# Patients' perceptions on losing access to FPs

## Qualitative study

Tom Freeman MD CCFP FCFP Judith Belle Brown PhD Graham Reid PhD Moira Stewart PhD Amardeep Thind MD PhD Evelyn Vingilis PhD

#### **Abstract**

**Objective** To examine the health care–related experiences of individuals who have lost their FPs.

**Design** A qualitative design using phenomenology.

**Setting** Southwestern Ontario.

Participants Eighteen participants (9 women and 9 men, with a mean age of 48.9 years) from urban or rural areas who had lost their FPs.

Methods Semistructured interviews were conducted, which were audiotaped and transcribed verbatim. An iterative approach using immersion and crystallization was employed for analysis.

Main findings Participants reported having lost their FPs because of reasons specific to their physicians (eg, illness, retirement, career change) or system issues (eg, poor remuneration for FPs, cutbacks in health care leading to physician emigration). Participants described feelings of loss, abandonment, frustration, and anger related to losing their physicians. They expressed concerns about the difficulty of getting prescription medications, lack of continuity of care related to medical records, and preventive care. They faced considerable hurdles in accessing primary health care, turning to walk-in clinics and emergency departments despite concerns about quality and fragmentation of care. Some of those with chronic medical conditions prevailed upon specialists to help meet primary health care needs.

Conclusion Losing access to FPs evoked a variety of strong feelings among these participants. They engaged in a number of strategies to meet their primary care needs but not without reservations. In a health care system appropriately built on primary health care, the lack of access to FPs is regarded as the loss of a basic right to care.

#### **EDITOR'S KEY POINTS**

- In the Canadian primary health care system, inability to access FPs presents a barrier to care. Many individuals lack access to regular sources of primary health care and must find alternative ways to meet their health care needs or do without.
- The goal of this study was to better understand patients' perceptions of the roles of FPs in their lives and the health care-related experiences of those without access to FPs.
- Having lost their FPs, patients were forced to use walk-in clinics and emergency departments, seek alternative sources of information such as pharmacists, and rely on their own resources to meet their needs. Some patients described the lack of access to FPs as a loss of a basic right as Canadians.

# Ce que les patients pensent de la perte d'accès aux MF

## Étude qualitative

Tom Freeman MD CCFP FCFP Judith Belle Brown PhD Graham Reid PhD Moira Stewart PhD Amardeep Thind MD PhD Evelyn Vingilis PhD

#### Résumé

Objectif Examiner les expériences en matière de soins de santé qu'ont vécues des personnes qui ont perdu leur MF.

Type d'étude Étude qualitative utilisant la phénoménologie.

Contexte L'Ontario du sud-ouest.

**Participants** Neuf hommes et 8 femmes (âge moyen: 48,9 ans) provenant de régions urbaines ou rurales, qui avaient perdu leur MF.

*Méthodes* Des entrevues semi-structurées ont été enregistrées sur ruban magnétique et transcrites mot à mot. Une approche itérative utilisant l'immersion et la cristallisation a été utilisée pour l'analyse.

**Principales observations** Les participants ont déclaré avoir perdu leur MF pour des raisons relevant de leur médecin (p. ex. maladie, retraite, changement de carrière) ou du système de santé (faible rémunération des MF, compressions dans les soins de santé causant le départ de médecins). Selon les participants, la perte de leur médecin engendrait des sentiments de perte, d'abandon, de frustration et de colère. La difficulté d'obtenir des prescriptions pour des médicaments, le manque de continuité des soins en rapport avec leur dossier médical et l'aspect des soins

préventifs les préoccupaient. Ils se butaient à d'importants obstacles lorsqu'ils essayaient d'accéder aux soins primaires, se tournant vers les cliniques sans rendez-vous ou les services d'urgence mêmes s'ils étaient inquiets par rapport à la qualité et à la fragmentation des soins. Certains de ceux qui souffraient de maladies chroniques s'adressaient à des spécialistes pour mieux répondre à leurs besoins de santé de base.

