The perceptions of frail older adults on contributing factors causing the onset of crises leading to hospital admissions; a qualitative study

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Research Article

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Abstract

Background

Frail older adults living alone are frequently admitted to the emergency department (ED) with a chronic disease exacerbation and are at high risk for adverse outcomes like morbidity and mortality. The aim of this study was to explore the perceptions of frail patients who lived alone, on possible contributing factors causing a health crisis as perceived in the approximately nine months leading up to an ED-visit, and to create a combined patient journey map.

Method

An exploratory-descriptive qualitative study was conducted, using purposive sampling to recruit frail older patients of an urban academic ED. Semi-structured interviews were performed and analysed by thematic analysis. Patient journey mapping was used to identify, combine, and depict chronological similarities.

Results

Fifteen interviews contained five themes: ‘continuity of healthcare’, ‘self-perception on frailty’, ‘self-management’, ‘impact of support system within an urban environment’, and ‘acute event prior to ED-visit’. The patient journey map identified uncoordinated care by healthcare providers, deterioration from at least six months before the ED-visit, and an unexpected event that leads to an acute health problem four weeks prior to the ED-visit.

Conclusion

While patients were aware of the health event leading to the acute hospitalization, they were less aware of the impact of contributing cascading events in the months before. The journey map suggest strategies can be applied to inform older adults, be more patient-oriented, and provide an anticipated plan towards advance care, healthy ageing, and admission avoidance.

Key Points

- Multidisciplinary care that comes from multiple centres, creates misunderstandings for frail older adults which can escalate into health crises and ED-visits. A generalizable patient journey map can decrease misunderstandings between health care professionals and patients.
- The found contributing factors to health crises - ‘continuity of healthcare’, ‘self-perception on frailty’, ‘self-management’, ‘impact of support system within an urban environment’, and ‘acute event prior to

ED-visit' - identify a lack of awareness and a negative stigma, calling for knowledge dissemination on frailty for patients, social network, and professionals.

- When already frail, a relatively small change in daily life can set off a negative cascade, causing a health crisis in about four weeks after, for which medical intervention is necessary.
- More approachable guidance within the general practice or home care, for example a case-manager, ensures better monitoring and more easily deployed interventions when necessary.

Introduction

Consistent with global trends[1], in the Netherlands more older adults live with age-related chronic-degenerative diseases[2–4], making them frequent users of the Emergency Department (ED)[3, 5, 6]. Approximately 47% of older ED-patients are assessed as 'frail'[7], which is defined as *a syndrome characterized by reduced functional reserve due to a cumulative decline in systems, increasing an individual's risk of an adverse outcome when exposed to a stressor*[7], needing little to escalate into a crisis[8–10].

A crisis is idiosyncratic[11], but is generally described as: *'a sudden change in the health status of the patient or loss of (in)formal care, leading to a substantially different content (function and/or location) and extent of care required, making admission necessary within 24–48 hours, to prevent unacceptable health risks or damage to the patient and/or his family and/or living environment'*[11, 12]. When admitted to hospital, the older patient has increased risk for adverse health outcomes[13, 14], leading to (further) functional decline, repeated ED-visits, institutionalization, and death[2, 13–16].

The reasons preceding a crisis can often be approached twofold; an acute illness or injury event, or problems related to the patient's underlying health status[17, 18]. In the latter case, the admissions are frequently related to ambulatory care sensitive conditions (ACSCs) and end-of-life care[18–20], with deterioration in the weeks/months prior to the ED-visit[3, 18, 21]. ACSCs are chronic conditions such as asthma, diabetes or heart failure, for which adequate management, treatment and interventions delivered in a primary care setting, could potentially avoid admission[22].

While factors initiating a crisis may be easy to spot in hindsight, it is not always clear to patients themselves[23]. Furthermore, not all older people are sufficiently aware of 'frailty', tending to overestimate strengths, capabilities and social network[24]. Their perceptions can be divergent compared to those of healthcare professionals, leaving the patient wondering when to turn for help, which additionally could cause unnecessary physical and mental burden.

In metropolitan areas, health care crises can be of a greater challenge than in rural areas[6, 12, 25]. The large number of older adults living alone, diversity in background, education and income, and an increasing demand on primary healthcare and municipal care facilities[26], seem more urgent in deprived areas of larger cities and associated with more ED-visits[27].

To gain more insight into a patient’s care journey and possible contributing factors leading to an ED-visit, the aim of this study was to explore the perceptions of patients with frailty living alone, on possible contributing factors causing a health crisis, as perceived in the approximately nine months leading up to an ED-visit, and create a combined patient journey map. We hypothesized similar perceived factors in these months prior, like dealing with a fragmented healthcare system and possible (over)estimation of self-management capacity. Combining contextual and patient related factors chronologically, and schematically displaying them in a patient journey map, may help intervention strategies for future geriatric care, and avoid unnecessary ED-visits.

