ORIGINAL PAPER

A Phenomenological Exploration of Families' Experiences of the Mental Health System of Care in the Monadnock Region

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Abstract

Accessing mental health treatment in rural locations is a unique challenge for families with youth experiencing adverse mental health conditions. Families often experience a variety of difficulties accessing and negotiating changes within the system of care. This study aimed to understand the experiences of families and their youth in navigating the mental health system in a rural community. Interpretative phenomenological analysis was used to examine how participants interpret their experiences within the local system of care. Qualitative interviews were conducted with eight families. Results included five main themes: youth experience, family experience, access to a system of care, relationships between stakeholders, and larger societal beliefs. Families highlighted their experiences accessing the local care system and their hope for strengthening community access and partnerships. Findings indicate that prioritizing family voices should be encouraged by local systems.

Keywords System of care · *Mental health care · Family* engagement · Youth mental health · Rural mental health

The number of youths requiring services from the mental health care system has grown exponentially in the United States. Research shows that nearly 1 in 5 children carry at least one mental health diagnosis (Whitney & Peterson, 2019). Along with this challenge of dealing with mental health, these children rely solely on their families and guardians to connect them to needed care. Issues of provider availability and access can influence the amount and quality of care youths receive. In rural settings, these issues may present more of a challenge when it comes to identifying and treating the mental health needs of children. Most recently, Whitney and Peterson (2019) found that 49.4% of children

with a mental health disorder did not receive needed treatment or counseling from a mental health professional. This basic level of care is imperative to the ability of local communities to prepare for financial and educational necessities to engage children with mental health diagnoses.

Youth taking part in mental health care systems are usually guided by the decision-making of their families and guardians. Family units are included in the decision-making process around youth mental health needs, including diagnostic testing, inpatient hospitalization, and medication utilization (Langer & Jensen-Doss, 2018). As families frequently engage with the mental health system, it is an added strength to have their insight as stakeholders in the mental health services process for youth. This level of involvement can be challenging in rural locations, suffering from scarce programming availability (Pullman et al., 2010).

Best practices within the system of care (SOC) paradigm include family participation in the planning and treatment of mental health care (Stroul & Friedman, 1996). Involving families in mental health treatment has been linked to positive outcomes for children, families, and communities (Mayberry & Hilifinger, 2012; Whitson et al., 2009). The positive effects of family participation in the SOC often continue to impact the community at large. Macgowan and Pennell (2002) found that families who partnered with programs and

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policymakers were often empowered to care for both their well-being and that of the community.

Although previous research has documented the benefits of family engagement in the mental health care system (Mayberry & Hilifinger, 2012; Whitson et al., 2009), little research has been devoted to exploring the experiences of families in rural locations. Rurally located families are more apt to experience specific challenges with engaging the local mental health systems, including limited access to inpatient settings, lack of mental and medical providers, and lack of proximity to treatment locations.

This study focused on developing a deeper understanding of how families experienced and were impacted by the mental health programs within the Monadnock Region System of Care (MRSC) in Cheshire County, New Hampshire. In this paper, we outline the challenges families face when interacting with systems of care. Attention is given to the influence of policy on the experience of family involvement and engagement.

Familial Mental Health and Stigma

Families of children with mental health challenges face numerous barriers to participating in mental health services. These barriers can include the child's level of functioning, the severity of behavioral and emotional symptoms, collaboration across providers, insurance status, and maternal mental health (Pfefferle & Spitznagel, 2009; January et al., 2015) found that the parents of children with mental health challenges frequently experienced increased stress and parental strain, in addition to difficulty navigating community-based systems designed to aid their families. Difficulties with navigating these symptoms may lead parents and guardians to feel blamed, judged, and criticized about the quality of their parenting and the possible role their parenting plays in the cause, exacerbation, or persistence of their child's mental health challenges (Eaton et al., 2016). The strain caused by the stigma of having a child with mental health concerns can isolate parents in powerful ways both socially and within the social service system.

