

Patients' perceptions of frequent hospital admissions:

A qualitative study with elderly above 65 years

Miaolin HUANG

Carolien VAN DER BORGHT

Promotor: Prof. Dr. Geert Goderis

Copromotor: Merel Leithaus

Proefschrift ingediend tot het
behalen van de graad van
Master in management en beleid van de
gezondheidszorg

Academiejaar 2018-2019

Voorwoord

Na onze intensieve masteropleiding, leggen we de laatste hand aan deze masterproef. In de voorbije drukke, maar leerrijke periode kregen we de kans om nieuwe kennis op te doen en om persoonlijk te groeien op zowel wetenschappelijk als professioneel vlak. We stonden er echter niet alleen voor om deze thesis tot stand te brengen en daarom zouden we graag van deze gelegenheid gebruik maken om de mensen die ons steunden te bedanken.

Eerst en vooral willen we onze hoofdpromotor prof. Dr. Geert Goderis en copromotor Merel Leithaus bedanken voor hun tijd, begeleiding, enthousiasme en behulpzaamheid gedurende deze masterproef. We wensen hen verder nog heel veel succes toe in hun professionele en academische carrière.

Verder willen we Prof. dr. Johan Flamaing, afdelingshoofd van de dienst Geriatrie en de hoofdverpleegkundigen Stefanie Muylle (E455), Raf Beneens (E641) en Bart Vander Elst/An Cuveliers (E640), evenals de gehele verpleegkundige staf hartelijk bedanken voor de hulp tijdens de datacollectie op hun geriatische afdeling. We wensen hen nog veel succes toe in hun professionele carrière.

Tot slot willen we onze familie en vrienden bedanken voor hun steun, maar vooral hun luisterend oor wanneer dat nodig was.

Patients' perceptions

of frequent hospital admissions:

A qualitative study with elderly above 65 years

Table of contents

| | |
|---|-----------|
| Abstract | 1 |
| Introduction | 3 |
| Methods | 5 |
| Results | 7 |
| <i>Participant Characteristics.....</i> | <i>7</i> |
| <i>Perceived Causes of Frequent Hospital Admissions</i> | <i>7</i> |
| <i>Contributing Factors</i> | <i>8</i> |
| Medical | 9 |
| Non-medical..... | 10 |
| Patient..... | 10 |
| <i>Perceived Consequences of Frequent Flyer Status.....</i> | <i>11</i> |
| Mental status | 11 |
| Spiritual/existential dimension | 12 |
| Social participation..... | 13 |
| Body..... | 13 |
| Daily life functioning..... | 14 |
| Quality of life | 14 |
| Discussion..... | 15 |
| Conclusion | 19 |
| References..... | 20 |

List of figures

| | |
|--|----|
| Figure 1: Perceived causes of frequent hospital admissions..... | 7 |
| Figure 2: Perceived consequences of frequent flying status | 11 |
| Figure 3: Vicious cycle due to the patient's behavior..... | 16 |
| Figure 4: Vicious cycle due to lack of confidence in primary care physicians | 16 |

Abstract

Background

Although frequent flyers represent barely three to eight percent of the total patient population in a hospital, they are responsible for 12 to 28 percent of all admissions. This is a disproportionately high amount of all admissions. Moreover those hospital admissions are an important contributor to healthcare costs and overpopulation in various hospitals. A lot of quantitative research has focused on the frequent flyer, but only few studies have incorporated the patient's perspective.

Objectives

The overall aim of this research is to comprehend the phenomenon of the frequent flyer. Our objectives were to understand the patients' perspectives on the cause of their frequent hospital admissions and to identify the perceived consequences of the frequent flyer status.

Methods

This study took place at the University Hospital of Leuven, campus Gasthuisberg in Belgium. The inclusion criteria included: at least four overnight admissions in the past 12 months, age above 65 years and admitted at the time of the study. Data was collected during hospitalisation via semi-structured interviews and analysed according to QUAGOL guidelines.

Results

A total of seventeen perceived causes were identified which could be divided into six themes namely patient, drugs, primary care, secondary care, home and family. Most of the causes were preventable or modifiable. The perceived consequences of being a frequent flyer were divided into six themes namely body, daily life functioning, social participation, mental status and spiritual dimension. Negative experiences were linked to a frequent flyer status and could be situated mainly in the categories of social participation, mental status and spiritual dimensions.

Conclusion

This study offered an in-depth insight into the perceived causes of frequent hospital admissions and identified the experiences of frequent flyers. Few qualitative studies have been published in this field of research, while they can provide added value for understanding this phenomenon and ultimately ensuring that frequent hospital admissions can be avoided. Further research is therefore crucial.

Achtergrond

Hoewel *frequent flyers* nauwelijks drie tot acht procent van de totale patiëntenpopulatie in een ziekenhuis vertegenwoordigen, zijn zij verantwoordelijk voor 12 tot 28 procent van alle ziekenhuisopnames. Dit is een buitensporig hoog percentage van alle ziekenhuisopnames. Daarenboven dragen die frequente ziekenhuisopnames in belangrijke mate bij aan de kosten van gezondheidszorg en de overbevolking in verschillende ziekenhuizen. Er werd al veel kwantitatief onderzoek verricht naar de *frequent flyer*, maar er zijn slechts weinig studies die vanuit het perspectief van de patiënt vertrekken.