Method

Study Design

An exploratory-descriptive qualitative[28, 29] study was conducted. This design combines exploratory methodology for this relatively new aspect of interest of patients perceptions on contributing factors leading to an ED-visit, with a descriptive element which documents and describes these perceptions[28, 29]. The COREQ-criteria[30] were applied. An ethical waiver was obtained from the ethics committee of the Amsterdam UMC (W20_557#20.620)[31], under the Medical Research Involving Human Subjects Act (WMO)[32]. The researchers followed the ethical principles for research, according to the Helsinki Declaration[33]. All participants signed Informed Consent before the interview.

Study setting and participants

The study-population consisted of frail older adults ≥ 65 years, assessed having a Clinical Frailty Scale-score ≥ 4[7, 34, 35], living alone in the metropolitan area of Amsterdam, and admitted to the ED of an university hospital because of a health crisis. All participants were proficient in Dutch or English.

Excluded were patients not able to give consent, terminally ill, or who experienced a neuropsychiatric problem, such as a psychosis.

Participants were approached by purposive sampling to reach maximum variation in heterogeneity[29, 36, 37]. When willing to participate, an appointment for an interview was scheduled for approximately one week after ED-discharge.

Research team

This study was conducted by a trained researcher and ED-registered nurse (GH), under supervision of senior researchers (SRs), in collaboration with a research team in Geriatric Medicine. When admitted to the ED, patients were assessed for eligibility in collaboration with the Geriatric Specialist Team.

Data collection

Between February and April 2021, audio-recorded semi-structured interviews[37] were conducted, ranging from 40 to 70 minutes (mean = 45 minutes), at the patient’s home or follow-up facility. The interview-guide is depicted in Appendix A. A pilot-interview was conducted, to assess necessary alternations concerning interview-techniques.

For the construct of the interviews, deductive predetermined topics were used, reflecting the four frailty-domains of the Clinical Frailty Scale[7], and literature[3, 7, 25, 34]. Iteratively throughout the study, changes were made when questions deemed to be irrelevant or new questions arose from previous interviews. Each interview started with the opening question: “Could you tell me the reason you were admitted to the ED?”

Observational memo’s and field notes[29, 37] were made. To increase internal validity[37], a ‘member-check’[29, 36–38] was included during the interview, by restating and paraphrasing the information; this way, making it less burdensome for the participants afterwards.

To ensure heterogeneity, a minimum sample-size of twelve participants was assumed[29]. Inclusion continued until interviews no longer yielded new insights, and data-saturation was achieved[29].

Baseline characteristics, including activities of daily living (ADL) by using the Katz-index[39, 40], and ‘frailty’ by using the Clinical Frailty Scale[7], were retrieved from the participant and their electronic patient file to establish maximum variation of the sample[36–38]. The electronic database CASTOR-EDC[41] was used to store these records.

Data analysis

All interviews were transcribed verbatim[29], and coded using MaxQDA-software[42]. Thematic Analysis[43, 44] was used to conceptualize this data, following the six-steps of Braun & Clarke[43, 44].

Baseline characteristics were analysed descriptively, using SPSS-Statistics, version 25[45]; continuous variables by median and interquartile range (IQR); categorical variables by frequencies and percentages.

Data analyses started after three interviews. The researchers became familiar with the data by (re)reading the interviews and noting down initial coding. Preliminary categories and themes were iteratively identified throughout the study by an inductive approach[37, 38]. The whole process of analyses, coding, preliminary outcome, themes, thoughts, and changes was discussed within the research team for feedback, to reach consensus and increase trustworthiness[37]. Final themes were then defined, and illustrative quotes were selected. Data saturation[29] was reached after eight interviews. More interviews were conducted to achieve maximum variation of the sample.

Patient journey maps are increasingly used as an effective tool to visually compare processes, utilizing data from a variety of sources, e.g., observations, questionnaires and semi-structured interviews[46, 47]. It can provide an overview of a process, by separating specific experiences, feelings, into a series of consecutive events or steps[46–48]. In this case, we mapped the broader context of a patient's journey towards the ED-visit, to gain more insight in common themes between patient journeys in the month’s prior contributing to the onset of a crisis[47–49]. Individual patient journey maps[48, 49] were diagrammed after each interview, to clarify the trajectory in chronological order. Similarities within the individual journey maps were depicted in an overall combined patient journey map.

Results

Eligible participants (n=20) were contacted; fifteen were included and five waived the opportunity to participate due to insufficient recovery. Table 1 shows a median age of 78 years old. The average number of ED-visits was two visits in the last six months. Almost all participants had multiple chronic conditions and at least two medications daily. The majority indicated they were ADL-independent[39].

