

Family Perspectives on Pathways to Mental Health Care for Children and Youth in Rural Communities

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ABSTRACT: *Context:* There is insufficient literature documenting the mental health experiences and needs of rural communities, and a lack of focus on children in particular. This is of concern given that up to 20% of children and youth suffer from a diagnosable mental health problem. **Purpose:** This study examines issues of access to mental health care for children and youth in rural communities from the family perspective. **Methods:** In-depth interviews were conducted in rural Ontario, Canada, with 30 parents of children aged 3-17 who had been diagnosed with emotional and behavioral disorders. **Findings:** Interview data indicate 3 overall thematic areas that describe the main barriers and facilitators to care. These include personal, systemic, and environmental factors. Family members are constantly negotiating ongoing tension, struggle, and contradiction vis-à-vis their attempts to access and provide mental health care. Most factors identified as barriers are also, under different circumstances, facilitators. Analysis clustered around the contrasts, contradictions, and paradoxes present throughout the interviews. **Conclusions:** The route to mental health care for children in rural communities is complex, dynamic, and nonlinear, with multiple roadblocks. Although faced with multiple roadblocks, there are also several factors that help minimize these barriers.

Currently, there are as many as 10 million Canadians who can be considered rural residents—one third of all Canadians.¹ Children and their families in rural and northern communities may face more obstacles obtaining health services and supports than their urban counterparts.^{2,3} Problems of service access often result from geographic, economic, and cultural factors.^{4,5} In sparsely populated areas, travel expenses increase the costs of both providing and obtaining care. In addition, children from rural areas often must be

placed in residential care outside of their community because of the lack of resources within the community.⁶

Geographic and professional isolation make rural communities less attractive to mental health workers. It is difficult to recruit and retain specialists, who tend to concentrate in larger urban areas.⁷ Most rural communities are too small to sustain highly specialized personnel. Moreover, within the health research community, rural issues are often overlooked or dealt with generically. When rural perspectives are examined, it is frequently within the context of urban-rural differences, rather than as the sole focus of attention.⁸ When mental health is the focus, there is little literature documenting the mental health experiences and needs of rural communities, and a lack of focus on children and their families in particular.⁹

The purpose of this study is to examine issues of access to mental health care for children and youth in rural Canadian communities from the family perspective.

Canadian Health System. The Canadian health system is a publicly funded insurance program where

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costs are controlled, hospitals are nonprofit and doctors are private. Canada has a single insurance plan, or “single-payer,” in that each province pays the bills for everyone. One of the major differences between Canada and the United States is that in the US, ability to pay has a greater effect on the use of and access to services than in Canada. Each province has its own system and its own unique way of funding it. But, in spite of this decentralized approach, the provision of medical and hospital services to all Canadian citizens regardless of where they live or their economic means is something to which all provinces subscribe. Private practitioners are generally paid on a fee-for-service basis and submit their service claims directly to the provincial/territorial health insurance plan for payment. It is called single payer because there is only one “payer”; there is no alternative program, such as private health insurance, to which Canadians can turn for basic, medically necessary health care. The Canadian health care system ensures that all eligible residents have reasonable access to hospital and physician services on a prepaid basis, without direct charges at the point of service. In addition to hospital and physician services, provinces/territories also provide public coverage for other health services, including children’s mental health programs.

Methods

Qualitative in-depth interviews were conducted with 30 parents living in rural Ontario who had children, 3-17 years of age, formally diagnosed with an emotional and/or behavioral disorder. The criteria we used for inclusion regarding diagnoses was a formal mental health diagnosis as indicated by the children’s community mental health agency with which families were associated. Community focus groups were held in the 2 study sites for the purposes of promoting the research study and building local interest in the research, as well as assisting with sampling and recruitment strategies. Families meeting study inclusion criteria were approached by the staff of local community mental health agencies to gauge willingness to participate in the study. Those who expressed an interest in participating were then contacted by the research field worker in their area. A purposeful maximum variation sampling strategy^{10,11} informed participant selection to ensure key variables were represented (ie, child gender, age and diagnosis, region, frontline and managerial providers) and to capture a wide range of individuals, experiences, and events.