Doel

Het algemene doel van deze studie bestaat erin het fenomeen van de *frequent flyer* beter te begrijpen aan de hand van twee onderzoeksvragen namelijk wat is het perspectief van *frequent flyers* omtrent de oorzaken van hun frequente ziekenhuisopnames en wat zijn de gevolgen van een *frequent flyer*-status?

Methode

Deze studie vond plaats in het Universitaire Ziekenhuis van Leuven, campus Gasthuisberg. De inclusiecriteria hielden in: minstens vier hospitalisaties met overnachting in de afgelopen 12 maanden, een leeftijd boven de 65 jaar en gehospitaliseerd op het moment van de studie. De patiënten werden tijdens hun hospitalisatie ondervraagd via semigestructureerde interviews en de gegevens werden vervolgens geanalyseerd aan de hand van de QUAGOL-richtlijnen.

Resultaten

In totaal werden er zeventien gepercipieerde oorzaken geïdentificeerd die in zes thema's onderverdeeld werden, met name patiënt, geneesmiddelen, eerstelijnszorg, tweedelijnszorg, thuis en familie. De meeste oorzaken konden bijgestuurd of voorkomen worden. De gepercipieerde gevolgen van de *frequent flyer*-status werden onderverdeeld in zes thema's, namelijk het lichaam, dagelijks functioneren, sociale participatie, mentale status en spirituele dimensie. Negatieve ervaringen werden gelinkt aan *frequent flying* en konden vooral gesitueerd worden in de categorieën sociale participatie, mentale status en spirituele dimensie.

Conclusie

Deze studie biedt diepgaand inzicht in de gepercipieerde oorzaken van frequente ziekenhuisopnames en brengt de ervaringen van *frequent flyers* aan het licht. Er zijn weinig kwalitatieve studies gepubliceerd in dit onderzoeksgebied, terwijl ze een toegevoegde waarde kunnen bieden om dit fenomeen beter te begrijpen en uiteindelijk kunnen leiden tot minder frequente ziekenhuisopnames. Verder onderzoek omtrent dit onderwerp is daarom cruciaal.

Introduction

In Belgium, the demand for healthcare continues to rise while the supply stagnates. In 2017, the total health expenditure climaxed at 28,539 billion euros, corresponding to 10,0 percent of the gross domestic product. Although there has been a marked decline in health expenditure growth in the recent years, cost containment and efficiency remain essential to keep health care accessible and affordable (1,2).

In secondary care, hospitalisation is one of the main sources of health expenditure. The number of hospital admissions has increased by 11 percent from 2006 to 2015 (1). This can partly be attributed to frequent flyers which are patients who have been admitted at least four times in 12 months (3-6). Although frequent flyers represent barely three to eight percent of the total patient population in a hospital, they are responsible for 12 to 28 percent of all admissions. This is a disproportionately high amount of all admissions (7,8). In addition, the readmission ratio of Belgian hospitals within 30 days of discharge varies between 2,4 percent and 7,8 percent. Hence, admissions for these patients are more complex and almost twice as likely to result in another readmission. Finally, those frequent hospital readmissions are an important contributor to healthcare costs and overpopulation in various hospitals (9).

The group of frequent flyers can be divided into elderly over 65 years, patients with psychiatric disorders, patients with chronic conditions and patients with a low socioeconomic status (10). In this study, the focus lies on the group older than 65 years because of the increasing life expectancy of the Belgian population. Over the past twenty years, annual life expectancy has increased by an average of 76 days and is currently 81,4 years. The ageing of the population has a number of health implications, such as a marked increase in chronic diseases, comorbidities and care needs. The incidence of one or more chronic diseases or disabilities in the elderly is 48,80 percent. Moreover, these patients have a relatively long disease duration and the average number of days spent inpatient is twice as high as for patients aged 15 to 65 years. This means that the costs of medication, treatment and hospitalisation for the elderly constitutes a significant additional cost for health care (2,11,12).

Recently, the concept "hospital dependency" was introduced. It describes patients who improve during their admission but quickly deteriorate after dismissal, resulting in recurring hospitalisations. Frequent flyers also fit into this category. It remains unclear whether the admissions are appropriate and whether the hospital dependency can be reduced by interventions or by addressing factors (13). In Europe, intervention programs reducing frequent hospital admissions are becoming a priority in any case (14). Frequent flyers often have multiple chronic conditions and unique requirements that are not always met by conventional approaches to healthcare delivery (15).

Ultimately, great attention must be paid to frequent flyers as they are vulnerable individuals with a high need of care. Although a lot of quantitative research has focused on the identification of risk factors, triggers and the implementation of interventions, only few studies have incorporated the patient's perspective. This is, however, very important as patients may be aware of healthcare aspects that healthcare providers do not know. Several studies have demonstrated that some knowledge, for instance about adverse events and medical errors, was only detected from the patient's perspective and not by other methods (16). Therefore,

this study aims to comprehend the phenomenon of the frequent flyer from a patient's perspective. The objectives were to get an in-depth understanding of the perceived causes of frequent hospital admissions, to identify the perceived consequences of being a frequent flyer and to expose the contextual elements of frequent hospital admissions (perceived causes, contributing factors and perceived consequences) and the interactions between these elements.

