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Experience of being a frequent user of primary care and emergency department services: a qualitative systematic review and thematic synthesis

Magaly Brodeur ,[1] Eva Margo-Dermer,[2] Maud-Christine Chouinard,[3] Catherine Hudon [1]

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[1]Département de Médecine de Famille et de Médecine d'urgence, Universite de Sherbrooke, Sherbrooke, Quebec, Canada
[2]Département de Médecine de Famille, Université McGill, Montreal, Quebec, Canada
[3]Département des Sciences de la santé, Université du Québec à Chicoutimi, Chicoutimi, Quebec, Canada

Correspondence to
Dr Magaly Brodeur; magaly.brodeur@usherbrooke.ca

ABSTRACT

Background Frequent users of healthcare services are often categorised as 'heavy-cost patients'. In the recent years, many jurisdictions have attempted to implement different public policies to optimise the use of health services by frequent users. However, throughout this process, little attention has been paid to their experience as patients.

Objective To thematically synthesise qualitative studies that explore the experience of frequent users of primary care and emergency department services.

Design Qualitative systematic review and thematic synthesis.

Setting Primary care and emergency department.

Participants Frequent users of primary care and emergency department services.

Methods A qualitative systematic review was conducted using three online databases (MEDLINE with full text, CINAHL with full text and PsycINFO). This search was combined to an extensive manual search of reference lists and related citations. A thematic synthesis was performed to develop descriptive themes and analytical constructs.

Study selection Twelve studies were included. All included studies met the following inclusion criteria: qualitative design; published in English; discussed frequent users' experiences from their own perspectives and users' experiences occurred in primary care and/or emergency departments.

Results The predominant aspects of frequent users' experiences were: (1) the experience of being ill and (2) the healthcare experience. The experience of being ill encompassed four central themes: physical limitations, mental suffering, impact on relationships and the role of self-management. The healthcare experience embraced the experience of accessing healthcare and the global experience of receiving care.

Conclusion This synthesis sheds light on potential changes to healthcare delivery in order to improve frequent users' experiences: individualised care plans or case management interventions to support self-management of symptoms and reduce psychological distress; and giving greater importance on the patient–providers relationship as a central facet of healthcare delivery. This synthesis also highlights future research directions that would benefit frequent users.

Strengths and limitations of this study

- ► To our knowledge, this is the first systematic review and thematic synthesis to focus on the experience of frequent users of primary care and emergency department services. By translating these results into a single study, we make this information more readily available to practitioners, policy-makers and researchers.
- ► This study provides a comprehensive view of frequent user' experiences within and outside the healthcare system.
- ► Although database and manual searching was extensive, it is possible that not all relevant studies were found due to inconsistent terminology for this topic.
- ► The review was limited to English language studies, which may have led to over-representation of studies conducted in English-speaking high-income countries.
- ► Patients were not involved in the development of this systematic review.

INTRODUCTION

Frequent users of healthcare services are often categorised as 'heavy-cost patients'. Studies show that between 2% and 10% of the population accounts for 15%–80% of healthcare costs.[1–6] Even if past research did not consistently define frequent users, a recurring definition of frequent use of emergency department (ED) is four or more visits in the previous year.[4 7–13] In the recent years, many jurisdictions have attempted to implement different public policies to optimise the use of health services by frequent users. However, throughout this process, little attention has been paid to their experience as patients. Because of their regular use of healthcare, frequent users are expected to become 'laymen's experts' of their own health conditions as well as healthcare services.[14]

Frequent users, therefore, hold valuable insights for both researchers and policy-makers.

In the recent years, patient-centred healthcare has become an international standard of practice. This new standard requires healthcare professionals pay attention to their patients' experiences in order to better meet their expectations.[15 16] As outlined by Barry and Edgman-Levitan: 'If we can view the healthcare experience through the patient's eyes, we will [definitely] become more responsive to patients' needs and, thereby, [provide better care].[17] Frequent users' input is therefore crucial to the improvement of healthcare.