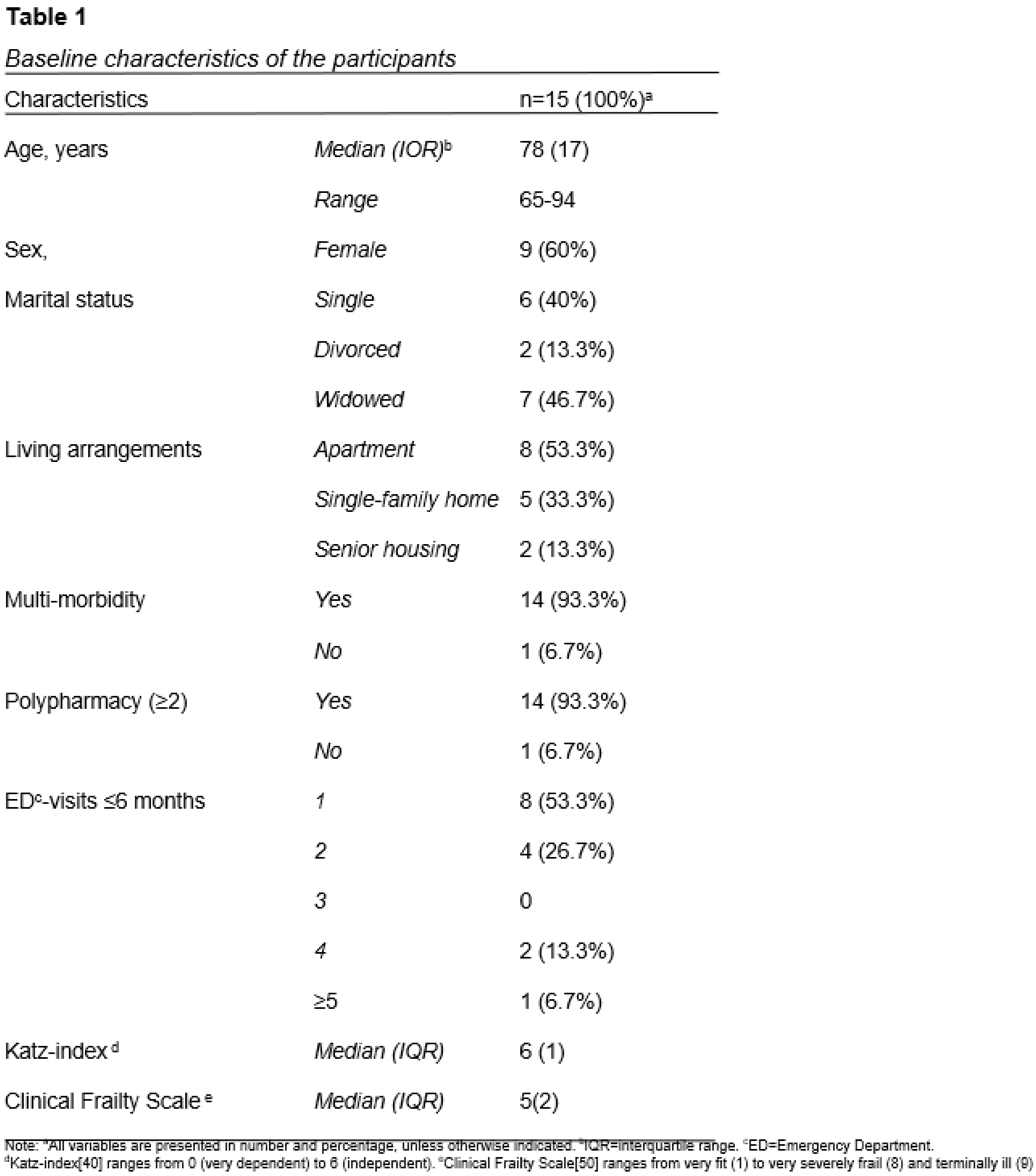

Table 1

Baseline characteristics of the participants

Characteristics		n=15 (100%)[a]
Age, years	*Median (IQR)*[b]	78 (17)
	Range	65-94
Sex,	*Female*	9 (60%)
Marital status	*Single*	6 (40%)
	Divorced	2 (13.3%)
	Widowed	7 (46.7%)
Living arrangements	*Apartment*	8 (53.3%)
	Single-family home	5 (33.3%)
	Senior housing	2 (13.3%)
Multi-morbidity	*Yes*	14 (93.3%)
	No	1 (6.7%)
Polypharmacy (≥2)	*Yes*	14 (93.3%)
	No	1 (6.7%)
ED[c]-visits ≤6 months	*1*	8 (53.3%)
	2	4 (26.7%)
	3	0
	4	2 (13.3%)
	≥5	1 (6.7%)
Katz-index [d]	*Median (IQR)*	6 (1)
Clinical Frailty Scale [e]	*Median (IQR)*	5(2)

Note: [a]All variables are presented in number and percentage, unless otherwise indicated. [b]IQR=interquartile range. [c]ED=Emergency Department. [d]Katz-index[40] ranges from 0 (very dependent) to 6 (independent). [e]Clinical Frailty Scale[50] ranges from very fit (1) to very severely frail (8) and terminally ill (9)

Perceptions on contributing factors to health crisis

The following themes emerged from the thematic analysis: 1) Complexity of healthcare; 2) Self-perception on frailty; 3) Self-management; 4) Impact of a support system in an urban environment; 5) Acute event prior to the ED-visit.