This research was based on an approach designed to have decision makers participate in all aspects of the study from implementation to dissemination. As such,

an advisory committee comprising service providers, academics, and health policymakers was put into place to guide the study. These stakeholders acted as ambassadors of the study and provided the local context to inform the investigative team. They also served a critical role in the dissemination of study processes and findings.

The definition of rural used in this study is based on the Statistics Canada definition, which refers to people living outside the commuting zones of larger urban centers, especially outside Census Metropolitan Areas (population of 100,000 or more) and Census Agglomerations (population of 10,000-99,999).¹² For this study, we utilized a distance of at least 50 km (31.07 miles) from Census Agglomerations.

Participants were recruited from rural areas of 2 regions in Ontario. The first was the catchment area around the city of Owen Sound in southwestern Ontario, which is one of the most rural districts in southern Ontario. The population of the catchment area served is approximately 150,000, with a total of 14,145 km² (8,789 square miles). Owen Sound is the largest center with the population of approximately 22,000 people. Distance is a big factor in service delivery. Poor winter driving conditions compound the problem. Residents must often travel out of the area for specialized medical services, which usually means a 5- or 6-hour round trip. Since there is no passenger train service and limited air and bus service, travel is mostly by private vehicles.

The second region was the catchment area of Sudbury, comprising a total population of slightly more than 150,000 over 5,398 km² (3,354 square miles). The great majority of the people reside in the City of Greater Sudbury. Outside the city, the population density is much lower. The francophone population accounts for about 28% of the total population. There are three hospitals in the Sudbury District, one of which is a fairly large community hospital with tertiary care capability. The other two are small rural hospitals.

Data Collection. Extensive field notes were taken throughout and were used in conjunction with data from interview transcripts. In-depth interviewing, described¹³ as a “directional conversation that elicits inner views of respondents’ lives as they portray their worlds, experiences and observations”^(p385) was used. A semistructured interview guide was developed and further refined with input from the study’s advisory committee. This guide included a cover sheet for basic demographic data for the participant group. Two trained field researchers, one from each study site, were hired to participate in varied aspects of the research, including recruitment, interviewing, data analysis, and

write up of the results. Both field researchers were trained at the graduate level and were familiar with qualitative methods and the mental health system. Individual interviews were conducted in an agreed-upon locale, the majority being the family home. In a few cases, interviews were conducted in the offices of local community centers. Interviews ranged in length from 1 to 2 hours. All interviews were audiotaped, transcribed verbatim, and converted into the format required for use with Ethnograph (Qualis Research Associates, Colorado Springs, Colo), a computer program for the analysis of text-based data. This program assists with the task of identifying, coding, and collecting segments in order to compare them, develop themes and propositions, and revise initial segmentation and coding decisions.

Analysis. The analysis of qualitative data involved utilization of a 7-step method.¹⁴ Each research team member (the principal and coprincipal investigators, the research coordinator, and the field researchers) examined all transcripts. Themes were identified and discussed, and a coding scheme was developed to reflect these themes. The team used the codebook developed as a result of the aforementioned processes to systematically review the textual data.

Results

The 30 family members interviewed for this study were primarily mothers (N = 24). The majority of the respondents were married (N = 25), and 18 were employed. Of the 30 family interviews, 3 had more than 1 child with a diagnosable mental health problem; therefore, our results account for a total of 35 children. The mean age of these children was 11.6 years (22 males, 13 females). Children with mood disorders, anxiety-related disorders, and oppositional-defiant disorders accounted for one half of the sample. Seventeen children were diagnosed with 2 (N = 11) or more (N = 6) comorbid disorders, while 17 children presented with single diagnoses (missing diagnosis on 1 child). Analysis of the interview data indicates 3 overall thematic areas that capture the main barriers and facilitators to care for children and youth in rural Ontario. These include personal, systemic, and environmental factors.

