Patient Experiences, Emotions and Reasons for Frequently using Emergency Health Care for Long-Term Conditions: A Qualitative Study

Abstract

**Background:** Chronic illness is associated with increased health service utilisation including frequent use of the emergency department (ED).

**Objectives:** In a qualitative study, we aimed to address the reasons for which patients with long-term conditions (LTCs) seek frequently urgent or unscheduled care in the ED.

**Methods:** Semi-structured interviews were conducted with 35 patients with diabetes, COPD, and rheumatological disorders attending the ED (23 frequent and 12 non-frequent users). Themes concerning the meaning attributed to the symptom, previous ED experiences and expectations, emotional state, emotional responses during the ED visit, illness perceptions, and accessibility to ED and health care services satisfaction were examined. Analysis was carried out using content analysis method.

**Results:** Previous negative ED experiences and associated emotions were mainly the case for frequent users; frustration of the patient’s needs, devaluation of the patient’s urgent condition and inadequate information provision were underlying their accounts. Elements of poor clinical communication between the patient and the healthcare providers appeared to mediate the emotional state and whole quality of the service provided only for frequent users, especially for those who reported exhaustion related to the chronicity of the illness.

**Conclusion:** Frequent ED use by people with LTCs seems to be associated with negative emotions and unmet patients’ needs to experience a trustful environment and feel safe about his health condition. Improving the clinical communication between the patient and the healthcare providers in the ED and fulfilling the patients’ emotional unmet needs may prove effective in reducing urgent healthcare use by people with LTCs.

**Keywords:** Healthcare utilization; Patient experiences; Qualitative research; Long-term conditions; Emergency healthcare; Chronic obstructive pulmonary disease; Diabetes; Rheumatological disorders

Introduction

People with long-term conditions (LTCs) account for an increased health service utilisation including frequent use of the emergency department (ED)[1,2]. It is a reality often associated with high health care costs, overcrowding of the ED services and decreased quality of care [3,4]. Moreover, frequent ED use by people with LTCs poses the question of whether their actual medical and psychosocial needs are being met by the health care system [5]. Thus, understanding the factors influencing the frequency of the ED use is important both for patients’ well-being and for urgent health care services’ efficiency and quality of care. A number of quantitative studies have pointed out that individual and general factors need to be taken into account when considering the health service utilisation by people with LTCs. Socioeconomic difficulties and previous ED visits, along with psychological morbidity, especially depression, feature as the most prevalent correlates [6-8]. However, their impact on the frequency of healthcare use seems to be modulated by the presence of other parameters, such as demographic variables, severity of the underline illness, patients’ illness perceptions and health beliefs, or beliefs about the role of the specific health care services [9-13]. It is thus evident that frequent ED use by people with LTCs is a complex phenomenon defined by a complex interplay among background and individual factors, the illness and its chronicity as well as external factors [14-16], demanding for a multileveled approach.

Qualitative studies propose a more in-depth analysis of patients’ experiences, in order to better understand the reasons leading to frequently seek urgent healthcare. ED frequent users are often being found to attach a specifically negative and dramatic meaning to their symptoms or they feel obliged to use ED services as the only appropriate place to treat a condition that exceeds their self-management capacities [17,18]. In addition, previous positive or
negative ED experiences seem to play a significant role in shaping the overall ED experience. Technical and medical expertise, for instance, or the quality of doctor-patient relationship are emphasized in patients' accounts, along with feelings of safety or abandonment [19,20]. Other factors, such as the role of the patient's family, the healthcare system organization, or common-shared representations of ED services are also recurrent themes in patients' accounts [21]. Even though patients' accounts offer a more in-depth view regarding the healthcare utilization, few qualitative studies have been carried out in this respect, while, to the best of our knowledge, no studies have compared frequent ED users’ accounts with those of non-frequent ED users, both presenting with a long-term condition. Prompted by this fact, the aim of the present study was to analyze the experiences of past ED use accounted by both frequent and non-frequent users with LTCs in order to better understand the factors influencing the frequency of urgent or unscheduled ED use.