Decision-Making

Many families of children with mental health care needs face considerable external challenges that make it difficult to navigate systems. This can include greater financial barriers, living in unsafe neighborhoods, challenges with the educational system, and more negative health plan experiences; thus, they are more likely to reduce their participation in programs for their child than families without as many external challenges (Busch & Barry, 2009; Porche et al.,

2016). Parents experiencing a series of internal and external stressors may be less involved in their child's mental health care. Butler et al. (2014) found that families of children who experienced mental health conditions or a combination of mental health and physical conditions were less likely to be included in shared decision-making as compared to children with physical conditions only.

Financial Barriers

Consequently, the most vulnerable populations of families within the mental health system may be the ones who have the least voice in their mental health care. Many communities have a shortage of availability and access to quality mental health services. While a lack of availability is a detriment to accessing service, the difficulty is compounded for families with lower levels of income, education, and health system engagement to gain entry to available systems. Pastore et al. (2012) identified several impediments to providing quality mental health care to clients with severe mental health disorders, including clients who have difficulty maneuvering the care system, establishing new client appointments, developing interpersonal relationships, or caring for complex mental health needs.

In 2011 mental health disorders were noted to be one of the five costliest conditions for youth in the U.S. ages 17 and under (Soni, 2014). Along with the national issue of cost, there are other widely felt barriers to mental health care for children. Busch and Barry (2009) indicated that a significant barrier to accessing treatment for children is a national shortage of child psychiatrists. In both urban and rural locations, there are fewer providers available to engage the number of youths in need of psychological testing and medication management. If a family cannot access care from qualified providers, satisfaction with care will inevitably decrease (Busch & Barry, 2009).

Policy

Funding and policy can also impact access to and quality of mental health services. Children's mental health policy reform has focused on the implementation and expansion of systems of care for the past several decades (Knitzer & Cooper, 2006). Although government agencies provide funding for mental health facilities and programs, funding is limited and often fluctuates with federal and state election cycles. The U.S. Department of Health and Human Services (DHHS) recognizes the need of protecting and supporting vulnerable families, and offers grants emphasizing community partnerships, wraparound service planning, and collaboration.

The SOC service design focuses on building meaningful partnerships between community-based services and the families of children at risk for mental health challenges. The philosophy is based on providing culturally competent, strengths-based services that privilege family voices in decision-making and support (Stroul et al., 2010). These principles are believed to lead to higher quality services, greater family involvement and empowerment, and increased functioning of family members at home, school, and in their communities (Munson et al., 2009; LaMont, 2013) examined the movement of many social service systems toward organizational collaboration that can support positive outcomes for the health and empowerment of children and their families. When well-structured, community-based wraparound programs prioritize the preferences of youth and families, it is reflected in the design and implementation of the plan of care (Bruns et al., 2013). The SOC model also privileges the voice and strength of the families, service providers, and the local community.

Family Engagement

Involving families in the mental health care of their children has been shown to improve their children's health outcomes and have important positive effects on both the family and the mental health care system (Oltean et al., 2020). Family participation is often labeled family involvement, collaboration, and empowerment, all of which engage families in treatment on a multitude of levels. Family involvement often includes Curtis and Singh's (1996) four-part definition of (a) engaging families in all aspects of treatment, (b) educating families about the services and systems in which they are involved, (c) including families in the process and progress of treatment, and (d) enlisting families in decision making. Family collaboration in mental health treatment has been shown to positively affect family involvement and satisfaction with mental health services (DeChillo et al., 1994; Singh et al., 1995) elaborated that empowerment within the familial structure is a process in which families improve upon their circumstances with knowledge, skills, and resources that help them overcome. Empowerment of the family from family advocates has been shown to improve key factors of treatment, such as service use, retention, parent self-efficacy, and parent knowledge (Gopalan et al., 2010).