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Theme 1: Continuity of healthcare

The analyses of the interviews showed health care seeking behaviour, initiated by the participants, for the advancing symptoms in the months prior to the visit. They had contacted their GP/specialist for a specific, mostly minor, question, but did not discuss worries about their overall health status. Most participants mentioned they felt secure enough to express problems but felt a lack of involvement from their GP. They also indicated that they would have liked for the GP/practice to contact them from time to time, as a possibility to deepen this ‘involvement’. However, during the interviews these participants stated they had the impression they were not noticed by the GP.

‘And I'm like, shouldn't he just...what's it called…measure my blood pressure

or something? No, he doesn't. He just comes because of the reason I called,

then he gives something or says something, and then...he’s off again.’ [P2]

All participants were treated for multi chronic conditions at multiple hospitals/clinics, which sometimes caused for conflicting treatment or therapy advice, leaving problems unaddressed, and participants feeling to be given the run-around. This created lack of clarity about therapy, e.g., medications.

‘I've asked: “What am I actually taking?” I see a large white tablet, and a small white tablet and a black one…please tell me what it is. I'd like to know...but I haven't figured it out yet.’ [P10]

Participants described they did not always feel taken seriously, partly due to ambiguous reporting of medical history in the electronic patient record, having to repeat their status over and over again, therefore leaving things out.

‘Ma'am, I waited 5 months for an answer…5 months! After calling, calling, calling again,

asking again...5 months, ma'am! In April they took that test...and in October

I was able to speak to the doctor again, by the grace of God.

So, at this moment, that’s the biggest threat to my health.’ [P4]

In addition, they often noticed that their 'own' familiar doctors were not present at (outpatient) appointments, but a substitute, new doctor, or doctor in training, who in their opinion did not always acknowledge or recognize underlying problems.

‘I had a really good GP, but he has stopped, so I've had a new one since...well, maybe it's been

six months now...so I don't know him very well.’ [P6]

‘...so this doctor said, "Why did you come here anyway?" I say: Well, this is where I was sent,

because my heart played up again. Well, and he checks everything and listens, and he says,

“Well, ma'am,” he says, “You don't have to be here at all, you know. This is ridiculous”’ [P11]

They also perceived contacting a GP/specialist as a burden, and nuisance. As a result, necessary care was sometimes deferred.

‘I never see my doctor. Everything is done by phone...I hate that so much.

And when I do call them, they say: “I'll call you tomorrow”.’ [P12]

‘I must be honest...I'm not really keen on doctors. I don't know why,

but I...I just have something against them.’ [P15]

Theme 2: Self-perception on frailty

Participants described examples related to physical decline, multi-morbidity, polypharmacy, and social isolation in the months prior to the visit. However, nearly all participants indicated that they did not perceive themselves as ‘frail’. They perceived, ‘frail’ as ‘non-compos mentis’, stigmatizing, negative, and an infringement of their 'being'.

Well, someone...who no longer responds properly...normal. I think that's frail.

But the way I feel...we’re old, yes, that's all! But they keep nagging about “the oldies”.

If I read or hear about “the oldies”, I get pissed off...I get very angry.’ [P11]

Participants did not want to emphasize any decline, and they mentioned they were subsequently made aware by, for example family, that they tended to minimize (pre-)existing health problems or did not handle them accordingly, and delayed medical care.

‘They really let me have it! They said: “you shouldn't wait...if you have complaints.

You must get in touch right away". But I'm a bit stubborn.

I don't want to whine, you know. I'm always afraid to...burden people

for something unnecessary. That's just the way I am.' [P15]

*'He (*the GP*) already told me: you never complain. I said: I'm not going to call you for every small thing! There are already enough of those people. Who call on him for every little pain they have.'* [P2]

However, some participants also described 'being frail' as unavoidable for the years to come and mentioned applying lifestyle changes in preventing decline.

'You think: "everything goes without a hitch", but yeah...of course, you have to face reality.

I am 76; in 10 years I'll be 86...things will look different.' [P4]

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Theme 3: Self-management

All participants mentioned their desire to continue everyday life in their own home. They talked about the future, especially related to the ending of COVID-19. They described their views on taking responsibility for their own health, and health-related skills (e.g., medication management and wearing alarm-necklaces), and found them to be generally adequate.

Some participants also mentioned change in living status was probably needed in the future due to functional decline, but they equated the change to come with a loss of independence and quality of life.

Look, if someone is totally dependent... okay... then I'll have to. But not yet, for me. No, really!

