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Hurry up and wait. The experiences of young women in rural Nova Scotia accessing specialized care

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Introduction: This study explored experiences of waiting to access specialized health care among young women living in selected rural communities on the south shore of Nova Scotia. We asked women about the challenges they faced during wait times and how they perceived the impact of these experiences on their health.
Methods: We conducted qualitative interviews with 10 women aged 21–37 years. We used thematic analysis to identify common experiences among participants.
Results: Some women expressed feelings of frustration about waiting, but others resigned themselves to the wait. Women reported challenges such as caregiving for ailing family members who waited for care. Some women took control of their situation by accessing private health care or what they called "the next best thing" (e.g., care from alternative health providers), although in some cases this was financially costly. A few women sought assistance through support networks. Many women reported that wait times affected their health.
Conclusion: Our results support previous research indicating that young rural women's caregiving roles and support networks influence their experiences with wait times. Our research indicates that waiting to access specialized care can be financially costly for some women and may also affect their health.

Introduction : Cette étude a analysé les expériences vécues par de jeunes femmes vivant dans des communautés rurales choisies de la côte Sud de la Nouvelle-Écosse au chapitre de l'attente pour accéder à des soins de santé spécialisés. Nous avons interrogé les femmes au sujet des difficultés qu'elles ont rencontrées durant ces périodes d'attente et nous leur avons demandé comment elles en percevaient l'impact sur leur santé.
Méthodes : Nous avons réalisé des entrevues qualitatives auprès de 10 femmes âgées de 21 à 37 ans. Nous avons utilisé l'analyse thématique pour relever les expériences communes entre les participantes.
Résultats : Certaines femmes ont exprimé des sentiments de frustration vis-à-vis de l'attente, mais d'autres s'y sont résignées. Les femmes ont entre autre fait état de difficultés telles que prendre soin d'un proche malade en attente de services. Certaines ont pris le contrôle de leur situation en accédant à des soins de santé privés ou à ce qu'elles ont qualifié de « meilleure solution de rechange » (p. ex., soins dispensés par des professionnels des médecines douces), bien que dans certains cas, cela se soit révélé coûteux. Quelques femmes se sont tournées vers des réseaux de soutien. Nombreuses sont celles qui ont déclaré que les temps d'attente avaient nui à leur santé.
Conclusion : Nos résultats confirment les résultats de travaux antérieurs selon lesquels le rôle d'aidante des jeunes femmes des milieux ruraux et leurs réseaux de soutien influent sur leurs expériences face aux temps d'attente. Notre recherche indique que l'attente pour l'accès à des soins spécialisés peut se révéler coûteuse pour certaines femmes et qu'elle peut également affecter leur santé.

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INTRODUCTION

Waiting to access specialized health care is an increasingly common experience for Canadians.[1] Owing in part to the complex needs for health care associated with high rates of chronic disease in the Canadian population, specialized health care services are subject to greater demand than the health care system is currently able to meet.[2] Patients referred to specialized health care providers, such as specialist physicians and psychologists, are often placed on waiting lists, and their priority status is based on need. The measure and reduction of wait times are currently key priorities for the Canadian government, yet waiting to access specialized care continues to be a reality for many Canadians.[1]

There exists a lack of research exploring patients' experiences of wait times and how waiting may affect their lives. Understanding these experiences is critical, especially because wait times may have a detrimental effect on the physical and emotional health of patients and families.[3] Among Canada's rural population, young women report particularly poor health outcomes, which may result in greater use of specialized health care services, thus adding to the imperative to understand their experiences with wait times.[4–6] Research indicates that young rural women may have unique experiences with wait times because they typically carry more of the burden of unpaid caregiving than rural men and often find themselves providing care for ailing family members while they await care.[7–11] Low socioeconomic status may add to the challenges associated with wait times if a woman is unwell and cannot afford to pay for child care and other support services.[12,13]

This research explores the experiences of young rural women as they waited for specialized care for themselves or a family member, strategies they developed to deal with waiting to access specialized health care and how they perceived the effects of their experiences on their physical and emotional health. Implications for programming, policy and practice are discussed.

