development, and helping members navigate biological search, reunion, or complex family dynamics.[63] Overlaps exist with the LGBTQ community (who are at increased risk of suicide and must also "come out" in health

care settings),[49] immigrant and refugee populations (who have an increased exposure to trauma and limited access to health care),[56] people estranged from their biological parents (who have LFMH),[64] and people born via gamete donor-conception (who face uncertain identities and legal obstacles to obtaining family medical history).[65,66] Improving PCP resources regarding adoptees could improve care for these groups as well.

Guidance on Preventive Screening and Genetic Testing

Although family medical history taking is a cost-effective screening tool for a variety of heritable diseases, many factors limit it including barriers to health care, low health literacy, cultural and personal beliefs around illness, circumstances of adoption and estrangement, incomplete penetrance, and variable expressivity.[67] As genetic testing becomes increasingly available, further research is needed to identify appropriate use of genetic testing. As more adoptees with LFMH pursue genetic testing, they will need informed guidance to meaningfully interpret the accuracy and clinical utility of their results.[68] Substantial PCP knowledge gaps must be addressed regarding genetic testing and the limited interpretability of test results for adoptees with LFMH including the potential for false reassurance, false-alarm unnecessary interventions,[68-70] and the potential effect on patients' privacy and life insurance. Our findings reiterate calls by the adoptee community for the development of clinical guidelines regarding adoptees and genetic testing.[4,37,52,53,71,72]

Mental Health

Our findings corroborate those of other studies indicating that mental health and trauma among adopted people might be underrecognized and underaddressed for many reasons including a shortage of adoption-competent mental health clinicians.[11,13,25] Interviewees' recognition of trauma and mental health concerns among people adopted at older ages or those who had experienced foster care did not correlate with understanding that adoption itself can be a source of trauma, even for those adopted as young children. This is consistent with psychological research that has historically conceptualized adoption as a unidimensional, positive intervention.[20,21,73] Although the debate about the inherent trauma of adoption remains unsettled in the psychology literature[20,21] and the adoptee community, a vocal subset of adoptees believes that adoption is an inherently traumatic event regardless of the age at adoption.[23,74] Primary care physicians who fail to consider adoption as potentially traumatic (eg, loss of identity, separation from caregivers) could invalidate adoptee patients' experiences, weakening the patient-physician relationship.

In addition, many PCPs in the present study did not prioritize referring to therapists knowledgeable on adoption issues, and few knew of such clinicians in their communities. Whereas some assumed that all psychologists and social workers are prepared to address adoption issues, less than 15% of graduate-level family and marriage therapy, social work, and counseling programs offer coursework on adoption; a national survey found that more than two-thirds of psychologists received no graduate coursework on adoption.[75-77] Many adoptee narratives describe substantial challenges to accessing adoption-competent mental health care including encountering therapists who knew little about adoption, were blatantly offensive, or were downright harmful (even fatal in several cases of attempted attachment therapy).[11,13,75,78,79]

Many adoption professionals and adoptee organizations have advocated for expanding adoption-competency curricula for mental health professionals regarding adoptees, birth families, and adoptive families. Whereas recent efforts have increased the accessibility of training, the availability of adoption-competent mental health professionals fails to meet the demand.[11]

Family Medical History Pitfalls

Our findings showing imprecise family medical history taking suggest that adult adoptees with LFMH might be at risk of receiving inappropriate screening because of miscommunication. The disconnect reported by interviewees between patient and physician understandings of family medical history has important implications for the adopted patient and physician relationship. Physicians' perception that family medical histories are often inaccurate and rarely contribute to medical management contrasts with patients' perception of family medical history as important, given the disproportionate time spent answering these questions and the frustration experienced by patients with LFMH who are unable to provide answers. Physicians must understand that adoptees with LFMH, like other patients, often believe that genetics and family medical history are predictive of their own health. Miscommunication and mismatched perceptions regarding family medical history might result in perceptions of PCPs as dismissive and failing to address the health needs of adopted patients with LFMH, consistent with published qualitative studies of the health care experiences of adult adoptees with LFMH.[13,30,40,51,71]

Our findings also show the potential for PCPs to exacerbate adoption stigmatization and create conflict when adoptees feel compelled to choose between their families. Longstanding approaches to family history, including language that assumes patients are biologically related to 2 heterosexual parents, might invalidate adoptive families.[60,61] Such adoption microaggressions can strain the patient-physician relationship, decreasing trust, delaying care, and worsening patient outcomes (Table 4).