I enjoy myself too much living here...together with my cats. [P2]

However, they were reluctant to move to a residential care-facility, mainly because of decreased independent decision-making.

'No! The boys want me to live in a... I don't know...a home. But I do not want to.

No...it would be awful to live in a home.' [P11]

Although the majority indicated they were self-supported in daily activities, they also mentioned several difficulties. Finances were often handled by the support system, as they were unfamiliar with electronic banking. Housekeeping was not always done. Cooking was perceived by some as tiring; participants indicated eating microwave meals, just a sandwich, or relying on a (professional) support system for meal supply.

'I can reach the kitchen, then Homecare places everything on the kitchen table…together…completely arranged. Prepared. Then all I must do is sit down. Then I can manage.' [P7]

Participants were resourceful, and mentioned applying strategies to cope with limitations, e.g., using a magnifying glass and flashlight when walking around the house because of visual impairment.

'Housekeeping is a bit tough. I can do the laundry…but I need a

flashlight…because of my bad eyesight.' [P6]

Theme 4: Impact of a support system within an urban environment

All participants mentioned needing (professional/informal) support. This was perceived as 'normal', and not considered a burden for the caregiver. However, when talking about consequences of any loss or change within their support system, it was found difficult and confronting.

'Please, do me a favour! No, I depend on those two boys, and I just don't know what would happen

if they weren't there. I don't wanna think about it!' [P11]

Social isolation was mentioned, partly due to the COVID-pandemic, but mainly because of less social contacts, and reduced mobility. Participants described the importance of television to stay in touch with society; especially in the evenings, loneliness was felt the most.

'I am 92 years old. People of my generation passed away, so you are happy

when someone calls you…saying: "I'm coming over".' [P6]

'I feel lonely, yes. Very lonely too. I feel lonely every day. Especially in the afternoons.

In the morning it is not bad, but after six, seven o'clock I start to…get bored.

Because then I'm lonely. Everyone is away, everyone is with their families.

Yeah, you know, and I'm by myself…all day.’ [P7]

Living in the metropolitan Amsterdam, seemed to have a positive effect on perceived quality of life. Most of the participants did not want to move, indicating they would feel more isolated due to limited social contacts, events, and neighbourly watch.

‘I always sit in the conservatory. And I can look around.

I see the trams, I see the buses, I see people walking their dogs,

and…then I am blissfully happy just sitting there.’ [P6]

‘The neighbour across the street…a real Amsterdam mentality; you don't have to try or tell her anything…and with a heart of gold. We talk to each other and keep an eye on each other. Yes, yes, sure.’ [P3]

When having issues, health related or otherwise, several participants indicated they felt the need to discuss matters first with family or neighbours for consult, ranging from moving to a care-facility to calling the GP/specialist, causing possible delay in care and accumulation of problems. When asked about plans after discharge, a participant responded:

(Participant shrugs) ‘I don’t know…what will happen to me. I have to discuss it first

with my children, with the boys.’ [P11]

‘The night before I was in a lot of pain, and I’m sorry to say I had to call my upstairs neighbours in the middle of the night. They got me out of bed, and…uh…then I sat on the couch for the rest of the night. Well, then in the morning they called the doctor and everything was set in motion.’ [P6]

Theme 5: Acute events that led to the ED-visit

Participants described an acute event preceding the ED-visit. Most cited were a fall, urinary tract infection (UTI), and dizziness, one to three days prior.

‘I got up from the toilet…and…like a bolt from the blue…extremely dizzy.’ [P8]

‘…because I… apparently fell or bumped my head. And I really never fall. I don't even know how

this came about.’ [P10]

Although this acute moment was clearly identifiable for the participants, participants also often mentioned that during the months prior things were slowly going less in daily life. Approximately four weeks prior, specifically seemed to be a demarcation in time. Participants talked about how events occurring around that time, e.g., side-effects of newly prescribed or changed doses medication, vacation of a caregiver, previous admission, or infection, seemed to initiate a downward spiral.

‘Those complaints actually started somewhere after New Year…oh yes…from about 3 weeks ago.’ [P6]

‘…about one week after surgery, I couldn't keep anything down. No eating, no drinking,

even a sip of water…eh…and I tried for ten days…then I called the doctor,

and he said: “…this isn't stomach flu; there’s something else going on!’ [P15]

‘I've been letting it slip a bit, lately; that, well…I did eat, but mostly bread…that's been

around 3 or 4 weeks, you know.’ [P12]

‘I took care of my demented husband. I let it get a bit too far; I wanted to keep him at home.

Well, that was a bit too much for me. So, if I hadn't been so stubborn and let my husband

go to a care facility sooner, I might have avoided this situation a month ago.’ [P1]

For the participants, these contributing factors were not always seen as related or inducing a health crisis. However, the contextual thematic analyses show they could be seen as precipitating events and a cohesive part of the acute event.