Personal Barriers to Access and Utilization

Stigma. Perceived stigma and lack of anonymity were identified by families as barriers to care for their children, often delaying or preventing access. Family members seeking services indicated that, due to the small size of rural communities, everybody knows

when mental health service is sought for a child. Consequently, they felt that it was safer to make visits to health care professionals at night. The stigma included being “labeled” or “pegged,” and families felt that once the label is conferred, it remains.

Although the small size of the community and the tendency for most individuals to be on a first-name basis contribute to difficulties in maintaining anonymity, it also plays a role in the positive intimate and close-knit feel of the community. The importance of “word of mouth” and the supportiveness of the community emerged as facilitators to mental health care (see Small Size and Word of Mouth sections below).

Lack of Information. Lack of awareness of the availability of mental health services was frequently mentioned as a service barrier. This occurred despite the work done by service providers to promote such awareness. In the words of one participant

It would be awful handy to have a place where somebody could actually open up a book and get their kid help from there ... actually steer me to where I can go. There isn't that ... leaves parents like myself wondering where do we go? What do we do?

Financial Difficulties. Accessing mental health care for children was clearly affected by monetary issues on a number of different levels. Unique to rural communities is the need to travel great distances to access care, which often entails having to take time off work as well as the costs of gas, wear and tear on the car, parking, meals, and sometimes hotel accommodation. One participant said

They were very good at giving me time off, but it meant no pay. And then if I ever wanted to apply for full time there, my record would not be that good. I was concerned about my work record so I was giving up any opportunities to be able to get help.

Personal Facilitators to Access and Utilization

Word of Mouth. The role of informal supports in facilitating access to mental health care was apparent. It was serendipitous that families discovered ways to access services for their children.

Word of mouth is like wildfire. It's the number one thing, it's word of mouth. Word of mouth is valuable, invaluable. Indispensable.

You have to find it yourself. I learned about Dr L. from a lady I work with who has two kids with disabilities. She got me going to Dr L.

Advocacy. Being a “squeaky wheel” often resulted in greater attention and facilitated entry to service. Some of the words used to describe this advocacy work by family members were “demanding,” “very vocal,” “fighting tooth and nail,” “convincing,” “getting angry,” “yelling and screaming,” “knocking down doors,” “raising Cain,” “being rude,” “persisting,” “bugging,” “go getting,” “pushing,” “calling around,” “researching it,” “writing letters,” “following up,” “complaining,” and “going to the top.” Families faced the inherent tension between advocating to obtain help for their child and being thought of as a “pain in the butt.” The latter was seen as possibly making things worse.

We were very vocal and people have hated me in that school from day one, I have no doubt.

Because they are overworked or overloaded or whatever, so if you don’t make a noise, you don’t get ... the squeaky wheel gets the oil, you know.

Parents acknowledged that they frequently did not get services because they did not push hard enough. This lack of advocacy was often the result of many factors, including personal style, lack of education, and lack of time due to work obligations, and the parenting of other children.

Systemic Barriers to Access and Utilization

Human Resources. A frequently cited systemic barrier to accessing children’s mental health care in rural communities was shortages of human resources. Recruitment and retention of children’s mental health specialists and the shortage of specialized services such as psychological testing contributed to long waiting lists and out-of-town referrals. Family members indicated that “any help at all would have been acceptable.” They were not necessarily looking for a child psychiatrist.

We are limited to a select few physicians who are horribly overloaded, overworked ...

Children were seen by a wide variety of practitioners. These visits were mostly “brief encounters” of just 1-3 sessions, with practitioners frequently concluding that the presenting problem was just a developmental phase. This was very frustrating for families because they knew that their child was not fine. The practitioners did not live day-to-day with the child, and families often felt that their expertise and experience were ignored or undervalued.