Several recent studies have provided insight on the characteristics and healthcare outcomes of frequent users, as well as strategies to adjust their patterns of usage.[18] However, as highlighted by Pines *et al* in a literature review on frequent ED) users, little is known about their subjective perspectives and experiences as healthcare consumers.[18] It is essential to know more about their experience in order to improve management processes and their overall experience. This study aims to fill a part of this gap by synthesising existing qualitative studies that explore frequent healthcare users' subjective experiences. Our research question is, therefore, as follows: What is the experience of frequent users of primary care and emergency department as reported in published qualitative studies?

METHODS

This study is a systematic review of existing qualitative studies that explore the experience of frequent users of primary care and ED. This review was guided by established methodology for systematic review and thematic synthesis of qualitative research, developed by Thomas and Harden.[19] Reporting of this review has been guided by the Enhancing Transparency of Reporting the Synthesis of Qualitative Research framework.[20]

Data sources and search strategy

A systematic electronic literature search for English articles from inception to October 2018 was conducted in three databases: MEDLINE with Full Text, CINAHL with Full Text and PsycINFO. An experienced information specialist helped us develop and implement a specific strategy for each database using controlled vocabulary (MeSH) and keywords related to four concepts: 'frequent users', 'patient experience', 'primary care' and 'qualitative studies' (see online supplementary material 1 for a complete list of MeSH and keyword terms used). There were no limitations with regard to publication year. This search was combined to an extensive manual search of reference lists and related citations.

Study selection

Studies eligible for the review needed to meet the following inclusion criteria: (1) qualitative design; (2) English-language publication; (3) discussion of frequent users' experiences from their perspectives and (4) focus on primary care experiences. Excluded studies were: (1) not primarily about the experience of frequent users; (2) focused on a specific programme or programme evaluation; (3) about patients' experiences with medical specialties or (4) quantitative or mixed-methods studies. It is important to note that we wanted to study the patients' first point of contact with healthcare services. In that context, we included primary care and ED studies as both places are the first point of contact for numerous patients.

After removal of duplicates, one researcher (MB) reviewed titles and abstracts to determine inclusion for full-text review. Two independent researchers (MB and EM-D) reviewed each study retained for full-text review. Discrepancies between the two reviewers regarding inclusion or exclusion were resolved by submitting the reference to a third evaluator (CH).

Data extraction

For each article, all text from 'Results/Findings' and 'Discussion' were extracted and imported into NVivo V.12 software (NVivo Qualitative data analysis Software; QSR International, V.12, 2018). Our assessment of the other sections of the studies helped us to better understand and interpret the results but were not used in our analysis. Study characteristics were extracted by one author (MB) and revised by a second author (EM-D) using a data extraction grid. Characteristics included aim, setting, design, participants, methodology, year of publication, country and definition of frequent users.

Critical appraisal

All of the retained studies were critically appraised by two independent reviewers (MB and EM-D) using the Critical Appraisal Skills Programme checklist for qualitative research. Any discrepancies were resolved by consensus. Studies were not excluded or given weighting based on this assessment as there is currently no accepted method for this synthesis of qualitative research.[21] We also anticipated conducting sensitivity analyses on studies deemed to be of weaker quality.[22]

Data synthesis

We used thematic synthesis to better understand the experience of frequent users as described in qualitative research. The aim of thematic synthesis is to achieve analytical abstraction by examining similarities among different studies.[19] Thematic synthesis, as described by Thomas and Harden, has three stages: (1) coding of text 'line-by-line'; (2) development of descriptive themes and (3) generation of analytical themes.[19]

Two reviewers (MB and EM-D) independently conducted the thematic synthesis. Each study was read several times to ensure that all excerpts relating to patient

experience of frequent users were integrated. The initial codes were examined for similarities and differences and then organised into a hierarchy to create the final codes. Consensus meetings minimised conceptual overlap between codes. Team validation minimised researcher subjectivity, thus improving the credibility of the work (MB, EM-D and CH). The coding process was inductive and through this process we generated 19 initial 'descriptives' codes. The final 'analytical' codes were regrouped into two categories, for a final total of six codes (see online supplementary material 2). The whole dataset was coded by a first reviewer (MB) and then reviewed by a second team member (EM-D) to ensure validation. We also deepened our analysis by linking the different themes. The final analysis was validated by two team members (MB and EM-D).