What is this paper's contribution to the wider global clinical community?

- This article offers in-depth understanding of patients' perspectives of the cause(s) of their frequent hospital admissions.
- This article shows how patients experience the consequences of being a frequent flyer on their current state.
- This article exposes the contextual elements of frequent hospital admissions and their interaction.

Methods

Study Design

The qualitative study took place at the University Hospital of Leuven (UZ Leuven) in Belgium. This study has a phenomenological design and was carried out between January 2019 and May 2019. The COREQ (Consolidated criteria for Reporting Qualitative research) guidelines were followed to provide rigour to the study. For more information about the research team and reflexivity, see appendix 1 (17).

Study Population and Recruitment

The study population was recruited in the three geriatric departments of UZ Leuven campus Gasthuisberg. Once a week, eligible participants were identified by reviewing the electronic medical records. The inclusion criteria included: at least four admissions in the past 12 months, age above 65 years and admitted at the time of the study. The exclusion criteria were: poor hearing function, a known diagnosis of dementia, delirium, non-Dutch speaking, DNR3 and no speech. Eligible participants were approached by the researchers (CVDB and CMH) during their hospital stay and were given both oral and written information. The ones wishing to participate signed an informed consent (see appendix 2).

Data Collection

During the semi-structured interviews an interview guide was utilised which was based on literature and the objectives of the study (18-20). See appendix 3. The guide was first pilot-tested on a potential participant whose transcript was included in the final analysis. Depending on the obtained information, the guide could be revised to fill in the blind spots of the study. The interviews were audio recorded for subsequent transcription and coding. After each interview the findings were discussed among the researchers. The overall process was repeated until reaching data saturation i.e. when no new themes emerged. Finally, no compensation was given to the participants and no field notes were made.

Analysis

The recordings were transcribed verbatim, anonymised and analysed following the QUAGOL (Qualitative Analysis Guide of Leuven) guidelines, an iterative guidance tool for qualitative data analysis (21). First of all, all interviews were transcribed into a text document. The two researchers (CVDB and CMH) first became familiar with the interviews by reading, analysing and discussing the content of the transcriptions. The next step was to independently compile a narrative summary report for each interview. This report was then summarised in a conceptual interview schedule, in which the concrete findings were described on a more abstract conceptual level. The two authors re-read the interviews with the selected topics in order to discuss potential discrepancies. This was done during regular meetings in order to improve the quality of the conceptual interview schedules.

Subsequently, the coding process started. This process consisted of two parts, the preliminary coding and the effective coding. In the preparation phase, a list of topics was drawn up based

on the conceptual interview schedule. In this way, a codebook with code definitions was developed (see appendix 4). During the meetings, the first coding was discussed and further modified with the agreed terms in the codebook. The data was encoded in QSR International's NVivo version 11 Pro.

Finally, the Ishikawa diagram and spider plot were used to describe all concepts and integrate them into a general conceptual framework that illustrates the findings and provide answers to the research questions. Codes were divided into perceived causes and contributing factors. Causes were perceived as responsible in 'direct' causal way for frequent flying whereas contributing factors influenced frequent hospital admissions by increasing its likelihood, accelerating the admissions in time or affecting the severity of the consequences. Perceived causes were subdivided into 'underlying causes' and 'triggers' whereas contributing factors were subdivided into medical, non-medical factors and family. The model of Machteld Huber about positive health was used to subdivide the consequences that patients experienced, due to their frequent hospital admissions (22). After the study, the recordings were removed.

Results

Participant Characteristics

A total of thirteen interviews were collected. There were no dropouts, refusals or repeated interviews. In some cases first-degree family members were present. Their answers were also included. The interviews usually lasted 40-50 minutes. No transcripts were returned to participants. The participants were on average 85 years old, were admitted on average four times in the last 12 months and more than half were women (53,85%).

Perceived Causes of Frequent Hospital Admissions

A total of seventeen perceived causes were identified which could be divided into six different categories namely patient, drugs, primary care, secondary care, home and family. Most of the causes occurred in the categories patient, primary and secondary care. Each cause was either a trigger or an underlying cause. In total fewer triggers (35,3%) have been identified than underlying causes (64,7%). These triggers were found in the category drugs, secondary care and patient. In addition, most of the causes could be prevented or modified (76,5%). Some participants indicated that if these causes were solved, admissions would happen less often. Finally, it is noteworthy that all the causes in medical care are preventable or modifiable. In primary care, admissions were related to underlying causes and in secondary care to triggers (see figure 1).