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Patient journey mapping

For patients, difficulty in accessing or navigating health care systems, can lead to delays in assessment, diagnosis, and treatment[51]. In research, patient journey mapping is used to explore patients experience on these issues, and studies shown their value to improve quality, identify gaps in services, and express their concerns and considerations about how health care services should deliver care.

By analysing and placing the data in chronological order, the following similarities were found, as depicted in Figure 1.

We found that in the six-nine months prior to the ED-visit, most participants were treated for multi-morbidity by a GP and/or multiple hospital-based specialists. However, annual check-ups were cancelled due to deferred care. As a result, e.g., necessary blood samples or discussing medication-schedules were postponed, leaving details on health status unattended.

From about six months, the participants indicated poor sleeping habits, poor appetite, and increased fatigue, causing reduced mobility and physical decline. As a result, most participants had not been outside in the months prior to the interview. Problems arose, but could still be disguised by using, e.g., a mobility device. The GP/specialist was contacted; however, this was only regarding a specific question, not addressing ‘the bigger picture’, and the overall deterioration.

We noticed a time demarcation about four weeks before the ED-visit. The participants indicated an inducing event, e.g., increase in stress or anxiety, changes or side effects of medication, a medical procedure, previous admission, vacation of caregivers, or new GP. This caused a negative shift between load and capacity, reducing participant’s reserves to recover.

One to three days before the ED-visit an acute event occurred: a fall, UTI, or (severe) dizziness. The participants did not primarily contact their GP, but mostly called their support system to consult. This caused a delay in an adequate medical response.

Either GP or ambulance was then usually called by family or neighbours because of increasing complaints and deterioration of the patient. The GP mostly assessed this situation by phone, after which an ambulance was called, and the participant was transferred to the ED.

Discussion

Five themes emerged from interviewing frail older adults who lived alone. These included: 'continuity of healthcare', 'self-perception on frailty', 'self-management', 'impact of support system within an urban environment', and 'acute event prior to the ED-visit'. The patient journey map identified uncoordinated care by healthcare providers, deterioration from at least six months before the ED-visit, and an unexpected event that leads to an acute health problem four weeks prior to the ED-visit.

We found that older adults perceived an acute event as the main reason for the ED-visit, being a fall, UTI or dizziness. However, more contributing factors emerged as well, which analysed contextually showed clear connections to this 'acute event' from a health care perspective but were not necessarily perceived as such by the participants. Also, as hypothesized, chronological similarities were revealed when comparing individual patient journey maps. The combined journey map gave us more insight in the period before the ED-visit and showed that often a health crisis is preceded by general decline and difficulty in ± 9 months prior.

The beginning of the journey map, and first theme, showed a lack of continuity in care provided to the older patient, also related to the complex structure of health care. 'Navigation' challenges may result in parts of the system becoming overloaded (such as emergency services) while other sections (such as preventive and primary health care services) become underutilized[51]. The theme also revealed that participants sometimes felt left out, also due to, e.g., under-coordinated care between multiple health care professionals/facilities, causing ambiguities about when to do what. In frail patients, apparently minor things can result in a cascade of negative medical events[17]. And with health care systems largely evolve to identify and address single pathologic conditions[20], such as a heart attack, stroke, or fractures, it makes them less capable of recognizing these minor issues, especially in settings of acute illness or injury. Literature endorses being addressed on own strengths and capabilities as difficult for older people with limited health skills, social skills or low literacy and having difficulty finding, understanding, and asking for information about care and support[52, 53]. Understanding the barriers and facilitators of patient access to appropriate and timely care, is an important step toward improving quality and safety[51]. There seems to be a need for a central point-of-contact or case-manager, who can guide and anticipate adequately if necessary. This could be, for example, a Nurse Practitioner specialized in geriatric care[54, 55] in close collaboration with specialized district nurses. Furthermore, uniformity in registering data and standardizing events to make information easily exchangeable inter-organizational, could improve monitoring of the older adults' situation[53], e.g. by using the International Classification of Functioning, Disability and Health[56].

The second theme 'self-perception on frailty', described the felt perceived negative stigma. Although a familiar term, frail older adults tend to reject this when used on themselves, also making a distinction between 'being frail', in the clinical sense, and 'feeling frail'. This is in line with recent studies[23, 57], which associated negative perceptions with poorer health outcomes, including disability and functioning, and cognitive performance. Inadequate interpretation of 'frailty' triggered resistance and reluctance to seek help. An earlier acceptance of limitations has demonstrated a positive impact on health behaviour and outcomes[57, 58]. Disseminating knowledge on frailty[57, 59] could alter feelings of this stereotyped frail identity, especially since the individual course of frailty varies[59], and therefore may need customized planning as well[60, 61]. We should also consider how healthcare professionals communicate about frailty with older patients; choice of words is crucial to not provoke a negative reaction and avoid stigmatizing[57, 62]. Maybe new terminology is required; the ‘Decade of healthy ageing’[63] uses the term “intrinsic capacity” when referring to healthy aging. This is less focused on deficits, and more from a holistic view by using state of well-being, physical and mental health, independence, and social participation[62].