Although there are a variety of ways to define family participation in the mental health care of youth, research consistently indicates benefits to families, children, service systems, and communities. January et al. (2015) elaborate that systems of care programs effectively reduce stress while greatly influencing parents' awareness of external supports and their well-being. It has been found that community-based coordination of care and interventions produce positive outcomes, such as improved individualized functions, reduced hospitalization, increased service retention, and overall cost savings (Bruns et al., 2015).

Early engagement of vulnerable family systems with collaborative interventions may decrease the risk of pervasive social and public health declines that can accumulate over the lifetime of these families (Repetti et al., 2002). Although the system of care design has positively impacted many families and communities, family engagement continues to be a challenge. *Family voice and choice* is a principle that emphasizes the central role families need to play in "making decisions throughout the wraparound process" (Bruns et al., 2010). Service providers, policymakers, and communities must collaborate to ensure the effective treatment of mental health for children and their families. It is critical that more training, support, and clear expectations for engaging families be available to primary healthcare providers (Tolan & Dodge, 2005).

Despite increasing recognition of the importance of understanding family voice, few qualitative studies of client experiences have been published (Ashworth et al., 2015; Lawrence & Lee, 2014; McManus et al., 2010; Lundkvist & Thastum, 2017). Scheer and Gavazzi (2009) called for more qualitative studies that capture the family voice to improve systems of care. The present qualitative study aimed to bridge the gap in the research and uplift the family voice by exploring the lived experiences of families receiving mental health services in the Monadnock Region.

Method

For this study, researchers explored how families experienced the mental health care services offered in the Monadnock Region and how those combined experiences create the essence of the local care system. Researchers utilized an interpretive phenomenological analysis method (IPA), with data collection via semi-structured interviews (Smith et al., 2009; Neubauer et al., 2019) elaborate that phenomenology works to describes a phenomenon by analyzing it through the lens of those impacted by it. These researchers summarize phenomenology as a study of lived experiences, thus making this concept a qualitative approach to data collection. Palinkas (2014) elaborated that qualitative methods create circumstances of more substantial validity in the finalization of data collection. Palinkas explained that by utilizing participant perspectives, researchers could compare their perspectives with those being studied. This creates a stronger foundation for the voices of these populations to be heard and supported, as this method will allow participants to be honest and feel validated in expressing their experiences. This method is comparable to methods utilized in

gathering information that expands upon community-based participatory research (Suarez- Balcazar, 2020). This is vital to understanding communal disparities while promoting meaningful participation in conversations about the community by its members.

Recruitment and Sample

The project manager of the MRSC grant collaborated with agency and school representatives to identify families willing to participate in this study. Researchers used purposive sampling to identify participants with shared characteristics, with later recruits added via snowballing sampling methods. Community contacts forwarded a description of the study to potential families along with the principal researcher's contact information. The families were responsible for contacting the principal researcher if they were interested in participating in the study. Researchers used earmarked funds from the MRSOC grant to provide financial remuneration of $20 per hour to family units for their participation. The study participants were eight families consisting of 11 youths, ages 9–21, where the youth were at risk of developing mental health disorders or had previously received a mental health disorder diagnosis (see Table 1). All participants identified as White and/or Caucasian and resided in eight different townships throughout the Monadnock region.

Data Collection

Two investigators interviewed family participants for 60–90 min using semi-structured interviews. These

Table 1 Demographics

	Families	Percentage
Ages of youth (n = 11)		
9–11	4	36.4
12–14	2	18.2
15–17	2	18.2
18–21	3	27.2
Income		
$0–30,000	3	37.5
$31,000–69,000	2	25
$ 70,000 and above	3	37.5
Township location		
Chesterfield	1	12.5
Greenfield	1	12.5
Jaffrey	1	12.5
Keene	3	37.5
Peterborough	1	12.5
Winchester	1	12.5

All participants identified as White

interviews focused on how families with at-risk children experience the MRSC. Before answering the interview questions, families completed a demographics questionnaire. The researchers ensured that the disclosure of privileged information could be conducted in a safe, protected, and voluntary setting in which the participant held power to seek additional support, request clarification, provide further explanation, review transcripts for accuracy, and, if necessary and for any reason, withdraw from the interview and research process. Minors were interviewed with permission, and in the presence of their parents in all cases. Interviews occurred at home and local clinic offices made available by the researchers' department of affiliation.