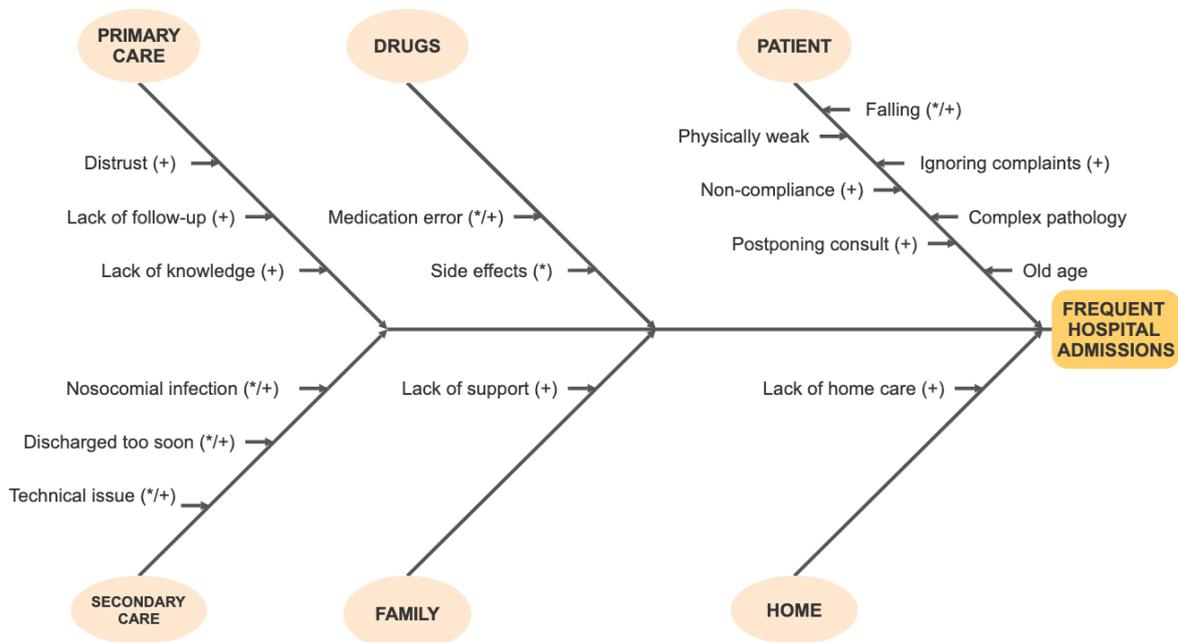


Figure 1: Perceived causes of frequent hospital admissions (*= trigger, += preventable/modifiable)

In the patient category, old age, physically weak and complex pathology were the most common causes but they are not modifiable. However, falling was a major trigger that can be prevented.

“Getting old is nice, but being 25 years is much nicer. (...) Ageing is a blessing in disguise. You can't keep up anymore because of the age.”

Participant 2, old age

In addition, causes related to the patient's behaviour were also identified namely ignoring complaints, non-compliance and postponing consult. This behaviour has led to frequent hospital admissions but it is modifiable or preventable. In some cases, this kind of behaviour was induced by the bad experiences of other patients.

“If I had taken my antibiotics earlier, I might not have caught it chronically. It's because of me and not the clinic.”

Participant 2, non-compliance

Furthermore, side effects and medication errors also triggered frequent hospital admissions. In theory they are preventable, but in practice it is difficult to avoid side effects. The lack of home care and family support were identified as well as underlying causes of frequent hospital admissions. The need for family support was strongly highlighted during a number of interviews.

“He [son] doesn't come to the clinic very often and certainly not because of his clinic phobia, so he doesn't come to the clinic and he doesn't come to the nursing home much either. (...) Only the daughter who is coming to get me now. She knows that she is the only one and then it starts to bother her.”

Participant 1, lack of family support

Finally, there were medical causes such as lack of follow-up, lack of knowledge, technical issue, discharged too soon and nosocomial infection that can be prevented. The distrust in primary care physicians went hand in hand with the confidence in specialists. As a result, the participant wanted to be treated by his specialist and no longer by the primary care physicians.

Contributing Factors

Alongside the perceived causes of frequent hospital admissions, contributing factors were found. A total of 14 categories were identified and divided in three areas i.e. medical, non-medical and patient. For an overview of all the contributing factors see appendix 5. As expected, some overlap between causes and contributing factors was found according to the expressed nuance of the participants and indicating a continuum in the 'degree' of perceived causal determination.

Medical

First, the problems with general practitioners were about lack of follow-up, lack of information, lack of initiative, lack of knowledge, lack of patient involvement, wrong estimation and professional jargon. These factors may have led to a loss of confidence in general practitioners.

“The doctors [general practitioner and physician in nursing home] didn't want to find a solution on their own. They have been saying long “yes they said that in the clinic” but it did not come from them.”

Participant 1, lack of initiative

In addition, the availability of general practitioners was also a drawback. The search for a good general practitioner was a difficult task and even if they had a good one, the participants felt that little time was provided for them.

“In September I had a stroke and at the clinic they said to me: your doctor must come to you this evening [Friday]. I come home and I make a phone call. I don't have time, I'll send my colleague... ON MONDAY.”