The theme ‘self-management’ supported findings of previous studies[23, 64] with participants not perceiving themselves, or wanting to be perceived, as needing assistance. Asking for help was seen as a turning point in their sense of well-being, and a threat to their independence. However, the necessary healthcare skills and behaviour concerning self-management were not always naturally present in the participants or seemed to lag. As frailty being strongly related to decline in self-management abilities[53, 58, 65, 66], enhancing self-management skills through, e.g. organized community-programs, can mediate this negative effect[64, 66].

In addition, the fourth theme ‘impact of a support system within an urban environment’, described the high reliance on daily support by caregivers, being essential for maintaining independence. The participants did not always find it easy to admit, afraid of possible consequences of conclusions that they were not able to manage it at home and that a care-facility would be a better option. But also, networks may get overburdened or unavailable, leading to isolation with major consequences. Research stated that frail older adults with poor psychosocial resources showed an increased odds of both a 12-month mortality, and a need for higher levels of care if they had lower levels of wellbeing, social activities, and enjoyment of their home/neighbourhood[3, 53, 58]. In a large city like Amsterdam, the principle of 'a good neighbour is better than a distant friend', proved to be valid. Neighbours and/or the neighbourhood, are an important part of the social system of older people, and appeared to be an invaluable asset to them, which is supported by literature[67]. By acknowledging and recognizing their social support system, and actively including them in decision-making practices, would be an essential step in signalling burden, thereby reducing negative effects for older adults in the long run.

The fifth theme ‘acute event prior to the ED-visit’ showed the direct reason for the ED-visit according to the participants, but also a possible precursor occurring approximately four weeks prior. This time demarcation showed an 'event' taken place, accelerating deterioration. Such an event could be change of medication, a caregiver going on holiday, different or substitute GP, previous admission, etc. This specific time demarcation corresponds with two previous studies[15, 16], and suggests the onset of severe imbalance in ‘load and capacity’, indicating the need for closer monitoring during this period to prevent escalation.

The combined patient journey map showed clear similarities, indicating that anticipating strategies on future clinical practice, e.g., closer monitoring and knowledge dissemination, may reduce healthcrises and hospitalizations. If we use this to assess frail older people, and treat underlying causes of deterioration using an integrated care pathway, there is great potential to make them less dependent, immobile, fearful and by doing so, less reliant on hospital care[68].

Strength and limitations

As a strength, purposive sampling created heterogeneity of the sample. Data saturation on all themes was achieved within the fifteen interviews, strengthening the transferability of the results. To improve trustworthiness, the data were independently analysed by three researchers, discussed within the RT, and peer-debriefed by other junior-researchers to reduce risk of bias, resulting in quality enhancement. Using the Braun & Clarke TA-checklist[43, 44] and COREQ[30], increased reliability and transparency. Member-check was used to deepen the discussion during the interviews, which established credibility of the data.

As a limitation, recall bias on accuracy of self-reported data over the past six-nine months, must be considered. Furthermore, although purposive sampling was applied, participants admitted to a metropolitan university hospital, differ from the population of a more rural general hospital, which may be aligned to selection bias related to the setting, and should be considered in future research.

We recommend a more inter-organizational approach, using a framework for uniformity in data-registration and standardizing events, to prevent continuous repetition of medical history and thus avoid possible miscommunication between patients, social network, and professionals. For example, the International Classification of Functioning, Disability and Health[53, 56], can identify patients with frailty at the most appropriate stage of the patient journey.

In this same context, the geriatric patient could benefit by an assigned case-manager for continuity and clarity. In addition, the patient journey map shows that in the event of a change related to the social network or medical treatment, a quick follow-up is necessary to properly identify and anticipate any problems; a process that a case manager could also supervise.

Given the negative stigma[23, 57], knowledge on 'frailty' should be disseminated among community-dwelling older people, combined with interventions to promote healthy aging to delay the onset of frailty, or reduce its adverse outcomes. Also, normalizing early advance small case care planning is important to avoid unnecessary transfers to the hospital, with all the consequences this entails.

Larger-scale research is needed to validate and confirm the four weeks’ time demarcation evident in the patient journey. We identified specific triggers around this time, given us the opportunity to monitor in more detail to avoid these crises situations.

Conclusion

Frail older adults’ perceptions on factors related to health crises, were directly linked to an acute event. More contributing factors leading up to a health crisis, were not interpreted accordingly. This gradually created a cascade of problems, difficult to counter when someone is already frail. By generating knowledge, standardizing frequent assessments of daily life, and intervening at an earlier stage, the risk of a potential crisis and hospitalization could be reduced.