Patient and public involvement

Patients and the public were not involved in the review.

RESULTS

Literature search and selection

The search strategy identified 1122 references. All search results were transferred to Zotero reference software and duplicates were eliminated, after which 749 references remained. Thirty-two studies were retrieved for evaluation. A final sample of 12 studies was retained (see figure 1). As mentioned earlier, we anticipated conducting sensitivity analyses on studies deemed to be of weaker quality; but, all were assessed as reasonable quality and so sensitivity analyses were not required.[22]

Characteristics of included studies

The reviewed studies were published between 1996 and 2018. Four studies were from Sweden,[6 23–25] two from the UK,[26 27] two from USA,[28 29] two from Canada,[30 31] one from Australia[32] and one from New Zealand.[33] Sample sizes ranged from 9 to 52 participants, and various types of frequent users were studied (frequent users of ED, general practice, with chronic obstructive pulmonary disease, mental health problems, medically unexplained symptoms, etc). Five studies were conducted in a primary care setting[6 25–27 29] and seven were conducted in ED[23 24 28 30–33] (see table 1 for the characteristics of the included studies). The definition of frequent use varied among studies.

Quality assessment

The quality assessment revealed that all studies were assessed as reasonable quality by the review team. All studies were judged to contribute conceptually to the synthesis.

THE EXPERIENCE OF FREQUENT USERS OF PRIMARY CARE

Our analysis identified two primary aspects of frequent users' experiences: (1) the experience of being sick and (2) the experience with the healthcare system. The former represents individuals' daily lives with their conditions outside of any interactions with the healthcare system. The latter is their interaction with the healthcare system itself and encompasses both positive and negative aspects of this (see figure 2).

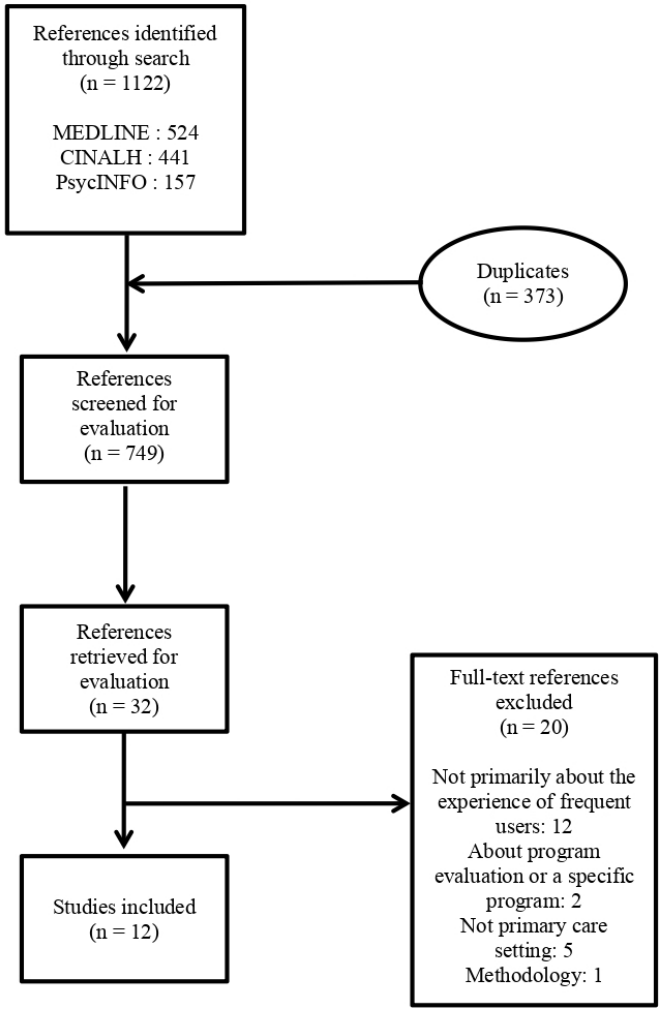

Figure 1 Flow chart of systematic search and study selection.