Participant 9, too busy general practitioner

Secondly, in the nursing homes poor coordination, miscommunication and insufficient care were identified as contributing factors. It was mentioned that physicians did not take enough initiative to address the problem and gave insufficient attention to patient involvement. Also wrong estimations and medication errors were made in the past. All this had also led to a distrust towards physicians in nursing homes.

Thirdly, the hospital and specialists were mentioned. On one hand, fragmented and insufficient care were revealed. For example, it was mentioned that there were too many treating physicians, that responsibilities were passed to others, that double therapy occurred and that overreporting took place. Patients were not treated with a holistic approach and patient-specific care was lacking. A criticism of the profession was that it is over-specialized. On the other hand, the hospital was also praised by some participants. They felt well cared for and had confidence in the hospital. One participant argued for admission because he wanted to be treated by the specialist and not by a primary care physician. In addition, many participants have pointed out that although they prefer to be at home, the hospital admissions were experienced as pleasant and professional.

“It's laughable. ENT (ear, nose, throat), it won't take long before there comes a doctor one for the nose, one for the throat and one for your ears. One for your left ear and one for your right ear. So far, this is how the specialisation is progressing.”

Participant 11, over-specialisation

Finally, polypharmacy was cited in almost every interview. The participants were taking a lot of medication without proper knowledge of its indication. Many participants did not prepare their medication themselves, but let others prepare it for them e.g. family members or home

nurses. Transmural care also remained an issue, where sometimes no proper care and information were provided after dismissal. As a result, participants did not know how to continue their treatment after they were discharged.

"I don't know what I'm getting anymore. At least 10, 11 or 12 pills early in the morning and in the afternoon about 3 and in the evening about 2-3 pills. Then also an inhaler"

Participant 1, polypharmacy

Non-medical

Non-medical problems included family, home care and social environment. This study identified a lack of home care, neighbourly contact and other social contacts. Some participants have no friends left because these have already passed away. Because of this, participants mainly rely on their existing family members. In some families a lack of support and contact was seen. Some participants even have a quarrel with their family and they do not speak to each other anymore. Others disagreed with their relatives about the care they should receive. Finally, the loss of a loved one and widowhood were also mentioned as contributing factors of frequent hospital admissions.

Patient

Patient-related problems included behaviour, physical factors, finances, lifestyle and others. Most of the contributing factors were related to the patient's behaviour. For example, there were participants who did not care about the medical advice they received and were easily satisfied. Others were interested in their medical condition, but they could not understand everything and were afraid to ask for clarification. There were also participants who would not independently seek help without the permission of their general practitioner.

In addition, there were participants who had postponed their treatment because of the bad experiences of their family members. Some lied to their physicians about quitting smoking. There were also participants who did not accept home care because they were afraid of strangers. Others were too proud to admit that they cannot do everything on their own and need help.

Furthermore, healthcare also involves high costs which played a role in the decision making of the patient and his family members. In some situations, the participant did not receive the necessary home care because of the financial barrier for the family. On the other hand, participants with private health insurance were reassured that all the expenses would be covered.

Alcohol and smoking were also important contributing factors. Many participants who have been smoking and consuming alcohol for many years, had to quit. That was not an easy task. Some have succeeded in quitting, others have not. Those who did not succeed, justified their alcohol consumption/smoking behaviour.

"I also had a few pints at night. That was my sedative. And once you're retired, you have to go to bed early. It was only getting later and later. So I took another cigarette and another

pint. Just beer, no heavy beer. And 25cl, not 33cl. Sometimes 5-6 beers a day. I did that regularly. Not to say every day."

Participant 11, alcohol and smoking

Finally, it was pointed out that participants had too much time to think and to contemplate. After many years, physicians still did not know the origin of certain complaints. The participants themselves did not know much about their illness and background. There were also misconceptions among the participants, for example that a vaccination makes you immune to the flu virus.

Perceived Consequences of Frequent Flyer Status

The perceived consequences were subdivided into six categories namely body, daily life functioning, social participation, mental status and spiritual dimension (see figure 2). Most participants identified consequences related to the category mental status and spiritual/existential dimension. Moreover, social participation was also an important element.