**Conclusion** Chez ces participants, la perte d'accès à un MF a engendré plusieurs émotions fortes. Ils ont utilisé un certain nombre de moyens pour obtenir les soins primaires dont ils avaient besoin, mais avec certaines réserves. Dans un système de santé correctement axé sur des soins de santé primaires, le manque d'accès aux MF peut être considéré comme la disparition d'un droit fondamental aux soins de santé.

### POINTS DE REPÈRE DU RÉDACTEUR

- Dans le contexte du système de soins primaires du Canada, l'incapacité d'avoir accès à un MF constitue un obstacle aux soins. Plusieurs personnes n'ont pas accès régulièrement à des ressources pour des soins de santé de base et doivent se tourner vers d'autres façons d'obtenir les soins dont ils ont besoin, sinon s'en passer.
- Cette étude avait pour but de mieux comprendre comment les patients voient les rôles du MF dans leur vie et les problèmes en termes de soins de santé auxquels sont confrontés ceux qui n'ont pas accès à un MF.
- Les patients qui avaient perdu leur MF étaient forcés de recourir aux cliniques sans-rendez-vous ou aux services d'urgence, de chercher des sources alternatives d'information comme les pharmaciens ou de se fier à leurs propres ressources pour répondre à leurs besoins. Certains d'entre eux voyaient la perte d'accès à un MF comme la perte d'un droit fondamental pour tous les Canadiens.

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ccess to a regular source of patient-centred primary health care has been associated with improved outcomes, 1,2 greater equity 3 and lower costs, 4,5 fewer emergency department (ED) visits and hospitalizations,6 greater adherence to recommended guidelines,7 improved receipt of preventive services,8 improvement in primary care for depression,9 and lower mortality.10 The concept of a patientcentred medical home in the United States has many of the characteristics of primary health care delivered by FPs in Canada<sup>11</sup> and has been found to reduce ED visits, improve quality of care, and reduce hospitalizations. 12,13

Health care systems, such as the one in Canada, that are based on a foundation of strong primary care depend upon primary health care providers to coordinate access to secondary and tertiary care. In Canada, primary health care is mainly provided by FPs; however, it is estimated that 13.7% of Canadians have no identified FPs.14 Many have lost their FPs owing to retirement or changes in practice. In Ontario, recent gains in the number of FPs have not kept pace with population increases,15 and there remain many individuals who lack access to a regular source of primary health care and who must find alternative ways to meet their needs or do without. For example, in a population-based study of individuals in southwestern Ontario, we found that individuals without FPs turned to walk-in clinics, hospital clinics, other providers, or EDs as their main source of health care, while 6% of individuals without FPs simply did not receive care.16

In a health care system based on primary care and family medicine, inability to access FPs presents a barrier to care. In essence, a natural experiment is occurring in Ontario that tests the public's perception of the role of FPs in their lives. The present study was stimulated by a desire to better understand this by examining the health care-related experiences of individuals who lost access to their FPs.

#### **METHODS**

This qualitative study, using a phenomenologic approach, explored patients' ideas about, perceptions of, and experiences with not having access to FPs. Phenomenology was chosen because it provided an in-depth exploration of individuals' experiences in specific situations; in particular, the meanings, emotions, motives, and perceptions they assigned to that experience. 17,18

#### Participant recruitment

A purposive sample was sought to reflect maximum variation with regard to sex, age, culture, place of

birth, urban or rural residence, length of time in current location, length of time without access to an FP, and acute versus chronic illness. Participants were recruited from several hospital clinics and EDs in London, Ont, and surrounding rural areas. Recruitment was conducted through posters placed in these facilities and by FPs who identified "orphaned" patients in their clinics and EDs. Participants were also recruited through a posting on the London and District Academy of Medicine website. Participants were enrolled in the study until saturation was achieved (ie, no new key concepts, themes, or disconfirming evidence surfaced in the interviews).