The experience of being sick: the individual experience

In 10 of the 12 studies, researchers described and analysed frequent users' daily lives outside of interactions with the healthcare system.[6 24–32]

Physical limitations

Physical limitations imposed by health conditions represent an important aspect of frequent users' experiences described in included studies. Difficulties completing day-to-day tasks were a recurrent theme and illustrate the extent to which frequent users' lives are transformed by their conditions[6 24 25 29 32]:

> Almost everything has changed. I'm not able to shovel snow, mow the lawn or take care of the house. … You just have to bite your teeth and do it, even if it is self-punishing. But one can always take a pill and go on. But sometimes it isn't possible, and it's so frustrating to ask my fiancée.[25]

Table 1 Characteristics of included studies and appraisal score (by alphabetical order)

Author and appraisal scrore	Year	Country	Setting	Design	Data collection tool(s)	Sample population			Frequent users definition	Aim
						No of participants	Age range	% Men		
Digel Vandyk *et al*[30]	2018	Canada	Emergency Department (ED)	Qualitative study design/ Interpretative Description/ Thematic Analysis	Semistructured interviews	10	22–66 years	40	Twelve or more visits to the ED for mental health reasons within a 1-year frame	Explore the experience of persons who frequently present to the ED for mental health reasons.
Dwamena *et al*[29]	2009	USA	Primary care	Qualitative study design/grounded theory	In-depth semistructured interviews	19	31–65 years	16	Eight or more visit a year for two consecutive years (see study protocol)[41]	Describe and analyse perceptions and lived experiences of high utilising primary care patients with medically unexplained symptoms.
Hodgson *et al*[26]	2005	UK	Primary care	Qualitative study design/thematic analysis	In-depth, semistructured interviews	30	24–81 years	60	At least double the average number of visits in 12 months and an assessment that the visits did not have important clinical outcomes.	Explore frequent users' points of view on their healthcare usage, expectations from visits and perceived relationship with their people who presented on multiple occasions.
Malone[28]	1996	USA	ED	Interpretative phenomenology	Informal interviews with participants and care providers; in-depth, loosely structured interviews with participants; group interviews with care providers; patient observation; medical records review	46	30–60 years	65	Four or more ED visits per year	Describe the context for frequent ED use and what it means to both patients and healthcare providers.

Continued

Table 1 Continued

Author and appraisal scrore	Year	Country	Setting	Design	Data collection tool(s)	Sample population			Frequent users definition	Aim
						No of participants	Age range	% Men		
Moss *et al*[33]	2014	New Zealand	ED	Qualitative study design/thematic analysis using Tronto's ethic of care framework	Semistructured interviews	34	17–77 years	32	Six ED visits in 1 year	Understand frequent users' experience with healthcare providers and how this influences their subsequent choices in healthcare.
Neal *et al*[27]	2000	UK	Primary care	Qualitative study design/thematic analysis	Semistructured interviews, 36-item health status questionnaire	28	Mean: 54 years	29	Regular frequent users: at least one primary care visit in each 90 days period, no period of 10 visits in 90 days Burst/Gap Frequent users: at least one burst (ten visits in 90 days) and at least one gap (period without visits over 90 days)	Understand the reason for frequent users' high rates of primary care visits.
Olofsson *et al*[23]	2012	Sweden	ED	Descriptive phenomenology	In-depth interviews with open-ended questions	14	71–90 years	36	Three or more ED visits in the past 12 months	Describe and understand chronically ill elderly patients' experiences during ED stays.
Olsson and Hansagi[24]	2001	Sweden	ED	Qualitative study design/thematic analysis	In-depth interviews with open-ended questions	10	23–82 years	50	6–17 visits in the past 12 months	Explore why patients believe they frequently use the ED.
Robinson *et al*[32]	2017	Australia	ED	Qualitative study design/thematic analysis	Semistructured interviews, half of which included patients' carers	19	Not specified	63	Three or more ED visits in 12 months	Explore COPD patients' experiences in frequently using ED services