Materials and Methods

The health care setting

The Greek health care system incorporates different organizational patterns, including public integrated, public contract and public reimbursement models [22]. The National Health Service System (ESY) is a part of public sector and provides for emergency pre-hospital, primary and inpatient health care through rural surgeries, health centers and public hospitals. Access to ED is available to every citizen, and patients can visit the ED of any public or private contracted hospital without having to contact first a primary health care service. In addition, large university hospitals provide a high technological expertise, a wide range of expensive diagnostic and medical services, outpatient services, day care services, and emergency services. The present study was conducted at the University Hospital of Ioannina, a large, tertiary, teaching hospital with 800-beds linked to the medical school of the University of Ioannina. The hospital provides care for a population of approximately 350,000 individuals living in the Epirus County, but it also provides care for populations of nearby regions which lack of adequately equipped AED services.

Study design and participants

Data were collected as part of a longitudinal cohort study entitled “Applying effective and beneficial strategies to reduce unscheduled and urgent visits of patients with LTCs to Greek Accident and Emergency departments”. The main objective of the study was to develop effective psychosocial strategies to reduce the need for frequent unscheduled care in patients with chronic medical conditions. To do this, patients with diabetes mellitus (DM), rheumatological disorder (RD) or chronic obstructive pulmonary disease (COPD) seeking unscheduled or urgent care at the ED of the University Hospital of Ioannina were recruited during a one-year period (9/2012-9/2013). A more detailed description of the study’s methods has been described elsewhere [13,23,24]. Of 349 patients within the cohort study, 226 (64.7%) consented to be contacted further. Out of those, we purposively sampled 112 people to invite for interview at home, aiming to achieve variation in age, gender, type and number of LTCs, and different levels of self-reported use of ED. Out of this purposive sample, 47 agreed to be interviewed, and a final sample of 35 people participated in semi-structured interviews. Of them, 23 were frequent ED users (i.e. had visited the ED more than 2 times during the previous year) and 12 non-frequent ED users (none or 1 ED visit during the previous year).

All the procedures followed were in accordance with the World Medical Association Helsinki Declaration. The study was approved by the hospital’s ethics committee (23/19-09-2012). Signed informed consent was obtained from all participants.

Data collection and analysis

Semi-structured interviews (conducted by AN, VP and ED) took place in the participants’ homes (30-120 min. duration, mean 50 min) after the last ED visit and provided that the patient was in his/her usual state of health and without presenting any acute symptom or syndrome other than the known underlying chronic illness. Interviews were audio-recorded with the participant’s consent, anonymised and transcribed verbatim. Each interview explored six main themes: the meaning of the symptom, previous ED experiences and expectations, emotional responses during the last ED visit, perception and impact of the illness, accessibility to and level of satisfaction of the healthcare services, and patients’ suggestions concerning ED services’ and their own conditions’ improvement. Patients were encouraged to talk freely about their experiences, but follow-up questions were made when a main theme of the interview was not being clarified. Themes, around which the interview was constructed, were chosen based on preliminary bibliographical research and researchers’ ED field experience during the collection of baseline quantitative data. Analysis of the transcripts was carried out following content analysis method [25]. We compared cases of using frequently the ED with cases when ED was used occasionally, both across and within cases. Categories were checked and discrepancies were negotiated between researchers.

Results

Sample characteristics

Of the 35 patients participated in the study, 12 had DM, 12 COPD and 11 RD. The majority were females (n=23). Median age for frequent users was 63 years and 58 for non-frequent users, and both groups presented with similar number of comorbidities as assessed using the Charlson’s comorbidity index [26] and similar disease duration (15.5 years for frequent and 14.4 years for non-frequent users). The majority of the participants were married (n=24) and had a pension (n=22). All but one had a social security registration. Regular visit to one’s personal physician in order to have medical prescription was more often reported by frequent users (n=16/23) than by non-frequent users (n=6/12).

Findings

The use of the ED appears to be related to the meaning attributed to the particular symptom. The negative previous experiences of relevant emotions was mainly the case for the frequent users; devaluation and frustration were underlying their accounts. The perceived quality of the communication between the patient and the healthcare provider along with the medical and technological expertise experienced in the AED differentiated the two groups.
Attributing a meaning to the experienced symptom

Patients’ accounts revealed that before seeking urgent health care, they felt helpless when a symptom rose. This was the case for both the patients who experienced the symptom as “a threat” to their life and also for those who reported that the symptom “limited the self-management capacities”.