#### Data collection

Interviews were conducted by a research assistant who used a semistructured interview guide and additional probes to explore areas in greater depth. Questions included the following: How long have you been without a family doctor? What are your feelings about this, and how have you managed your health? The interviews were face-to-face and conducted in the participants' homes; they were between 20 and 120 minutes in length, and they were audiotaped and transcribed verbatim. In appreciation of their contribution, participants were given a \$25 gift certificate.

### Data analysis

An iterative, interpretative approach guided the data analysis. Initially 3 of the researchers (T.F., J.B.B., and A.T.) individually and independently read each transcript noting emerging themes; they then met to compare and corroborate the themes. The interviewer's field notes were consulted to enhance the understanding of the transcripts. As the analysis proceeded, a coding template was developed to assist in the organization of the data and allow for the expansion of key themes. New themes that emerged in subsequent interviews were added to the template. Throughout the analysis, the strategy of immersion and crystallization assisted in synthesizing the data in order to provide a comprehensive description of the key themes and overarching concepts.17

#### Credibility and trustworthiness of data

To ensure the trustworthiness and credibility of the data analysis, all interviews were transcribed verbatim and rigorously checked for accuracy. The trustworthiness of the data was further enhanced by detailed field notes compiled after each interview. Team analysis assisted in identifying potential personal or professional bias of the researchers.

Ethics approval was obtained from the Health Sciences Research Ethics Board of the University of Western Ontario in London.

#### **FINDINGS**

Table 1 outlines the demographic profile of the final sample. Five overarching themes emerged from the interviews with participants.

- Why I do not have a family doctor
- How I feel about not having a family doctor
- What will happen to me without a family doctor?
- · Challenges in accessing a new family doctor
- Strategies I am using to get my primary health care needs addressed

**Table 1. Profile of the 18 study participants:** *Median* age was 48.9 years (range 19 to 77); the length of time spent without an FP ranged from 1.5 to 48 months.

CHARACTERISTICS	N (%)
Sex	
• Female	9 (50)
• Male	9 (50)
Place of birth	
• Canada	13 (72)
Area of residence	
• Urban	9 (50)
• Rural	9 (50)
Length of time in current location	
• > 10 y	12 (67)
Have chronic illnesses (eg, diabetes, depression, cardiovascular disease, polio syndrome, cancer)	8 (44)

Why I do not have a family doctor. Participants identified several reasons why they no longer had FPs. Some participants reported that their physicians had individual and personal reasons for leaving their practices, while others described system issues. For some participants, the relationship was terminated owing to their physicians becoming ill, while for others their FPs had either retired or closed their practices to assume other positions. One participant said, "Our doctor went to work in emerg ... and he didn't have a practice anymore, and he couldn't find anybody to replace him."

Participants noted that as FPs retired or altered their practices, there were no new FPs to replace them. "There aren't enough coming through the system to even replace the ones we have."

Some participants did not understand why their FPs left their practices. "He just got up and closed his practice."

Some participants' opinions focused more on the system, and they expressed views on how the government had provided inadequate remuneration for family doctors. "I'm not mad at the doctors at all ... I'm mad at my government."

Other participants described how the health human resources crisis was related to cutbacks:

We train the doctors here ... all of a sudden they go to the United States because they can't find anything here because the government keeps cutting back.

The way the government is treating the doctors, they're rebelling ... they're human beings and they can only take so much stress ... and I think they're stressed right to the limit.

Some participants recognized the connection between remuneration and lifestyle issues for FPs.

The system really doesn't support family doctors well at all. They don't make very much money and work very hard. They have to run their own office and hire their own people. In the hospital ... you work about half the time, you get paid about as much, and when your shift's over you go home.

How I feel about not having a family doctor. Participants described a range of emotions as they recounted their feelings about not having family doctors, including feelings of stress, surprise, and frustration. "It's frustrating to not know where you're going to go, who's going to see you."

Some participants expressed a sense of loss and abandonment: "I was angry with him for kind of abandoning us ... I understood why he was doing it ... but on the other hand, we no longer have a doctor and no access to one."