METHODS

Recruitment and data collection

Eligible participants included English-speaking rural women aged 18–39 years who had accessed specialized health care for themselves or members of their families within the previous 12 months. We chose the 18–39 age range to explore a diversity of experiences among women who may be responsible for the care of young families as well as older parents, and who may be experiencing the demands of employment outside the home in addition to unpaid caregiving responsibilities.[9] For the purposes of this study, "rural" was defined as a region with a population of 10 000 or less.[14] Participants were recruited from several rural communities within the South Shore District Health Authority of Nova Scotia. This district serves about 60 000 residents and spans a distance of 100–150 km from Halifax, NS, where the nearest tertiary care hospital is located. We recruited participants using posters and newspaper advertisements, and by speaking to local health professionals and other key informants about the study and having them pass the information to potential participants. A purposeful sampling strategy using screening questions allowed us to ensure we collected data from a diverse sample of women who had different experiences with accessing specialized health care. This sample included women who accessed locally provided care and women who travelled to the nearest tertiary care centre, as well as women who accessed care for themselves and women who helped a family member access care.

Before recruitment of participants, this study was approved by the Dalhousie University Research Ethics Board.

Data were collected using a semistructured interview guide. The questions for the interview guide were developed based on an extensive literature review of young rural women's access to health care. The interview guide was pretested with 2 young women who had experiences with accessing specialized health care from a rural area. All interviews were face-to-face. Interview questions were designed to ask women to describe their experiences with accessing specialized health care, including some of the challenges they faced, support services they relied on to help them access care and how they perceived the effects of these experiences on their health. Interviews were about 1–1.5 hours in duration and were audiotaped with participants' consent. In addition, participants completed a brief sociodemographic survey. This survey included questions about participants' age, marital status, whether they had children, employment status and approximate annual household income.

Data analysis

The interview audiotapes were transcribed verbatim by either the first author (J.H.) or by an experi-

enced transcriber. Information that could identify a participant was not transcribed. All transcripts were uploaded into the ATLAS.ti program, which is a qualitative data management software package. The grounded theory approach to qualitative research shaped our analysis of the data. Using this approach, we read interview transcripts several times, developing familiarity with the data and looking for key concepts that were similar across the interviews.[15] These concepts formed a coding structure, or a set of concepts or themes, that described the data. For example, one concept in our coding structure was caregiving. Each interview transcript was read for sections in which the respondent spoke about caregiving, and this section was coded as "caregiving." Once all the interviews were coded, each code was reviewed for common and contrasting themes among and across participants. This process of constant comparison of themes was conducted within each of the codes and across all codes until no new themes were identified. Themes were then organized into higher-level conceptual ordering (e.g., experiences of waiting). A summary of preliminary findings was distributed to participants, who were then contacted by telephone so that they could provide feedback. Eight of the 10 participants were contacted, and all agreed with the preliminary findings, with few suggestions for changes. Two participants could not be reached.

RESULTS

Ten women aged 21–37 years participated in the study. Five of the women had a partner and 8 had children. Eight of the participants were unemployed or had part-time or casual employment, and 2 were employed full-time. Six of the 10 women's incomes were below the poverty line for their associated demographic (e.g., single individual, married couple with 2 children).[16] Ten interview audiotapes were recorded and transcribed, 7 by the lead author and 3 by an experienced transcriber.

Experiences of waiting to access specialized care

Why do we wait?

Several women's descriptions of their experiences with wait times began with their questioning why they had to wait to access specialized health care and positing answers to this question. Some participants attributed wait times to the lack of specialized health care services in the region. One participant talked specifically about the lack of local mental health personnel, saying that she believed this shortage was the reason her son waited to see a psychologist: "They're short-staffed … one more body would take the weight off of the people that are there … I'm not sure why … they can't get one more therapist down here."