A threat to one’s life – helplessness: More frequent (n=6) than non-frequent users (n=3) experienced the symptom as a threat to their life. Such an experience did not draw from a similar previous situation that deteriorated their health. A threat to their life was considered to be either a plausible possibility or an imminent danger, justifying the use of urgent healthcare:

“They say that 99% of people don’t suffer a stroke, but I could belong to the 1% of them and suffer it, you never know”

(P22, Female, 65 yrs, DM, frequent user)

“I think that I’m dying that moment. I feel like a fish you see floundering outside of the water. That is I was suffocating”

(P01, Female, 66 yrs, COPD, frequent user)

A limit to one’s self-management capacities – helplessness: The majority of frequent (n=13) and non-frequent users (n=9) reported the symptom to exceed one’s capacities of self-management. This raised helplessness, although it did not involve a direct danger to one’s health. In particular, the ED services were seen as the most appropriate place to effectively treat their condition in case:

a) particular actions taken, such as taking medication (n=4), waiting for some time (n=2) or trying to contact a health specialist (n=2), did not work:

“I tried different medicines…none of them worked. I was in great pain and I had to…to get a special treatment, maybe an injection”

(P09, Female, 49 yrs, RD, frequent user)

b) the symptom was experienced as “distinct” (n=11). Symptoms experienced as acute (n=7), difficult to be assessed in reference with one’s health condition (n=3) or inexplicably repeated (n=1), led them to visit the ED:

“I couldn’t stay still, turn, bend down […] I couldn’t make anymore […] I cried in pain”

(P24, Male, 72 yrs, COPD, non-frequent user)

“I didn’t even know what was that […] that pain seemed like something was going-on with the gall again”

(P08, Female, 45 yrs, COPD, frequent user)

“To experience the same incident in one, one and a half months’ time…”

(P28, Female, 69 yrs, RD, non-frequent user)

it’s been years since I experienced such a thing and I got scared. I said to myself “something is happening”

(P28, Female, 69 yrs, RD, non-frequent user)

Some non-frequent users (n=3) reported that it was not the “distinctiveness” of the symptom or the ineffectiveness of previous actions, but rather the symptom’s possible comorbid action with the long-term condition that posed a problem in self-management capacities. In fact, patients were not directly concerned about the symptom, but rather about the possible deterioration of their health condition due to the symptom’s combined effect with their long-term illness:

“Whoever has a chronic disease, such as diabetes, if something happens to him […] he needs like twice the time to recover. It’s a matter of being aware of the overall health deterioration that increases the possibility a simple symptom to turn out to a serious problem…”

(P35, Male, 49 yrs, DM, non-frequent user)

Previous AED experiences

Both frequent and not frequent users reported some positive and negative experiences with regard to the quality of treatment received in the ED which involved both (a) relationships with doctors and staff, and (b) organizational factors. Relevant sentiments and emotions were also reported by the patients.

Negative experiences

i) Relationships with doctors and staff: Negative experiences involving elements of poor clinical communication with ED healthcare providers was particularly the case for frequent users. Most of them (n=17/23) reported several aspects of devaluation. These concerned the following:

(a1) Lack of empathy on the side of the doctors (n=7) towards the patient’s condition and personal suffering:

“I don’t like their behavior, neither their sense of humanity […] it’s like they make fun of you […] they are cold [and] generally they say “we won’t waste our time with you; we can’t bother about your anxiety that doesn’t correspond to any serious real problem…”

(P09, Female, 49 yrs, RD, frequent user)

In non-frequent users, devaluation was reported only by four participants and it concerned lack of empathy:

“He told me “what, you came to the hospital because you have a fever! Is that all?”