Continued

Table 1 Continued

Author and appraisal scrore	Year	Country	Setting	Design	Data collection tool(s)	Sample population			Frequent users definition	Aim
						No of participants	Age range	% Men		
Spence *et al*[31]	2008	Canada	ED	Qualitative study design/Thematic Analysis	Semistructured interviews with patients and ED staff	52	18–45 years	100	Individuals who present themselves frequently to the ED	Investigate the repeated use of the ED by men with a history of suicidal behaviour and substance abuse to understand the needs and barriers to care for this high-risk group.
Wiklund-Gustin[25]	2011	Sweden	Primary care	Inductive hermeneutic design	In-depth interviews with open-ended questions	9	25–64 years	44	Five or more primary care visits in the last 12 months	Describe patients' subjective experiences with the healthcare system as frequent users.
Wiklund-Gustin[6]	2013	Sweden	Primary care	Qualitative study design using cognitive behavioural therapy framework	In-depth interviews with open-ended questions	9	25–64 years	44	Five or more primary care visits in the last 12 months	Describe frequent attenders' conception of life and their interaction with the healthcare system from a cognitive perspective.

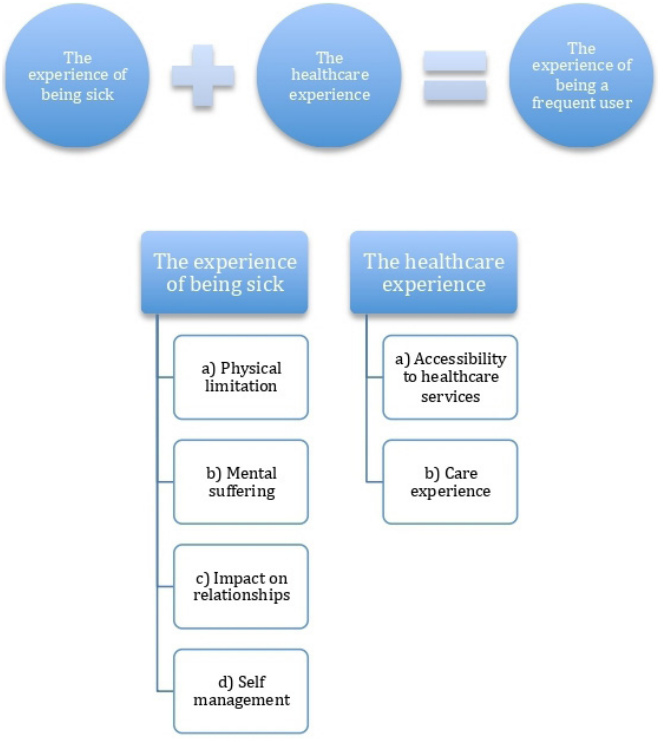

Figure 2 The experience of being a frequent user.

Many frequent users even feel obligated to forego recreational or leisure activities because of their physical limitations:

> I spent quite a bit of money buying special stuff to be able to go fishing… I've never used it because I can't even walk from here to the car.[32]

> I wish my arm would be OK again. That's the main problem right now. If I can't play the guitar, then … I don't know how to say it, and then life doesn't seem worth living.[25]

> I can't do things with the grandkids anymore.[32]

And, in some cases, they are not able to do simple tasks anymore:

> There's a lot of times I can't even make a cup of coffee.[32]

As outlined by Dwamena *et al*:

> The patients talked about how painful and debilitating their symptoms were …. They reported often that they could not or would not perform social obligations like housework or grocery shopping.[29]

In turn, these physical limitations create an element of mental suffering that creates substantial difficulty. This situation is reflected by many frequent users[6 24–26 29–32]:

> I'm just over it. I'm just physically and mentally exhausted…Sometimes I sit down there and cry.[32]

> It's hard to explain for someone who is not open-minded…that you are hurting inside. It doesn't show, unless you have a soggy handkerchief in your hand. And when they don't believe you they can't help… And with the family… you try to put on a smile …but actually, you're not enjoying anything anymore.[25]