Another participant suggested that limited access to local operating rooms was the reason her mother waited to access a specialist. "With Mom's [specialized physician], he only gets the OR for 2 days a month … you can only have the operating room so many days a month and the people … go down the [wait] list."

From frustration to resignation

When describing their experiences with waiting to access specialized health care, many women spoke of themselves as mired in frustration and feelings of helplessness. For example, one participant spoke about several attempts to access a local detoxification program. The health care system could not meet her immediate health needs, and she noted, "It was a very, very frustrating process because I really needed to go the first time [I attempted to access the program] and I ended up relapsing again … I mean, you feel so rejected."

Some women described their experiences of waiting in terms of feelings of resignation. One woman, who helped both her daughter and her mother access a variety of specialized health care services, said, "There's a lot of hurry up and wait … 'cause you have no choice … there's nothing you can do but wait."

Waiting and the challenges of caregiving

Many of the women spoke of unpaid caregiving as a key aspect of their day-to-day lives. They described how these responsibilities became increasingly burdensome when they were faced with caring for a family member whose health declined as they waited to access specialized health care. One woman talked about her role as caregiver for her family while she waited for specialized health care for her son.

> I mean, first you're a mom … you're the supporter, you're the one that's pattin' their back because they're nervous about something, you're the one that's giving them encouragement because something's good. [But when] you have to wait … it's pretty much upheaval in your family. That forces you [to] grin and bear it and hopefully your family doesn't break apart. When your child's in a situation like that you want them seen as soon as they can.

Women's strategies for dealing with wait times

A number of strategies were discussed by participants as being critical to helping them during wait times. Some sought private health care while they waited. Others accessed what they called "the next best thing," and yet others sought assistance through social support and information networks.

Seeking private health care

Some health care in Canada, such as services provided by psychologists, is available privately as well as publicly. Several participants spoke of paying out-of-pocket for private health care that could be accessed more rapidly than public health care services. One participant described how she could not wait to access a local psychologist for her son and talked about seeking a private psychologist so that she could access care more quickly. "The first appointment that [publicly funded mental health services] were willing to give us was [6 months away] … we ended up seeking out private services because it's just too long of a wait."

Accessing "the next best thing"

Many women dealt with the challenge of waiting by accessing something one participant called "the next best thing." This refers to local health care resources that are more readily available and accessible than specialized health care services, and included primary health care providers, such as nurse practitioners, as well as alternative health care providers, such as homeopaths. None of the women reported seeing their family physicians as "the next best thing" — many had challenges with either not having a family physician at all or having to wait to get an appointment. Women perceived accessing "the next best thing" as being very helpful for alleviating some symptoms while they waited to access specialized care. One woman commented, "In between [specialist appointments] [Mother] goes once every 2 weeks to a homeopathic doctor to get some needles in her knee so that she can walk."

Some of the services women described as "the next best thing" were freely available, such as local self-help groups. In contrast, alternative health care, which is not publicly funded in Canada, was often only accessible to women who were able to pay out-of-pocket, or to those who had additional health insurance coverage (either individually purchased or paid for by an employer). The woman whose mother accessed a homeopathic doctor said,

> The homeopathic doctor is covered by insurance … [but] I don't have the insurance that [Mother] has, so I couldn't go, or if [my daughter] needed that. We couldn't get that because I don't have the insurance to pay for that.

Seeking social support and information

Many participants actively sought social support services and information that helped them cope with waiting to access specialized health care or actually helped them shorten the wait time. Two women, for example, relied on support from friends and family to help with child care while they provided care to another family member waiting for specialized treatment. Another participant talked about information her mother received from a community member that enabled her to locate a specialist physician with a shorter wait list than the specialist to whom she had initially been referred. This information was obtained "through the grapevine" and led to her shortening the originally scheduled wait time. "Somebody knew somebody who knew somebody who'd been to the new doctor in the city, so [Mother] went back to the family doctor and said I wanna go see this [new doctor]."