(P26, Male, 59 yrs, COPD, non-frequent user)

(a2) “Underestimation” of patients’ experience of suffering by doctors and staff (n=5). Dismissing the nuances of personal suffering in favor of an absolute categorization between dying and non-dying people constituted a factor of devaluation of their experience. Patients seemed to consider the doctors as being unavailable and indifferent to any case apart the ones that faced the danger of dying:
“They told us “there is a more urgent case, you are not dying”. I didn’t like this behavior [...] I’m in pain, I suffer, I can’t stand this pain anymore [...] they said “you are not dying”

(P08, Female, 45 yrs, COPD, frequent user)

(a3) The limited information provided to patients regarding the cause of the symptoms and the treatment they received (n=6): “They didn’t explain anything to me. They just did this and that [...] that’s all. I mean, I was given the necessary medical examinations, some blood tests, X-rays, ECG, but that was all. I had no idea what they were dealing with”

(P07, Female, 54 yrs, COPD, frequent user)

(a4) Doctors’ patterns of behavior experienced by patients as stigmatizing (n=2): “Doctors were scolding me [...] they told me] that I need a psychiatrist. I said “Hey, I can’t even breathe here, I don’t need a psychiatrist. I’m not crazy, you made me seem like a crazy person”

(P01, Female, 66 yrs, COPD, frequent user)

(b) Organizational factors: The interviews indicated no difference between frequent and non-frequent users concerning negative aspects of organizational factors. The majority of frequent (n=16/23) and non-frequent users (n=8/12) reported both long waiting hours and overcrowding in the ED: “Even though I got to the AED by ambulance, I had to wait there many hours to get examined. I mean, I got there at eight and a half or nine o’ clock in the morning by ambulance, and ended up to receive some treatment late in the evening”

(P14, Female, 63 yrs, RD, frequent user)

“There are so many people suffering there and only few doctors. We were squashed into a room...”

(P33, Male, 64 yrs, DM, non-frequent user)

Some patients (one frequent and two non-frequent users) linked overcrowding with a fear of virus transmission: “You could go there being healthy and leave having caught something, like the flu [...] you can catch anything in there”

(P33, Male, 64 yrs, DM, non-frequent user)

Positive experiences

Positive emotions were mainly reported by non-frequent users (n=17/23). Frustration was underlying all of the following frequent users’ experiences. Interestingly, these came along only with experiences of poor clinical communication with the doctors:

i. Helplessness (reported by the majority, n=10):

“I said to myself “My God, if only there was a doctor outside [AED] to go, if only I had painkillers to calm down”; pain is unbearable. Whether you die or not, you are in pain”

(P08, Female, 45 yrs, COPD, frequent user)

ii. Lost and confused (n=3):

“A doctor would say to another “you take care of him [the patient]”, another doctor would say to another “you take care of him [the patient]”; another one would be busy with the PC, another one is speaking on the phone. I felt absolutely confused in such a context, I didn’t know who to address to... there was no space for me...”

(P02, Male, 70 yrs, COPD, frequent user)

iii. Anger (n=3) due to the poor organizational factors like long waiting hours:

“I was nervous [...] I was hostile toward the doctor [...] and the longer I was waiting the further I sighed and the lesser the blood pressure decreased”

(P17, Female, 66 yrs, DM, frequent user)

Overcrowding and poor conditions in the AED waiting area were reported by one frequent user as an attack to one’s individuality, raising feelings of humiliation:

“The waiting room was full of people [...] one was crying [...] another one was half-naked [...] they were like animals [...] While I went to the AED three times, I only remember one of them”

(P20, Male, 79 yrs, DM, frequent user)

Positive sentiments and emotions

Positive emotions were mainly reported by non-frequent users (n=9/12) rather than by frequent users (6/24). These appeared to involve safety and security both with regard to medical and technological expertise and rich clinical communication; the...
primacy of the first and the second was the case for the non-frequent and the frequent users, respectively. For non-frequent users (n = 9) safety during their ED visit involved either elements of positive clinical communication or the anticipation to “meet” technological and medical expertise; some patients reported both:

“The doctors should have seen that I’m desperate. They don’t believe that I’m suffering. It seems that they can’t communicate with me at all, they can’t see my real condition. If they saw the points I made I had to have more medical examinations done by doctors… to identify the real cause of suffering (not breathing). I leave the AED without my problem been treated, they treat the symptoms… One day I said to my friend “this situation has driven me crazy, I will wait for death to take me, not even the doctors put themselves in my shoes and get into grips with my health problem…”

(P01, Female, 66 yrs, COPD, frequent user)

My husband] is also fed up with my condition. He says “She is sick all the time” […] I think I’ve had enough, nothing seems to work and neither I nor my husband have a clear idea of what I’m suffering […] Doctors are supposed to care about their patients, to give them information about their condition. I never feel like I’d got enough information about my illness. I can’t say that I’ve ever experienced a true concern and real care in the AED. They may say so but they never spend time to explain the whole problem to me and give me the whole picture.