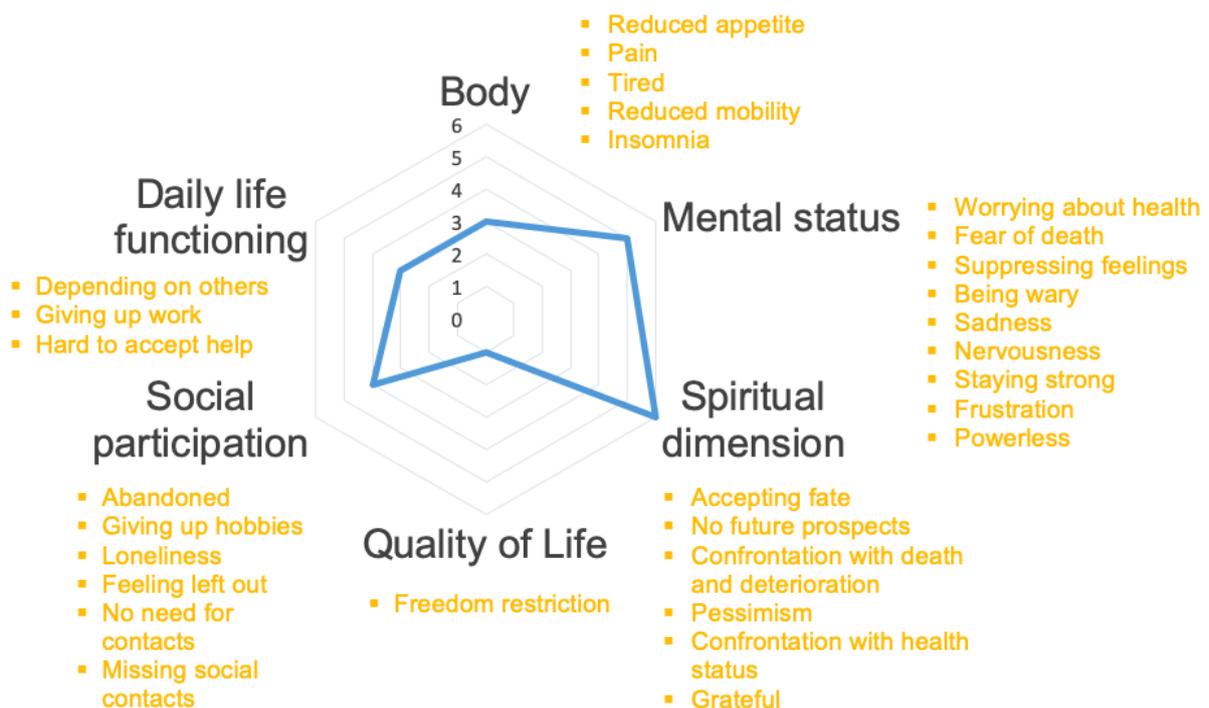


Figure 2: Perceived consequences of frequent flying status (the blue line indicates to what extent the six categories were present in this study.)

Mental status

Participants predominantly described three feelings in the mental status category, namely powerless, fear of death and frustration. They felt powerless because they experienced a deterioration in themselves. They could not do activities of daily living themselves and had become more dependent on others. This led to a difficult feeling of losing control.

The second feeling that often came up, was the fear of death. Many participants have a lot of time to reflect on everything around them. They were concerned about their state of health and did not see any improvement in their medical condition. For this reason, the thought of death came to mind more often in these patients.

"If you have nothing else to do than to wait and sleep, then you hope to wake up the next day."

Participant 5, fear of death

A lot of participants were also frustrated about the fact that things were not as easy as they used to be. It was a confrontation with physical decline. Especially after their frequent hospital admissions, many participants noticed that they had become considerably weaker over the past year. The most frustrating part was the awareness of their own decay.

Interviewer: *"Was it difficult to resume your daily routine after hospitalisation, to get back home?"*

Participant 4: *"Yes you have to be able to resettle. You want to do a lot of things, but you can't. That is difficult, very difficult."*

Participant 1: *"No, but I have experienced that I confronted myself with the fact that I could perform less than before."*

Participant 4 and 1, frustration

Spiritual/existential dimension

The spiritual/existential dimension illuminated pessimism, gratefulness, confrontation with death and accepting fate as important perspectives. Some participants were pessimistic because they lost sight of future prospects and the meaning of life. They did not see their state of well-being improve and only felt deteriorated. Some of them were still struggling with those unpleasant thoughts and others evolved to acceptance of fate.

"Well, today the food was good, and that all matters. If you have nothing else to do than to wait, you have time to think. You have nothing else to do than to think and yes...the next day I hope to wake-up again. There is not much future for me."

Participant 5, spiritual dimension

In addition, many participants were grateful for the help and the support they received from their families. Other participants received very little support or had even lost contact with their family. This lack of contact affects their state of mind and some even indicated that it could play a role in their frequent hospital admissions. Furthermore, several participants were confronted with death. Many of their friends and acquaintances had already died.

Social participation

In social participation, missing social contacts and giving up hobbies were mainly discussed. A number of participants indicated that they missed social contacts in their life. Some participants felt lonely and were more dependent on others for transport, which made it more difficult to maintain their social life. Also many of their friends passed away, which meant that their social circle was getting smaller and that they had fewer remaining relationships as a result.

"I cannot drive a car anymore. I'm going to see my friends a lot less. It is harder for me to go there. I live on Sint-Maartensstraat and if I want to go to the station with my friends, because they like to have a beer there, that will not work. I would also like to go, but that is no longer possible.

Participant 11, missing social contacts

On the other hand, there were participants who did not need a lot of connection. They were in search for rest and preferred to be at home with their families.

"I don't really have the need for extended social contacts anymore. I like to stay together at home with my husband. I am very happy with that."

Participant 4, no need for contacts

Also, some participants felt abandoned. They used to visit many friends who were sick at the time, but now that the roles are reversed they do not see many visitors. Other participants felt abandoned by their family, for example because of a family quarrel or for no particular reason.

"I'm very disappointed. In the past, when I could still get around and heard that someone was ill, I always went to visit them. Always. And they don't come to me now."