Perceptions of impact on health

Women spoke of the impact they believed wait times had on their physical and emotional health, as well as the health of family members who were waiting for care. One participant noted that her mother's physical health condition worsened during the wait period. "[Mother's health problem lasted] for 2 years before they caught it … and it was another 6 months before she got into the specialist. The wait times sometimes make it worse while you're waiting."

Another participant described the physical and emotional effects she experienced while waiting for specialized care for her son.

> You're waiting to see people, you don't know what outcomes are … it's stress and anxiety more than anything. And then that'll lead to other things … you start to not sleep as well and you don't eat the same way. I think generally, for me, that's my experience is the waiting isn't good.

DISCUSSION

Our research findings build on previous studies exploring young rural women's experiences with accessing specialized health care. The physical and emotional impact of wait times have been described

in previous research, and our study confirms these findings.[3,7,17,18] Existing research also indicates that young rural women may have strong social support and information networks, and our findings suggest that in the context of waiting for specialized care, these networks are very helpful.[19–23]

Many participants believed that wait times are a product of the lack of providers of specialized care in the region or the lack of infrastructure (e.g., limited time in the operating room for physicians). A number of women experienced feelings of frustration with waiting to access specialized health care, but other women were resigned to having to wait for care. The demands of caregiving during wait times were challenging for many. Wait times were reported to have some negative impact on the physical and emotional health of participants and their families.

A unique finding of our research is that at least some women take control over their experiences with wait times by accessing private health care or "the next best thing," even though this can be financially costly. Accessing "the next best thing" includes providers of alternative health care whose services are not funded by the Canadian health care system. For women who have coverage for private health care, accessing care from providers of private or alternative health care may not add a financial burden, but for women without such coverage or a substantial household income, this strategy is either out of their financial reach or means financial sacrifice. Although we do not know how many people in rural places are unable to access alternative or private health care because of the cost, research suggests that low socioeconomic status is common among young rural women and that paying for such health care may be challenging or impossible for many in this situation.[12,13]

Policies that would ensure more comprehensive coverage for health care and thus provide access to many health professionals who are currently working within the private sector may help to relieve some of the pressures on Canada's overburdened health care system. For example, increased coverage for private psychologists may reduce the patient load of publicly funded psychologists and reduce their wait times. More comprehensive coverage would increase costs to the health system in the short term, but, by increasing access to care, such coverage may reduce long-term costs associated with worsening health in patients who await care. As this research has shown, waiting for access to specialized health care can exacerbate the physical and emotional health problems of patients and their families, and even create new health concerns.

Help for women as they take control over wait times may also reduce the burden on the health care system. Such assistance may include wider access to social support and information networks, such as family resource centres or Web-based support programs.[11,24–27]

Limitations

This research was an exploratory study that aimed to collect data from a relatively small group of participants. As a result, there are limitations associated with the lack of diversity among the participants. For example, one limitation of this research is that all of the women were of similar ethno-racial backgrounds. A more diverse group of women may have different experiences with waiting to access specialized health care, and future research needs to focus on their experiences of waiting for access to specialized care. Another limitation of our research is that it took place in one rural geographic area, the south shore of Nova Scotia. The experiences of rural women may differ considerably depending on the particular place, given that access to specialized care may vary widely across rural areas. Social support and information networks may also be very different depending on the place.

CONCLUSION

The reduction of wait times for specialized health care is currently a key priority for Canadian policymakers.[1] However, given that wait times are a reality within the Canadian context, it is critical that we address the challenges faced by patients and their families, especially because waiting can have implications for their health. For many young women living in rural areas, low socioeconomic status has a big impact on their health, and wait times may further affect their precarious incomes if they have to pay out-of-pocket for access to support services while they wait. It is imperative therefore that we mitigate the challenges that wait times present.

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