(P09, Female, 49 yrs, RA, frequent user)

General health care context

Few frequent (n=7/23) and non-frequent users (n=3/12) shared a common representation of hospital use: patients reported the hospital as an institution established to treat any medical case. This representation is underlying their perception of the quality of the treatment provided by the ED as a unit located within the hospital and as the appropriate place for their treatment:

“The best thing to do is to go to the hospital; everything is there, doctors, equipment, expertise... everything that you need of”

(P04, Female, 78 yrs, COPD, frequent user)

Interestingly, many frequent (n=11/23) as well as non-frequent users (n=6/12) linked the use of the ED with the limitations of the health care system. They mentioned unavailability of out-of-hour health care services, lack of primary care services, increased financial cost of private consultations, and long periods of waiting to arrange appointments in non-urgent consultations:

“You can’t arrange an appointment in non-urgent consultations in due time. You need to wait at least over a month to have an appointment”

(P35, Male, 40 yrs, DM, non-frequent user)

“It was very late at night and we couldn’t find a doctor. We decided to go to the hospital”

(P10, Female, 70 yrs, RD, frequent user)

Discussion

The results of the present study confirm and extend earlier research findings reporting that previous ED experiences of patients with LTCs influence the use of the ED when they face a perceived acute state or illness exacerbation. In addition, present findings identified remarkable differences between frequent and non-frequent ED attendees as far as the reasons for which they seek frequently unscheduled or urgent care. Specifically,
for frequent users, a feedback circle seems to be emerged: the meaning attributed to the symptom (involving an underlying excessive threat) comes along with one’s need for empathy and elements of good clinical communication between the patient and the healthcare providers. Frustration of the patient’s needs, devaluation of the patient’s urgent condition and inadequate information provision about the illness increase the patient’s insecurity about the condition; this seems to reduce the patient’s satisfaction of the healthcare service, leading even to devaluation of the technological and medical expertise. The lack of a trustful experience in the ED enhances health anxiety and reduces the patient’s sense of control of the illness. As a result, a distinctively life threatening experience is underlying the bodily symptoms (beginning of the circle); this in turn enhances the need for empathy besides good healthcare provision in the ED. This feedback circle is not the case for the non-frequent users. Their visit to the ED comes along with feelings of safety and security stemmed from previous experiences and current poor experience and difficulties are compensated by a sense of control of their illness emerging from the effective healthcare and doctors’ concern. Although previous studies have reported the importance of previous experiences in the use of ED, this is the first time that the differences in previous experiences reported by frequent and non-frequent users with LTCs are explored.

Research has indicated chronic illness as a major factor of frequent health-care use [4,6]. The present study suggests links between the frequent use of the ED and clinical communication between the patient and the healthcare providers in the ED. Most frequent users with LTCs reported expectations for concern, compassion and understanding in their interaction with ED staff. For most of them, higher vulnerability and exhaustion due to the underlying chronic illness appeared to enhance their need for safety in the ED. In case their expectations were not met, frustration seemed to exaggerate any ED organization deficiency. The primacy of good clinical communication for frequent users is further supported by the accounts of the non-frequent users, who feel safe in the ED even in times they experience poor service; they appeared to draw from doctors’ expertise and ED infrastructure and appreciate the doctor’s abilities and concern.