Study Limitations

This study—one of the first exploring health care clinicians' approaches to the adult adoptee population—has several limitations. As noted by interviewees, adoptees are heterogeneous in their experiences, perspectives, access to family medical history, and desire for reunion with biological family or genetic testing. The study did not attempt to characterize subgroups of adoptees in its exploration of clinician approaches. Different subgroups of adoptees will likely

Table 4. Recommendations for PCPs

Ask open-ended questions.[31]
Avoid assumptions or judgement.
Assess how much information the patient wishes to know.
Normalize adoption and LFMH in health care settings including when reviewing patient questionnaires, interviewing.[16,28,31]
Reflect the terminology used by the adopted patient.[28,31]
Avoid unnecessary qualifiers (refer to adoptive parents as parents).
Avoid using terms like "real" or "natural" parents, instead use "biological" parents.
Do not assume reunion with biological family or "going back to [country]" is desired by or feasible for the adoptee.
Recognize the diversity in adoption processes (public vs private, open vs closed, domestic vs international).[16,28,31]
Be transparent about unknowns and offer to discuss what LFMH might mean for care.[28,31]
Use shared decision making regarding screening.[31]
Set realistic expectations, particularly regarding genetic testing and limits to interpretation.[69]
Refer to medical genetics counselor if possible.[69]
Recognize the relationship between adoption, mental health, and trauma.[16,31]
Screen for depression and anxiety, and refer to adoption-competent mental health providers.[28,31]
Listen to patients with LFMH, including adopted people.[28,31]

LFMH = limited family medical history; PCP = primary care physician.

Note: Some find the term "birth parents" offensive, with the perception that it minimizes preadoption parenting and decreases their role only to labor.

require different approaches to treatment and should be the focus of research informing adoptee care.

Our findings might not reflect the experiences of PCPs outside of Rhode Island and Minnesota or those of PCPs who did not participate in the study. Although we intended to recruit equally from family medicine, internal medicine, and internal medicine-pediatrics, three-quarters of our ultimate sample were family medicine physicians. In addition, the sample included only 1 resident physician, underrepresenting the trainee perspective. Furthermore, although advanced practice providers (physician associates and nurse practitioners) represent more than one-half of all primary care clinicians,[80] none were included in this study.

Despite interview questions focused on adopted adult patients, physicians trained in family medicine or dually trained in medicine-pediatrics often discussed experiences with their actual patients including adopted children. Given that clinicians cared for adoptees far less commonly than nonadopted patients, these comments were thought to be relevant to understanding PCPs' approach to adopted adults and were therefore included. Lastly, our reputational sampling method oversampled academic PCPs with personal connections to adoption, who were likely more aware of the health care implications of adoption and LFMH. They might practice differently from nonacademic physicians.

CONCLUSIONS

We found substantial gaps in knowledge, training, and resources among interviewed PCPs regarding adult adopted patients with LFMH. Practicing PCPs in this study exhibited heterogeneity in training and preparation to treat this population, and none had received what they considered to be sufficient training. This could result in miscommunication, inadvertent microaggressions, and undertreatment of physical and mental health challenges. Better medical education and guidance are needed regarding adult adopted patients with LFMH, especially regarding inclusive family medical history taking, adoption-competent mental health care, appropriate screening, and growing interest in genetic testing. These initiatives can contribute to much-needed improvements in primary care for adult adopted patients with LFMH, mitigating health care inequities. Future research on the care of adult adopted patients with LFMH should include the perspectives of PCPs without personal connections to adoption, medical trainees, and advanced practice providers. Further work should explore the views of adopted adult patients with LFMH on primary care and investigate cost-benefit analyses of genetic testing and its applicability toward personalizing care for this patient population.

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Key words: adoption; adoptee; limited family medical history; primary care; qualitative research; genetic testing; family medical history

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Supplemental materials

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