All personal information was de-identified by assigning a participant number, which was used for organizational purposes only. Audio recordings of all family interviews were transcribed for analysis. The investigators conducted in-vivo member checking by asking probing and follow-up questions to clarify responses and further develop a participant's description of their experience.
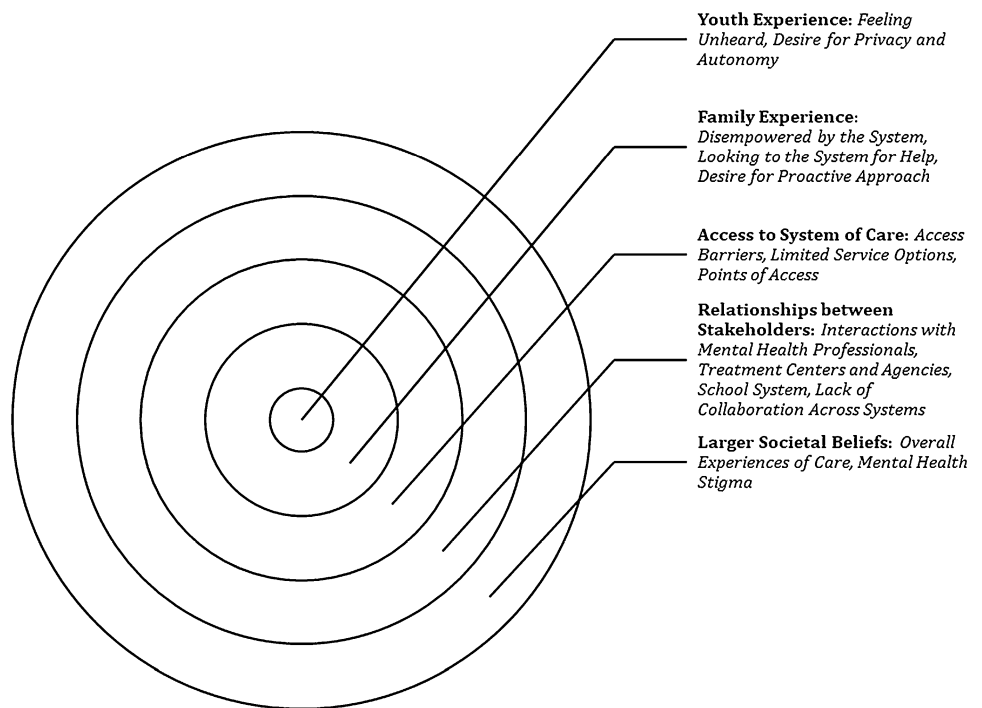
Data Analysis

Researchers used the IPA method described by Smith et al. (2009) to complete the data analysis process. Data analysis was conducted by three researchers, two of whom conducted all interviews, with analysis and triangulation taking place in subsequent phases with the primary researcher. Upon completion of the transcription analysis, themes were reorganized into main themes and subthemes. All transcribed results were shared with participants to ensure that family voices were captured accurately. Institutional review board (IRB) permission was granted to conduct this study by Antioch University New England. This research posed no known conflicts of interests. All authors certify responsibility for this manuscript.