Along the same lines, the importance of doctor-patient relationship for frequent users is highlighted by the “meaning” they attributed to the symptom. In line with previous research [17], more frequent than non-frequent users considered their symptom as “life threatening”. However, this seems to depict an underlying excessive threat that does not draw from past experiences and patients’ “familiarity” with their condition; frequent users did not report previous experiences of health deterioration in case of similar symptoms. On the contrary, non-frequent users appeared to draw from previous experiences to give meaning to the particular illness exacerbation. Although the impact of an acute state or illness exacerbation cannot be ignored, our findings indicate that frequent ED use goes beyond the “real threat”. We found that both frequent and non-frequent users reported the symptom as exceeding their self-management capacity. They had also similar burden due to comorbidities and illness chronicity, and similar perspectives of hospital use and doctors’ attendance. The frequent use of the ED seems to be associated with patient’s unmet needs to feel safe and secure. In accordance with our findings, previous research suggests that patients with LTCs expect to establish a trusting relationship with their health-care provider; a relationship which permits to negotiate their health situation in a partnership [27-29].

Concerning the frequent users, a negative emotional experience involving communication elements in the ED seems to mediate the whole quality of the service provided. Lack of empathy, underestimation of the patient’s experience, poor information provision regarding symptoms and treatment options, and stigmatizing attitudes that provoke anger, confusion and helplessness, are indicators of poor clinical communication, clearly linked to lack of safety and security about the condition. Such an experience leads to underestimation and devaluation of the medical and technological expertise, and seems to reduce dramatically the sense of personal and treatment control. Such an experience appears to mediate ‘candidacy’ and ‘recursivity’, in terms of undermining one’s reliance on that service [18]. This was particularly the case for the exhausted patients who reported clearly their need for a secure relationship with doctors, a relationship involving empathy, compassion and understanding. Additionally, the urgent need for empathy appears intertwined with the frustration of the ED service and seems to act as a self-fulfilling prophecy. The importance of the doctor-patient relationship reported by frequent users is supported by the accounts of non-frequent users who did not appear to devalue the doctors support and the technological expertise even in busy and crowded days at the ED; they rather appreciated the doctors struggle to cope with the increased demands that came along with gratitude, thankfulness and a sense of security. Previous research has pointed out that attributing frequent use of AED services to the lack of good clinical communication is rather simplistic: it has been suggested that patients with long-term conditions can frequently seek urgent health care and may have at the same time satisfactory communication with their GP [19]. The present study, however, reports on the link between the frequent use of urgent health care and the patients’ need for good relations to doctors and staff in the ED. The most exhausted frequent users made clear their need for doctors to report concern, compassion and understanding. Our study suggests that the clinical communication could be seen as a growing research potential to broaden our view focusing not only on frequent users but also on the underlying factors involved in the patients’ overall experience of the use of the ED that seems to influence, in turn, their experience of illness exacerbation.

**Limitations**

Our study has several limitations that need to be addressed. First, the accounts of non-frequent users were fewer than those of frequent users, introducing a possible in our attempted comparisons. Second, although patients reported regular visits to their specialty doctors, the quality of the patients’ relation with their doctors in their routine care does not belong in the scope of the present study. Finally, our findings should be interpreted with caution, as the use of ED in the Greek healthcare system is frequent per se, as ED services frequently “fulfill the role” of primary healthcare services, since primary healthcare is not adequately developed.
Conclusion

The results of the present study provide an insight on the patients’ experience, bringing together the experience of illness exacerbation and the personal experience of the use of the ED. Although the issue of the importance of clinical communication in the ED regarding its impact on ED frequent use is still inconclusive (19, 28, 29), our findings suggest that clinical communication should be taken into consideration if we are to enhance our efforts to reduce the frequent use of the ED by patients with LTCs. Courses aiming to develop specific clinical and communicational skills included in the training of ED doctors and staff may improve the patients’ satisfaction and have an impact in reducing future urgent needs for healthcare. Further research is needed to shed more light on this issue exploring also the quality of the doctor-patient relationship in routine care. Finally, for many frequent users, the need to establish a trusting and safe relationship with the healthcare providers in the ED indicates the need for system reorganization which would provide a context for many frequent users, the need to establish a trustful and safe relationship with the healthcare providers in the ED indicates the need for system reorganization which would provide a context enabling the patient to experience a doctor-patient relationship of high quality, and guiding the patient to make the appropriate choices regarding her/his healthcare service utilization.

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