Participant 13, abandoned

Several participants have also given up their hobbies. This was because of the reduced mobility and physical decline. Although some participants had just bought a vehicle, had a summerhouse or were still doing sports, this was no longer feasible. Because of this, they have lost a part of their own.

Body

In the category body, reduced mobility, reduced appetite and insomnia were most cited.

"It could have been a little better. It's the appetite, I'm not saying that the food is bad and today I have already eaten a bit more. I also do not sleep well either. I'm overtired and altogether yes... that creates problems."

Participant 3, reduced appetite and insomnia

Daily life functioning

The dependence on other people and the difficulty to accept help were two conflicting subjects. Participants were getting older and therefore more dependent on others. They needed, for example more help from others in order to be able to live at home. The participants were aware of this and many found it difficult to accept this help, especially from strangers. This could be a reason why they remain unaided.

"Yes, for the moment nothing is going to change, as long as she is well enough. When we notice that she is not doing well anymore, then we will call in more help. She wants to stay at home for as long as possible and we want to respect that, but in that case, she has to accept more help."

Family of participant 10, hard to accept help

Quality of life

In this last category, freedom restriction was a prominent element. Many participants indicated that, due to these frequent hospital admissions, they had to give up a lot of activities and were confronted with shortcomings in their daily life. This gave them the feeling they lost power over their own lives and that they cannot organise life according to their own wishes. Participants were also restricted in their freedom of movement due to reduced mobility. These elements resulted in a reduced quality of life.

Participant: "It is a fact that this reduced mobility is the result of physical complaints, especially with the back problems... I would like to work out, for example, but that is not possible because of physical problems. So yes, you always have to... Your environment is getting smaller and smaller."

Family of participant: "A year ago, for example, she was still driving a car. That is no longer an option. She did her own shopping, but this is not possible anymore. She cannot walk far now. She has become less mobile."

Participant 11, freedom restriction

Discussion

A striking result of our research is the finding that many of the perceived causes could be avoided or modified. The participants also indicated that if these causes were solved, they would be admitted less often. For only a small selection of causes, participants indicated that frequent hospital admissions were inevitable. Particular attention must be paid to patient-doctor relationships, the quality of care (both primary and secondary care) and family relationships.

Few articles have been published that explored the causes of frequent hospital admissions from the patient's point of view. When looking at the available findings, there were some similarities. For example, in the study of O'Leary et al the lack of family support, financial barriers, pain and limitations in activities were also observed (23). Besides that, the participants in the study of Liu et al felt safe in a hospital. This corresponds to our data on being pampered during admission and trusting hospital (13). Those articles, however, have not made a subdivision between causes, contributing factors and consequences.

While some of our findings reinforce those of previous studies, other upcoming information were opposing. According to the study of O'Leary et al, the participants had no desire to come to the hospital and did not describe being in the hospital as a favorable or positive experience (23). However, this is not the case in our study. One participant admitted to have more confidence in specialist/hospital than in generalist primary care. Moreover, many participants experienced their hospital stay as reassuring and appeasing. Furthermore, the study of Liu et al concluded that outside-hospital support would not decrease hospital admissions, while in our study lack of support (cause) and inadequate transmural care (contributing factor) emerged strongly (13). Hence, according to our results, increasing community services and support outside the hospital may reduce hospital-dependency.

Moreover, the consequences that frequent flyers experienced due to their status was divided into six main themes of which social participation, mental status and the spiritual dimension were prominent. It was striking that the consequences have a negative impact on all six dimensions on the model of positive health (22). This means that every dimension has to be taken into account. Currently there is not enough qualitative research available on the consequences that frequent flyers are experiencing.

The interaction between perceived causes, contributing factors and perceived consequences

Within each category of perceived causes, the interaction between the contextual elements i.e. perceived causes, contributing factors and perceived consequences was inevitable. They affect each other and it is difficult to see them separately. In some cases the interaction was observed in the form of a vicious circle. Three major examples are given below.

Firstly, the patient's behaviour and the way he deals with his illness, play a major role. Problems arise when the patient starts to ignore his symptoms. This may be due to the bad experiences of other patients, negligence on the part of the patient or the lack of medical insight. With the thought of "it will go away", their conscience is appeased but the problem and

a consultation with a physician are only postponed. Another reason why patients postpone their consultations is because of their pride. It is difficult to face the confrontation with physical and mental decline and therefore hard to accept help from others. The patient wants to be independent and wants to prove his independence. The more he rejects help, the more difficult it is to control the disease(s) and to remain compliant with the therapy. In this way, the patient is frequently admitted and remains stuck in a vicious circle (see figure 3). This problem can be tackled by listening to the patient, by informing him well and by following him up.