Psychological distress is common among frequent users and, as mentioned by Wiklund-Gustin, frequent users may find physical pain to be more tolerable than mental suffering.[6]

As further explained by Hodgson *et al*:

> [T]heir particular suffering is considered unique and cannot be fully understood, even by an authority on illness, such as a family doctor.[26]

The burden of frequent users' ailments permeates beyond their own daily lives and has an impact on relationships with loved ones.[6 25 26 29 30 32] Often time frequent users' support systems end up helping with household tasks in order to maintain their capacity to live at home. However, several of frequent users '[s]tart to view themselves as burdens not only in daily interactions with family, colleagues and friends but also burdens for society'.[6]

Not all frequent users have family and friends. Many frequent users live alone or are socially isolated, which create additional stressors:

> It's gone so far that I've even started to leave my door unlocked, so in case someone has to get in, the door will be open […] or else I leave a key with the neighbours so they can get in… I get twinges in my chest, I was almost dying, I have no one who can sound the alarm or help me, so I went (to the ED).[20]

Some need the constant presence of their loved ones: 'When I'm with my family, I have no problems. Being alone is a big problem. It's very hard to be alone. It's very hard to be without others'.[30] Loneliness is a common problem.

Lastly, self-management of symptoms is a central element of the frequent users' individual experiences.[6 24 26 27 29–33] Over time, a lot of frequent users become 'experts' on their conditions, therefore, the decision to seek care is often a last resort:

> I know when I need to go.[32]

> I just try to keep calm and use my puffers, or if worst comes to worst I've got these pills here (antibiotics and steroids)… If it gets too bad I just have to get an ambulance… I know when I get to the point of no return and you've got to get to oxygen and to the hospital.[32]

But, some frequent users are less capable 'self-managers' and rather than addressing symptoms as they arise, they endure their pain until it is intolerable. As outlined by Wiklund-Gustin:

> [p]articipants (often) describe how they 'bite their tongue' as long as possible, avoiding asking help and showing weakness unless it is perceived very urgent.[6]

The healthcare experience: the experience of being a frequent user

All 12 studies described varied experiences with healthcare systems among frequent users.[6 23–33]

Once frequent users do decide to seek care, they often encounter significant barriers accessing healthcare, including needing to call early in the morning to get appointments or physicians' overbooked schedules leading to long wait times (hours/days/weeks) before consultations[23 26–28 30 31]:

> You have to get up early, get on the phone at quarter past eight and keep ringing 'til you get through.[26]
>
> This GP I've got now, sometimes it takes up to two weeks to get to see him.[32]

Wait times discourage numerous patients, while others have a far easier time booking appointments, making for more positive experiences. For example, some frequent users benefit from excellent relationships with their practice's receptionist who enables them to book appointments on short notice or at times with a shorter wait:

> I can go anytime, just phone up and they fit me in.[26]
>
> I phoned up yesterday…and the receptionist knows my voice, and she says if I were willing to get in and sit for the last appointment…somebody would see me.[27]

And sometimes it's so '… hard to find a general practitioner (GP)' that patients '… felt that the ED was an appropriate care setting:'[a] reassuring and therapeutic environment' … with lots of attention, undivided attention…that GPs can't provide'.[31] But, there is often a long wait:

> After a short transfer from the triage unit to the ED's assessment unit, most of the participants perceived the ensuing waiting time as too long.[23]

In terms of the experience of receiving care, the majority of studies described negative experiences, particularly pertaining to healthcare practitioners not listening and lacking respect towards patients. Many frequent users struggle to get their physicians to take them seriously, which may lead to their symptoms being ignored. Some even experienced situations that compromised their dignity or led to feelings of humiliation[6 23–33]:

> Bernard reported an 'ignominious situation' that was experienced as an affront to his human dignity. He had a tendency to stress incontinence and he needed to move his bowels while his treatment was stabilising his breathing. Bernard requested assistance as he could not get to the toilet himself and was told to soil himself where he was.[33]

For others, healthcare workers' prejudices contributed to their negative experiences:

> So I asked for an X-ray, but the answer was that I had cost the county so much money already. It was so humiliating, so very humiliating.[25]
>
> Every time I go there is 'Oh you're here again, you're just a drug seeker'.[33]
>
> It feels like there's a bit of stigma there because he's got [Chronic Obstructive Pulmonary Disease] COPD and because he's a smoker.[32]
>
> There's a lack of empathy and care… They [nurses] are there to do a job not to judge. You can't penalize [patients] for the rest of their lives.[32]

Several frequent users have known diagnoses, but others either do not or are in the process of obtaining a diagnosis despite multiple medical consultations. This creates apprehension in many frequent users of wasting their doctors' time, being met with a lack of understanding from hospital staff, or that they may be labelled as a nuisance:

> … when I go, it's because I want to get better. I don't know if they always understand that, and sometimes. I find that difficult, how you're perceived, whether or not they think you're there to get well, or to get something, right?[30]
>
> My husband would say to me, 'Go to the doctor's if you don't get any better.' I would say, 'But why go, they don't know what is wrong with me and I am just wasting their time'. He said, 'Yes but Janet, you are not wasting their time, you aren't well'.[27]

Neal *et al* detailed that patients sometimes were concerned about consulting either too soon or too late in the natural course of their illness. Thus, there was a fear that their GP might consider the consultation as inappropriate and label them as a hypochondriac.[27]

On the contrary, some frequent users had positive accounts of their experiences when receiving care and felt respected and well treated.[23 24 26–33]

> I'm well looked after stitch up my cuts, and they're always very non-judgmental and accepting of being at the ED and '[people] treated me really respectfully and asked me appropriate questions.[28]
>
> I got the opportunity to tell them about myself and my pain…they wrote down everything. They worked efficiently and talked to me all the time. I thought I was in heaven.[33]

Also, frequent users who were socially isolated explained that being recognised by staff was impactful, as explained by Malone[28]:

> Frequent flyer ED patients revealed strong attachments to hospital emergency departments as institutions not only of helping, but of recognition and inclusion. During the study, patients repeatedly made comments such as, 'They know me here', when talking about the emergency department. This 'knowing' carried a special meaning for homeless [frequent users][28]

DISCUSSION AND POLICY AND PRACTICE IMPLICATIONS

This thematic synthesis is, to our knowledge, the first to highlight the subjective experience of frequent users within and outside of healthcare settings. It allowed us to learn significantly about the major impact of their illness on their lives as well as their experience as a 'manager' of their illness or their experience in accessing healthcare.

The literature largely demonstrates an interest in patients' experiences within the healthcare system but is generally lacking in information pertaining to their lives outside of it, where the majority of their time is spent. This is particularly relevant if we want to glean a holistic view of patients' experiences. Psychological suffering experienced by many frequent users can affect them at multiple levels: it can aggravate physical symptoms and could prompt patients to consult their healthcare practitioners even more frequently. Studies such as Grabe *et al*[34] show that frequent users are at greater risk of psychological distress. It, therefore, remains essential to address this distress. But, as mentioned by Wiklund-Gustin, it is a complicated issue because this 'could be understood in two ways: either as if the frequent attenders have psychiatric problems from the beginning and are somatising them, or the patients develop psychiatric symptoms as a consequence of unexplainable illness experiences'.[6] Despite lacking clarity on the source of frequents users' psychiatric symptoms, and as outlined by Digel Vandyk *et al*, it is essential that medical staff, particularly in EDs are trained thoroughly in order to be equipped to address mental health problems both empathetically and effectively.[30]

It is also important to emphasise that frequent users with diagnosed medical conditions tend to have elaborate self-management regimens.[6 24 26 27 29–33] Indeed, it seems that the decision to seek healthcare (either primary care or ED) is rarely taken lightly. This contradicts the myth that frequent users consult the ED or their primary care provider at the slightest issue.[24] Frequent users often benefit from individualised care plans or case management interventions that enable them to improve their understanding of their disease and the management of their symptoms and ultimately, to manage their conditions independently. These interventions have the potential, as outlined by Hudon *et al* to improve the experience of care they receive.[35]