Results

During the data analysis process, the clustered themes began to resemble Bronfenbrenner's ecological systems model (Bronfenbrenner, 1979). Bronfenbrenner theorized that the individual is at the center of a dynamic ecological system that connects and influences one another throughout one's lifespan (Gardiner & Kosmitzki, 2011). Bronfenbrenner's (1979) nested systems include the individual, microsystem (family), mesosystem (layer connecting family to exosystem), exosystem (community), and macrosystem (larger societal beliefs and messages). These nested systems emerged as clusters of themes within our data (Fig. 1). Five major themes and 14 subthemes emerged from the interviews: *Youth Experience, Family Experience, Access to*

Fig. 1 Results themes

Youth Experience: *Feeling Unheard, Desire for Privacy and Autonomy*

Family Experience: *Disempowered by the System, Looking to the System for Help, Desire for Proactive Approach*

Access to System of Care: *Access Barriers, Limited Service Options, Points of Access*

Relationships between Stakeholders: *Interactions with Mental Health Professionals, Treatment Centers and Agencies, School System, Lack of Collaboration Across Systems*

Larger Societal Beliefs: *Overall Experiences of Care, Mental Health Stigma*

System of Care, Relationships between Stakeholders, and Larger Societal Beliefs.

Theme 1: Youth Experience

The youth experience sits at the center of the ecological model and plays an integral part in the process. The two subthemes that emerged were *Feeling Unheard* and *Desire for Privacy and Autonomy.*

(a) *Feeling Unheard.* Youth and their caretakers described some of the challenges experienced by youth regarding mental wellness, including general mental health symptoms and negative feelings in response to the systems of care. Youth noted that when attempts to participate in the system of care were made, they felt silenced and/or unheard.

(b) *Desire for Privacy and Autonomy.* Privacy and autonomy were identified as important parts of youth treatment processes. Boundaries regarding agency and autonomy were reportedly violated, especially when youth felt mental health professionals were pushing them to reveal information too quickly. Youth valued their privacy and desired to maintain it throughout care, though this was difficult for caretakers who wanted to

be involved in treatment. Providers should consider empowering youth through engagement in youth support groups and services.

Theme 2: Family Experiences

The family system emerged as a second theme and included three subthemes: *Disempowered by the System, Looking to the System for Help*, and *Desire for Proactive Approach.*

(a) *Disempowered by the System.* While caretakers dealt with the stress and struggles of family life, they often felt disempowered at multiple points throughout the process. When meeting with professionals, parents reportedly believed their knowledge of the youth was unimportant, leaving them feeling unheard. Parents felt as though they had little power throughout the treatment process.

(b) *Looking to the System for Help.* Lingering feelings of fear, hope, and resilience propelled parents to seek help in the care system while also struggling with anger and fear of trusting the system. This was attributed to years of feeling disempowered by the system, not getting needs met by the system, or fear that there may be legal consequences involved.

(c) *Desire for Proactive Approach.* Many of the families identified the need for more proactive approaches to their care. Some felt that the more severe symptoms of stress could have been prevented with early support:

> So, if we're intervening with these kids, in their younger years, early elementary school, and giving them the services that they need. I'm not saying that the disability goes away, but the disability does not impact your education, your life... it doesn't have that big an impact, as when it's left untreated.

Theme 3: Access to System of Care

This third theme involves the connection between the family and the school, mental health professionals, and treatment centers. The subthemes include *Access Barriers, Limited-Service Options*, and *Points of Access.*

(a) *Access Barriers.* Families accessed care through various avenues but felt challenged throughout the process. Barriers to services include geographical, financial, and educational barriers. Some families spoke about moving to different states where services were more readily available. One family had to make decisions about keeping the family intact or moving to access services;

> So what's difficult about the placements is that they're all far away. And so, like when [child] was up in Jefferson, both those times. I was traveling up to see her on Saturdays and Sundays and it was a three-and-a-half-hour drive up and back.

(b) *Limited Service Options.* Almost all the families mentioned the lack of services, such as mental health, psychiatry, and medical care, as the main challenge in accessing care. Many attributed this to the lack of mental health care system funding. This absence of services impacts families struggling with managing their daily lives and trying to figure out how to access help. Accessing psychiatrists and mental health professionals was especially challenging for parents. The lack of psychiatrists in the area and long wait times make it difficult for professionals to spend adequate time with the youth, resulting in shortened appointment times and less care felt by the families.