The chronological similarities of the individual patient journey maps suggest that strategies can be applied in daily life and geriatric care, to inform older adults, be more patient-oriented, and provide a fitting plan together towards advance care planning, healthy ageing, and admission avoidance.

List of relevant abbreviations

ADL	Activity of Daily Living
CFS	Clinical Frailty Score
COREQ	Consolidated Criteria for Reporting Qualitative Research
ED	Emergency Department
EDQ	Exploratory-Descriptive Qualitative
EPF	Electronic Patient File
GP	General Practitioner
GST	Geriatric Specialist Team
RT	Research Team
SR	Senior Researcher
TA	Thematic Analysis
UTI	Urinary Tract Infection
WMO	Medical Research Involving Human Subjects Act; in Dutch: Wet Medisch-wetenschappelijk Onderzoek met Mensen
QDA	Qualitative Data Analysis

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Figures

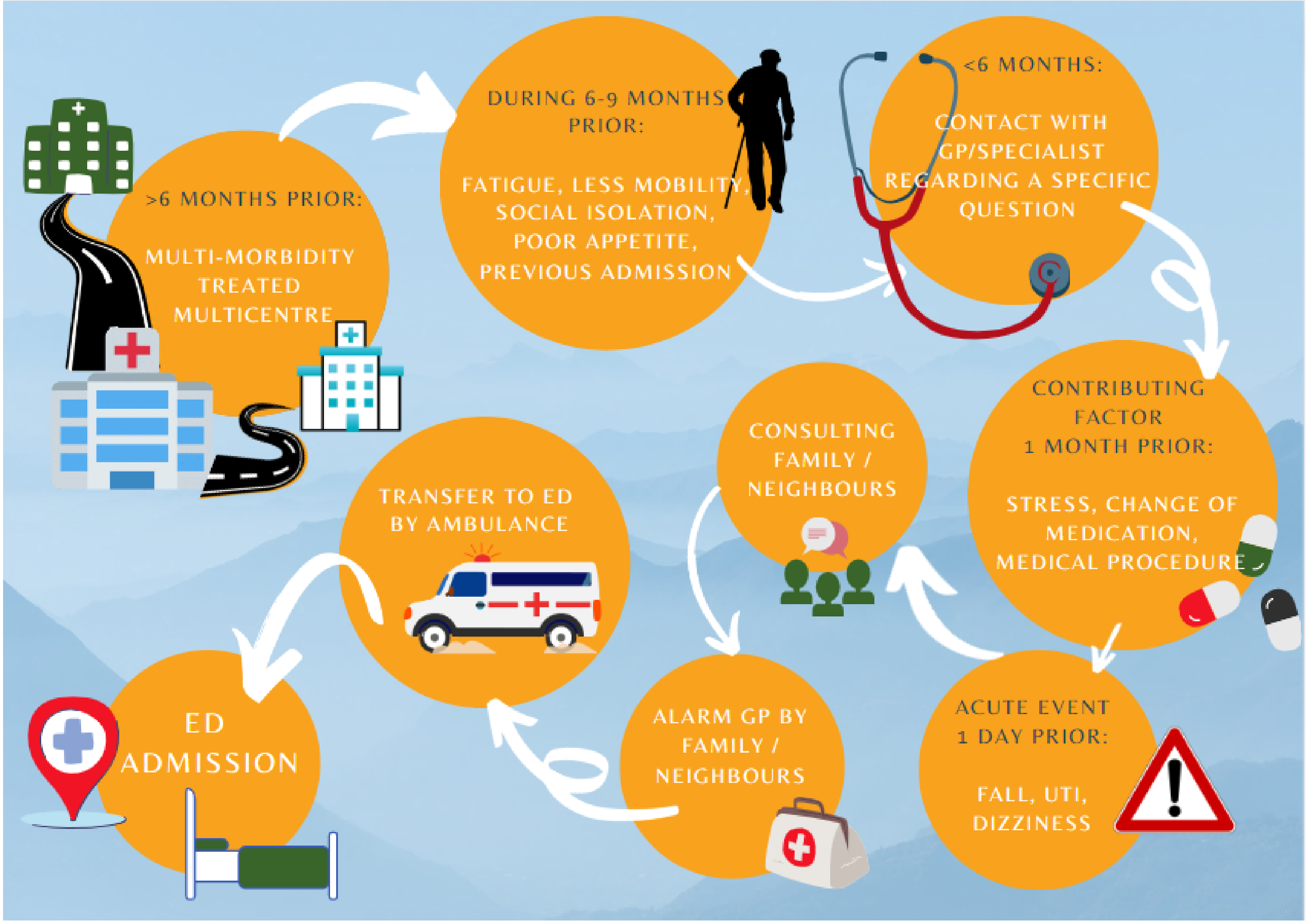

Figure 1

Combined chronological Patient Journey Map

GP=general practitioner; UTI=urinary tract infection; ED=emergency department

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- AppendixA.docx