Policy and Funding Issues. Study participants indicated that federal, provincial, and local policies interfered with the ability to easily access services. Service programs often adhered to rigid intake criteria.

For example, the issue of age was often raised as a problem in service access.

Once she hit the magic age of 16, there’s nothing ... too young for adult service, too old for kid’s services.

I know other moms with kids who are between 16 and 18 and who are pulling their hair out. These kids are totally depressed, they are not going to school, and they’re addicted to drugs. They can’t get any help. None, you know? So, it’s really, really maddening living out here for this reason and I was thinking of moving for that sole reason ...

Waiting Time. Wait times for mental health services are pervasive in rural communities. All regions in the current study had waiting lists. The length of time spent on a wait list varied from a few months to 1-2 years.

For someone working in the field, a month just flies by. But for me, as a parent, dealing with a child everyday who doesn’t want to live and who doesn’t want to eat and who doesn’t go to school, you know, every day is a huge challenge.

Several participants were able to access mental health care more readily under certain conditions; at times of crisis, for example, if the child was a harm to itself or others or suicidal. In these cases, “jumping the queue” occurred.

In grade 2, [child] brought a knife to school. It was probably one of the best things she did because then other people got involved. People jumped up and said “what’s going on here?”

Invisibility. Many interviewees addressed the difficulty of dealing with children’s mental health issues. These problems are not physical, hence often not readily visible. This results in difficulties in accessing help for something that is not tangible. The importance of obtaining a diagnosis cannot be minimized. However, paradoxically, once labeled, there is the problem of lasting stigma.

People have more sympathy for people when they have a physical impairment and you can identify it when you look at them.

... and because it’s invisible, it’s hard for it to be looked at as a disability ... I wish there was more information for the public to understand ...

Systemic Facilitators to Access and Utilization
Delivery of Personalized Services. The characteristics and flexibility of rural service providers reduced personal, systemic, and environmental barriers such

as stigma, cultural differences, distance, and human resource shortages. Service providers were described as being “good people,” “good to us,” “open minded,” “taking time,” “going above and beyond the call of duty,” “being there when needed,” and “a real godsend.” Participants said there was a perceptible willingness to accommodate the needs of parents and children, to go where the family was located, to provide transportation to clients (personally or through volunteer drivers), and to make home visits and offer services on nights/weekends. This was often necessary in order to keep families engaged.

So I mean the clinic itself is phenomenal, her counselor is very good. He’s very nice. Thursday night I called him at his own home to talk to him to get some advice on what to do and he called back later in the evening to find out how she was doing. He’s very accessible. He’s told us actually right from the beginning that if there was any problems after-hours that we could call him at home ... He’s always been more than courteous and encouraging towards both of us.

Offering Services in Local Communities. The interviews suggested that services offered locally mitigate personal, systemic, and environmental barriers. In terms of personal barriers, it is less disruptive to families, more convenient, and there is greater acceptance of local programs. Hiring locally is also more culturally acceptable, and retention rates tend to be higher. Most importantly, local programs allow children to remain with their parents in the community. Furthermore, it is easier for a service provider to visit a number of families in their local community rather than have families go to a central office. It is helpful for service providers to see families in their natural environment. Home visits develop relationships between families and service providers, building trust and rapport. Local services allow for more intense delivery of services and deliver better care since one is accountable to local citizens, resulting in an increased commitment to the community. Finally, local service delivery decreases barriers to service (eg, by reducing long-distance traveling) and encourages program participation, particularly programs offered in schools.

Environmental Barriers to Access and Utilization
Distance. Families identified difficulties in accessing needed services located at great distances from their home communities. Access to out-of-town services was further hindered by adverse weather conditions in winter, travel costs, lost wages, and

lack of public or private transportation. Other difficulties include the assumption that families have a car, the added stress of travel, and the negative impact of an unfamiliar location on the child or parent(s).