One participant poignantly described how he felt: "[I]t feels like it's all lost right now with having no family doctor."

Other participants were angry and insulted by the lack of access. "I felt more insulted ... I really felt a real kick in the old rear end .... I was left high and dry."

This anger was often linked to a sense of being denied one's civic right. "It's the frustration of not being able to access the same care that everyone else in society can access ... it's one of the basic rights."

A sense of panic and fear was expressed by some older participants. "I felt scared a bit ... if you've had your doctor for 20 years, it's like [he's] a friend and then all of a sudden he just disappears out of your life."

Another participant recalled feeling "very emotional and very scared" after losing her family doctor.

Participants expressed their concerns about the physical and emotional well-being of family members without FPs. For example, a participant explained how he worried about his family members not having access to medications. "[M]y parents are on medications and need a doctor but they don't have one, so I guess it's harder for them to get their prescriptions."

Another participant expressed concern about her mother's inability to access a new FP: "I saw how much my mom cried over it. She's older. She can't be out running around trying to find a family doctor."

Several participants described being concerned about their children's medical care. "Adults can suffer just a little bit. I mean, they can take the suffering and the pain, but ... I feel bad if I see my kids are suffering."

What will happen to me without a family doctor? Participants described many concerns about their current health, which were exacerbated by lack of access to FPs. Most often mentioned was lack of access to prescription medications. As one participant explained: "I think about it every day .... I worry about it every day .... I'm always counting my meds."

Many participants were receiving care at walk-in clinics or EDs, which resulted in a lack of continuity of care. This was often linked to the issue of prescription medication: "It causes some serious stress in your life, especially when one doctor is going to prescribe you one thing and then another doctor says, 'No, you don't need this.""

Linked to issues of continuity of care was participants' frustration with receiving care from providers who did not have access to their medical records and were unable to provide follow-up care. "Every time I've seen a different doctor. So there's no continuity of care and there's nobody keeping a chart of what care we've had before "

Also related to the issue of continuity was participants' concern about access to their own medical records: "I don't want to see my notes going lost anywhere. To me that's important. Somebody should have control over that and right now they're just sitting in a box in an office somewhere."

A number of participants raised lack of access to preventive care as a concern. One participant described her family history of cancer and how lack of adequate follow-up was a concern: "In my family there is a history of uterine and cervical cancer, and I haven't been able to have an annual checkup."

Furthermore, the absence of a screening procedure was perceived as resulting in a poor outcome: "By the time I manifest something in my body and I go and see about it, it could be months after a screening procedure would have caught it. So I'm likely to suffer more or have a poorer outcome."

Challenges in accessing a new family doctor. With respect to challenges in accessing FPs, participants articulated 2 key barriers: 1) being placed in a potentially humiliating position of being assessed as to their suitability to be admitted into a practice ("You have to pay up front ... \$150 to become a member of that clinic. They said that they would have a 'go see'"); and 2) being classified as "too sick" or "a complex patient," and hence rejected ("They were taking patients but they wouldn't take us because we needed too much care").

Participants often believed they were at the "mercy" of the system no matter how much they advocated on their own behalf

I felt like I was applying for a job .... I knew already that there could be issues in terms of if you have too many problems, or ... the burden that you're going to put on the practice .... It was like being accepted for care rather than just securing care.

Participants described the sense of frustration they experienced as they attempted to first locate and then secure a family doctor. A participant explained: "I'd been faxing and phoning and not receiving any sort of contact back ... for the past year when I haven't had a doctor it's been frustrating."

Many participants described being placed on a waiting list. "You make a phone call and they're saying 'No, there's a waiting list.""

In some situations participants were not even placed on waiting lists, leading to feelings of rejection and further abandonment by the health care system. "We called so many places, but they would say they are already full or they don't accept any more new patients, or they don't even talk to us."

For some participants it was not until they had a health problem that they recognized the severity of the health human resource crisis: "Unless you have some kind of ongoing situation you're not really conscious of this until you run into this wall ... and it's just an absolute, complete dead end."