(c) *Points of Access.* The families who eventually received services accessed them through medical providers, schools, legal systems, and insurance companies. Families described access to care through the severity of symptoms, with things becoming high risk before being able to receive help. Most families also accessed services through internet searches or word-of-mouth referrals. The families who received access to care through the school did so by either the school placing the youth in residential care or providing referrals for therapists. Families connected through the court system, noted the pathway created an emotional and financial burden for families.

Theme 4: Relationships Between Stakeholders

The fourth theme consists of various connections families experience as taking place within the ecosystem. Subthemes that emerged include *Interactions with Mental Health Professionals, Treatment Centers and Agencies, the School System*, and *Lack of Collaboration Across Systems.*

(a) *Interactions with Mental Health Professionals.* Parents and youth noted multiple interactions with mental health professionals over the years, including individual, couple, and family therapy. Families reported dissatisfaction primarily with psychiatrists, especially concerning medications and the importance of taking the time to sit with the youth to do a proper evaluation:

(b) *Interactions with Treatment Centers and Agencies.* When symptom severity required hospital and residential treatment centers, families generally felt dissatisfied with the services and the environment. Many families discussed their experiences with placement centers. Participants appeared to be ambivalent about the helpfulness of services, specifically connected to the skill level of service providers, and the structure of the placement environment.

(c) *School System.* One of the most salient themes that emerged from the interviews was the families' challenges with the school system. Families felt they had to fight with the school system to be heard and found it difficult to get youth-required services. Parents reportedly felt that some of the teachers, counselors, and staff lacked the necessary knowledge to handle mental health issues and, in some cases, escalated delicate situations involving the youth.

(d) *Lack of Collaboration Across Systems.* When families accessed providers in the system, they felt that communication between providers did not occur. Provider care felt disjointed, creating difficulty for families to receive clear answers and accurate diagnoses. Families described professionals as not being on the same page and, at times, disagreeing with one another, resulting in new plans and a feeling of starting again.

Theme 5: Larger Societal Beliefs

This final theme created a direct connection to macro-system views of mental health concerns for families. Subthemes include *Overall Experiences of Care* and *Mental Health Stigma*, which includes larger societal beliefs that the youth and families experience that influence their wellness.

(a) *Overall Experiences of Care.* All of the participants experienced general dissatisfaction with the overall MRSC. This dissatisfaction was felt on multiple levels as it related to aging out of the system, inability to meet the families' needs, lack of support, and feelings of frustration, stress, and anger.

(b) *Mental Health Stigma.* Stigma was noted as a barrier to families receiving care and support. Some families highlighted the difference in treatment received for physical health care versus mental health care. The stigma around mental health was further elaborated upon by parents when discussing the labeling of youth in society:

> He was already labeled a problem kid, a troubled teen. You know he carried a ton of labels, which destroyed his self-esteem...because once people keep telling you that's what you are, that's what you're going to be.

Discussion

This study aimed to develop a deeper understanding of how families experienced and were impacted by the mental health programs within the MRSC. This research amplifies family voices and in increasing the understanding of the needs of at-risk youth and their families. Though our findings are congruent with previous findings on the impact of family participation in the planning and treatment of mental health care (Bruns et al., 2010; Curtis and Singh, 1996; Gopalan et al., 2010), our findings from the youth shed new light on their experiences and engagement with the system of care.

Unlike the family unit, youth shared a common ideal of striving to develop autonomy and independence to develop outside of the constraints of their connection to the mental health care system. Though youth and family identify these systems as an integral part of family life, they sparingly identify these systems as places of welcoming connection. As these systems assist youth and families through crucial developmental stages as families adjust to mental illness, child development, and prospects of fulfilling future dreams, systems need to recognize the impact of their role as an extension of family development.