Travelling is a barrier. Here, you can pretty much do it only in the summer. Sometimes, they expect you to go in the winter, and I have to tell them ‘sorry, I’m not a winter driver, I can’t do it’.

You’re exhausted taking a child to see someone on a two-hour drive. Well, they’re either exhausted by the time they get there or they’re all wound up. Like, it’s not their normal.

Environmental Facilitators to Access and Utilization

Small Size. Living in a small community can assist parents in their efforts to seek help for their children. An active community presence and long-established relationships with service providers lent credibility to parental claims that something was wrong with their child.

In one sense, it’s wonderful because it’s more personalized. The counselor will drive down and pick up your kid at school and take her out for lunch for her counseling.

There was also frequent mention of being on a first-name basis with other community residents. The natural emotional and practical support system in such communities was critical to sustaining good mental health.

Discussion and Recommendations

Recommendations made by the parents participating in this study were varied, but several common themes emerged including the need for local accessibility to services and supports, integration, early intervention, education and promotion, school and child care, parental support, and a rural approach to service delivery. Although some innovative programs exist in these rural communities, ostensibly to address the barriers described by family members in this study, they remain sporadic and underfunded. They do, however, offer an excellent platform from which to promote and expand existing successful intervention mechanisms. For example, in one community, the school system was integrated into the mental health system as the site of problem recognition and intervention. In the area where this occurred, family

members spoke of its success. In the United States, the *system of care* movement has been used in both rural and urban communities to overcome many of the barriers to mental health care.¹⁵⁻¹⁸ In response to this movement, innovative intervention programs for youth in rural communities have emerged that stress the reduction of stigma, the importance of home-based services, the involvement of children and youth in service planning and implementation, as well as the integration of family and community services sectors, for example, the child welfare, mental health, and education systems.¹⁵

The route to mental health care for children in rural communities is complex, constantly changing, and nonlinear. It is more like a labyrinth or a tangled web than a pathway. Although faced with multiple roadblocks, there are also factors that help minimize these barriers. Service providers and family members are constantly negotiating a web of ongoing tensions, struggles, and contradictions that permeate their attempts to access mental health care for children. We found Montgomery and Baxter's¹⁹ notion of "dialectic tension" useful when examining the competing thematic categories. Most factors identified as a barrier were also, under different circumstances, a facilitator. Our analysis clustered around the contrasts, contradictions, and paradoxes present throughout the interviews.

For example, the small size of communities was often mentioned as a reason for ease of access to care through word of mouth in a close-knit community. This notion of a more supportive rural community has been noted.²⁰ On the other hand, the small size of the community contributes to the lack of anonymity and concerns about stigma associated with mental illness. Particular challenges have been identified in maintaining anonymity and boundaries between service providers, family caregivers, and clients that may be significantly different from those found in an urban setting.²¹ Rural communities are thought to be especially apt to create stigma for mental health service clients and their families.²² This "glare of rural familiarity"²³ could contribute to the reluctance of some people to use mental health services. The fear of being seen is frequently an important issue related to the decision to avoid seeking mental health services.²⁴ In fact, stigma has been cited as one of the greatest obstacles to the treatment of mental illness.¹⁷ The World Psychiatric Association's global antistigma program has shown positive outcomes resulting from their process for setting up antistigma projects in local communities.¹⁸ This process includes establishing a local action committee, conducting a survey of sources

of stigma, selection of target groups, messages and media, and evaluation of the impact of interventions.

Rural communities clearly differ from urban communities in some respects. What works in facilitating access to children's mental health services in urban centers may not work in rural communities. In addition, the assumption of a rural homogeneous reality masks the diversity and uniqueness of rural communities. While emphasizing the common themes prevalent in family member narratives across different rural communities, we have attempted to highlight the richly textured experiences that each participant shared with us. It is hoped that future research in this area will also recognize the rich narratives that family members can provide regarding their access to mental health care.

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