In terms of access to healthcare, for some, it is a non-issue while for others, there are considerable barriers. Those who struggle to get an appointment with their family doctor are more likely to consult the ED, which highlights a need to modify barriers by allowing advanced or adapted access to one's doctor, for instance.[36]

Overall, the experiences of frequent users with healthcare systems are quite varied. Some are genuinely satisfied while others have unpleasant or even humiliating experiences. However, there are few details with regard to their positive experiences. We know that healthcare practitioners' attitudes play a major role in frequent users' experiences and the relationships patients form with healthcare workers have a major role in their subjective experiences of receiving care.[37] But, we need to glean further knowledge from future research in order to better understand the role of healthcare workers in frequent users' experiences. Relationship-centred care then could be a valuable framework for healthcare delivery to improve patients' experiences; this concept recognises relationships' dynamics as central components of healthcare delivery.[38]

STRENGTHS AND LIMITATIONS

As previously mentioned, this is, to our knowledge, the first qualitative review on frequent users' experiences with the healthcare system. By translating these results into a single study, we make this information more readily available to practitioners, policy-makers and researchers. An exhaustive literature search was conducted by developing the search strategy with an information specialist, using multiple databases and manual searching was also performed. Our analysis allowed us to extract multiple recurrent themes pertaining both to people's experiences in their daily lives and to their experiences when consulting with healthcare practitioners. This recurrence adds validity to our results.[39 40] The results provide a holistic view of the experience of frequent users by focusing on their experience within and outside of healthcare services.

On the other hand, our review has its limitations. First, dissertations, commentaries and unpublished works were not included. Quantitative and mixed studies were also not included. Also, although database and manual searching was extensive, it is possible that not all relevant studies were found due to inconsistent terminology for this topic. We also were unable to fully capture frequent users' experiences; the citations selected from the included studies are a mere sample of patients' subjective experiences and of the researchers' own analyses. It is also important to outline that the review was limited to English language studies, which may have led to over-representation of studies conducted in English-speaking high-income countries. We also did not include patients in the development of this systematic review. Finally, our analysis was limited to the 'results' and 'findings' sections of the selected studies. Even if we only used results and findings sections of the studies to conduct main part of the analysis, we still considered all sections of the articles to deepen our understanding of the whole picture. We also acknowledge that themes developed in this synthesis may remain close to findings reported in the primary studies since it was not our intention to develop new interpretations or new theory. Since this study was looking at the patient experience, we wanted to stay close to the experience reported by the patients.

Many relevant aspects of the experience of frequent users, like, for example, appropriate or inappropriate use of ED services, were not explored in the included studies and will deserve attention in further studies.

CONCLUSION

This thematic synthesis provides us with a more comprehensive view of frequent users' experiences within and outside of the healthcare system. Our results suggest that adopting analytical frameworks of patients' experiences that emphasise both their day-to-day experiences with their conditions and relationships with their healthcare providers would give valuable insights. In turn, care plans and interventions could be better tailored to patients' individual needs and address necessary changes to providers' approaches to healthcare delivery. This could all also pave the way for future research on frequent users' subjective experiences as people who have recurrent contact with the healthcare system but perhaps more importantly, as people who strive for a greater quality of life in their time spent outside the healthcare system.

Twitter Maud-Christine Chouinard @MaudCChouinard

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Contributors MB conceived the study which was further refined by CH and MC-C. MB and CH developed the detailed methodology. MB undertook database searches and title and abstract review. Each study retained for full-text review was reviewed by EM-D and MB. Discrepancies between MB and EM-D regarding inclusion or exclusion were resolved by CH. EM-D and MB made the critical appraisal of retained studies. The thematic synthesis was conducted by MB and EM-D and revised by CH and MC-C. All authors contributed to the manuscript and approved the final version.

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Patient consent for publication Not required.

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ORCID iDs

Magaly Brodeur http://orcid.org/0000-0003-3856-1877
Catherine Hudon http://orcid.org/0000-0001-6140-9916

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