A specific finding from this research was identifying the many ecologically systemic barriers participants encountered when accessing mental health services in this rural location. Families indicated that the experience of utilizing care within the MRSC involved difficulties, including locational access to care, limited providers, and experiences of stigma. Along with other barriers to care, such as financial and insurance barriers, families echoed many common concerns experienced in rural healthcare systems. This is similar to other research findings by researchers who also explained that rural areas have experienced barriers preventing them from receiving quality mental health care (Jensen et al., 2020). Families' perceptions about youth accessing services through punitive interactions within schools and the legal systems speak specifically to the ecological connections families have to the multiple systems. The interconnected layout of these ecosystems will facilitate or impede the future stability of individuals and families living with mental health concerns.

Participants' responses alluded to poor relationships between stakeholder systems and the need for more collaboration between parties. The desire for structural changes to the delivery of mental health care within the system is important as it may shape the life and development of youth in the region. How youth with mental health concerns develop into adults will continue to impact local systems, particularly in areas of employment and education.

Implications

The present study has implications for structural changes in the MRSC. It is imperative that current systems make obtaining the input of community stakeholders a priority in structuring their plans for assisting youths and their families. Youth and families both have unique needs in advocating for themselves and their mental health needs. They should be given a platform more often to be heard and effect change in their local community systems. A continuation of this platform should allow community members to vocalize their needs and concerns to contribute to the availability of accessible resources.

Community-based resources should be provided to all members of the community to inform members of resources while aiming to inform and educate members of the community on the importance of mental health resources. Results concluded that lack of support from the education system and stigma were stressors experienced by parents within the community. If practitioners or local politicians can educate the community on the importance of these resources, there is a likelihood that schools and individuals within the community will adjust accordingly.

In addition to this, funding should be allotted to consider an increase in providing services to community

members. Accessibility was a primary concern addressed by parents within the study. If funding were provided, more mental health resources could be included within the community, allowing for parents to have more options to best assist their child's needs. Outside of external funding sources, local systems should find ways to financially prioritize activities that shed light on the needs of those they serve. This may include periodically including youth and family input in the development and restructuring of services through forums, community meetings, and surveys. Local systems should also take part in program evaluation measures to denote the outcomes of services provided. It is their duty to carefully examine the long-term influence their values, vision, and practice have on shaping the culture of the local community.

Limitations and Future Directions

As with all research, this study has its limitations. The purposive and snowball sampling method, which has some inbuilt limitations, shaped the population of this study. In this way, those who participated were self-motivated and had an active interest in sharing their families' experiences of the mental health system of care in the region. The participants' personal investments in sharing their experiences could have impacted the content of what they shared and how the narratives of their stories were constructed.

The small sample size for this research is consistent with the IPA in similar qualitative studies; however, it limits the generalizability of the findings. Also, the lack of diversity in the sampled population limited the experiences that the participants shared and the themes that emerged from the shared experiences. The Monadnock community is overwhelmingly racially homogeneous, with 95.5% of people identifying as White (U.S. Census Bureau, 2019). The participants' sociocultural experience may have impacted their narratives. Families from diverse racial and ethnic backgrounds living in a predominantly White county may experience further marginalization within this system. Exploring their experiences will be an important step in furthering the understanding of all families in the area.

Future directions should expand upon demographics as well as region. Further studies could expand upon current findings by interviewing others from various communities, especially urban communities when discussing financial restraints in affordable healthcare. Future studies should expand upon the family type as well. Future results may vary based on variations in family dynamics and familial structure. Additionally, future studies should consider the use of dialogic approaches, both as a research structure and as a means to arrange services to improve community based mental health service systems. This may include the use of group dialogues that include all stakeholders engaging in collaborative discussion to identify the need for accessible care, more shared decision making, coordination of services, individual preferences for services, and a way to invite the meaningful and ongoing inclusion of youth and family voices and choices into treatment. These future directions should continue to use techniques based on CBPR and phenomenology to allow other communities to elaborate their circumstances and worldview with a more flexible format.

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