When seeking a family doctor, the issue of proximity became readily apparent, particularly for those in rural communities: "We are on a very limited income... and we only have 1 vehicle to go there when we need an appointment. A trip there and back would be about 70 km ... and with the price of gas ..."

Strategies I am using to get my primary health care needs addressed. While searching for new FPs, participants used a variety of strategies to address their health care needs. Most participants reported accessing medical care through walk-in clinics, EDs, or both.

If I had an emergency during the day, I would go to a walk-in clinic and say that I'm not feeling well or I'm having a problem. But if it's a weekend or a holiday, then I probably would go to emergency.

Many participants also shared their negative experiences of using walk-in clinics or EDs, noting the long wait times and perceived lack of quality of care in those settings.

It is very frustrating when you knew that the only place we could go was emerg. There's no place to sit down. You might have to wait 6 or 7 hours, and maybe all you wanted was just a renewal of a prescription.

A participant commented on the different quality of care provided by the walk-in clinic versus the FP:

That's the difference between going to a walk-in clinic and going to a family physician, because the doctor will know your record and they'll know your family history. Chances are the quality of care will be better than going to a walk-in clinic.

For participants with chronic diseases who had access to specialist physicians, their primary health care issues were sometimes addressed by these providers: "Every time I go to my endocrinologist, he asks me if there are any prescriptions I need .... I don't want to walk around wondering where I'm going to get my prescriptions from." Some participants sought care from a variety of community-based services; however, their care remained fragmented and uncoordinated. "This woman doctor in town is willing to do Pap smears only ... because of my history I have a mammogram every year through the Ontario Breast Screening Program."

Pharmacists also represented a resource for some people. "For a cholesterol check, I'd wait for one of the pharmacies .... [T]hey put a notice up in their window."

Finally, some participants described innovative means to access the health care they needed. This included being assertive in stating their needs and expectations.

I walked into triage and said, "This is how it's going ... I was here, I got kicked out for having a cigarette, that has nothing to do with my cancer, and you're going to admit me today; you're going to relieve this pain; and you're going to see if this infection's cleared up." And I said, "If you don't do that I'm going to go park myself in the hospital lobby, and I'm going to get on the pay phone, and I'm going to call every newspaper from Windsor to Quebec, and I'll have them in this lobby and you can explain how you kicked out a person ... who is terminally ill .... I don't mean to come across as a threat, but enough is enough." I was admitted for 5 days.

#### DISCUSSION

All Canadians have health insurance coverage for medical care. However, in a health care system based on primary health care, those Canadians without FPs encounter considerable barriers to care. In this qualitative study, individuals described different reasons why they did not have FPs—reasons that reflected issues at both the local and system levels. It is noteworthy that participants were able to see beyond their own personal experiences (eg,

personal physician retiring) and included systemic explanations (eg, remuneration) for the lack of access to FPs. This study offered patients an opportunity to express their feelings, which included loss, abandonment, frustration, and anger about the situation in which they found themselves. Some patients believed they were being denied a basic right as Canadians. This is a misconception that has been encountered elsewhere. 19 The main concerns raised by the absence of a portal to care were lack of access to prescription medications, personal medical records, and preventive care, as well as continuity of provider.

Participants faced considerable hurdles in meeting basic primary health care needs in the absence of FPs. Particularly concerning were the experiences of those who had to "apply" to be considered for acceptance into a new family practice and who were, at times, rejected for being "too sick." The phenomenon of "cherry picking" patients to include in a physician's practice might, understandably, be perceived as unprofessional behaviour and that threatens to undermine the high regard in which the public holds FPs<sup>20</sup>; however, the issue might be more perception than reality.21 Careful selection of new patients might be understandable as an adaptive tactic to avoid burnout among those physicians who continue to provide care when their colleagues leave a community short-staffed.<sup>22</sup> In addition, there might be unintended financial disincentives that affect the decision of whether to admit complex patients into a practice.<sup>23</sup>

For those participants in rural areas, proximity to FPs emerged as an important item for consideration, as transportation costs represent a potential barrier to care. Use of alternative sources of primary health care might differ between urban and rural residents.24 In one qualitative study of 40 rural-dwelling women in Ontario, Wathen and Harris found that participants went to great lengths to be self-reliant in seeking health information and resorted to the Internet, friends, pharmacists, naturopaths, and even veterinarians in addition to FPs25 to achieve needed health care without excessive travel.

We found that those who no longer had FPs used walkin clinics and EDs for primary health care needs, despite their concerns about quality, lack of continuity, and fragmentation of care. Patient satisfaction ratings have been found to be higher with care provided by one's own FP compared with walk-in clinics and EDs.26,27 Studies that have compared satisfaction and quality of care in these 3 settings have focused on acute illnesses rather than chronic diseases and comorbidity and thus might not reflect the experiences of the participants in the present study. Those from marginalized communities (First Nations, the homeless, substance abusers, those with severe mental illness, chronic pain sufferers) might have nowhere to turn other than EDs. To some extent, the use of the ED might reflect the degree of social suffering in a community.28 Participants also expressed concerns

about how lack of access to FPs affected 2 other vulnerable groups: the elderly and children. In the present study, some participants with chronic diseases were able to prevail upon specialists with whom they had contact to deal with prescription renewals. Others resorted to increased assertiveness and personal advocacy to meet their needs.

#### Limitations

One key limitation of this study was that all of the participants were residents of southwestern Ontario, and the results might not be applicable elsewhere. However, the themes that participants raised are consistent with the existing literature from a variety of settings. Only those who had had FPs and who had lost their FPs were recruited to participate, so their experiences would be expected to differ from those who had never had a regular source of primary health care.

#### Conclusion

Even in a health care system with universal health insurance and a relatively strong primary health care sector, FP shortages result in many individuals facing substantial barriers to receiving adequate care. Having lost their FPs, participants were forced to use walkin clinics and EDs, seek alternative sources of information such as pharmacists, and rely on their own resources to meet their needs. Participants expressed feelings of loss, abandonment, frustration, and anger related to losing their FPs; they also described the lack of access to FPs as a loss of a basic right as Canadians. Participants were concerned about the lack of access to prescription medications, health records, and continuity of care. There is a perception among some patients that, unfortunately, individuals such as children, the elderly, and those marginalized for various reasons appear to be at most risk of adverse health outcomes owing to lack of access to FPs.

This study is a reminder to practitioners and policy makers of the central importance of the FP in the lives of Canadians. Further work needs to focus on ensuring timely access to primary health care characterized by comprehensiveness and continuity of provider. Research comparing long-term outcomes of alternative sources of primary health care for children, the elderly, the socially marginalized, and those with comorbidities is needed.

Dr Freeman is Professor, Dr Brown is Professor, Dr Reid is Associate Professor, Dr Stewart is Professor, Dr Thind is Associate Professor, and Dr Vingilis is Professor, all at the Centre for Studies in Family Medicine at the Schulich School of Medicine and Dentistry at the University of Western Ontario

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Dr Freeman contributed to the conception and design of the study, as well as the analysis and interpretation of data, cowrote the initial drafts of the manuscript, and oversaw the revisions based on comments from co-authors. Dr Brown contributed to the conception and design of the study, led the analysis and interpretation of the results, cowrote the initial draft of the manuscript,

and participated in the critical revisions. Drs Reid, Stewart, Thind, and Vingilis contributed to the conception and design of the project, and provided critical review and edited the manuscript for important intellectual content. All authors approved the final version of the manuscript.

#### Competing interests

None declared

#### Correspondence

Dr Tom Freeman, Centre for Studies in Family Medicine, Schulich School of Medicine and Dentistry, University of Western Ontario, 245-100 Collip Circle, London, ON N6G 4X8; telephone 519 858-5028; e-mail tfreeman@uwo.ca

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