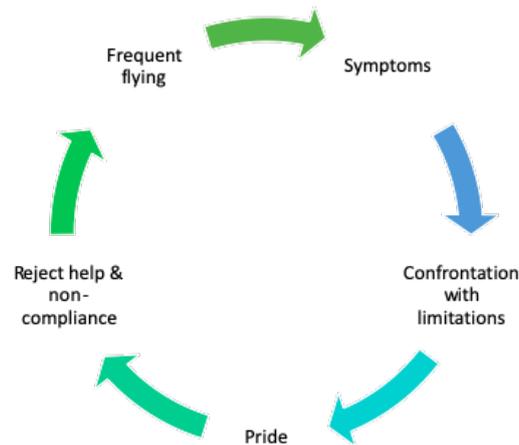


Figure 3: Vicious cycle due to the patient's behavior

Secondly, confidence in primary care physicians is shrinking, while confidence in relation to specialists is increasing. On the one hand, this can be a result of medical errors, misjudgments, lack of communication, lack of follow-up, lack of initiative and lack of knowledge in primary care. The patient also notices that primary care physicians are very busy and devote little time to them. On the other hand, the patient feels he's better treated by the specialist and will therefore play an active role in being readmitted in order to be treated by his specialist again. This imbalance in confidence will maintain frequent flying as the need for primary care remains present and is not met (see figure 4). This vicious circle can be broken by investing more in the training, retraining and the number of general practitioners.

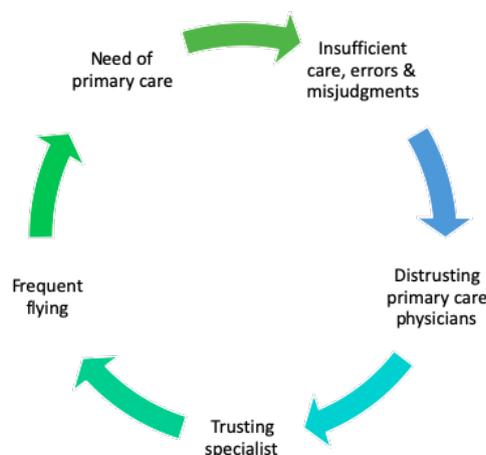


Figure 4: Vicious cycle due to lack of confidence in primary care physicians

Finally, at that age patients have already lost a number of family members, which reduces the family circle. The children and partner are mainly counted on, but the children have already started their own family, which makes it difficult to combine. In addition, anyone who still has a partner can count on an extra pair of eyes and hands. Widows lack that safety net and are often left with uncertainty and loneliness. If family support is lacking, both physical and mental problems can arise. Physical problems arise because there is little care provided and mental problems because patient's state of mind is affected by unpleasant feelings such as loneliness, hurt, frustration, sadness and isolation. They think about the meaning of life and whether life is still worthwhile.

Spiritual/existential dimension of frequent flyer status

Actual health systems, based on the World Health Organization (WHO) definition of health, are focusing on curing diseases in order to get a condition of complete physical, mental and social well-being (24). For elderly people and a priori those with a frequent flyer status, this is an illusion. In the second part of this research the perceived consequences, that are experienced by frequent flyers, were outlined. These consequences are related to the patient's environment and combined with a poor health status, they could cause a major impact on people's social, mental, physical and spiritual/existential well-being.

It is noticeable that the elderly is frequently confronted with negative experiences e.g. the death of a loved one, a poor health status, a family quarrel, etc. This leads to questions about the purpose of life and within this consideration, the thought of death often arises. In Dhoore's research on the fear of death among the elderly versus young people, they found that the elderly were more afraid of death than younger adults (25). Health status may explain this discrepancy. In our findings loneliness, psychological distress, lack of sense making and purpose of life often are mentioned as more depressing than physical illness. Therefore, it is important to adopt another lens in the care for elderly people by introducing spiritual (not necessarily religious, but also e.g. existential) dimensions in the care. Usually existential questions are not prominent in people's lives, but when people are confronted with serious life events or when life requires them to reorient themselves in society, existential questions become unavoidable. It has been described in literature that meaning of life has an important influence on physical health and well-being. Research by the Rush Alzheimer's Disease Center also showed that people with more purpose in life are less likely to have a rapid mental decline (26). In addition, meaning of life was also linked to reduced mortality and greater happiness in old age (27). It is thereby interesting to observe that these various dimensions of the positive health model are intertwined with each other and can influence one another (22).

The people who are most at risk of losing their purpose in life often have poor health, live alone, have a low socioeconomic status, are socially isolated, do not engage in any activities or are non-religious (28-30). However, some of the influencing factors have potential for improvement. In research literature, human relationships are seen as the most important source of meaning in life (31). Therefore, having and maintaining these social relationships and social communication is crucial for the elderly. Nevertheless, our study showed the opposite is true. Frequent flyers have a lack of social contacts and family support.

In conclusion, the meaning of life is an important concern for the elderly. In both theoretical and practical terms, addressing these existential/spiritual questions in the treatment of elderly

has become a new topic of research, which will receive more and more attention in the future (32). Therefore, it is fundamental that caregivers develop the competence to recognize the spiritual and existential dimension in patients in their daily work environment (34). The concept of positive health can be used to support the caregiver-patient relationship and the shift from institutional care to adaptability and self-management in the elderly (22).

Interventions

Integrated care is considered as a possible answer to meet the growing need for better health outcomes and patient experiences for patients suffering with multimorbid and long-term care. In the meantime, many models and approaches that ensure integrated care have been implemented and illustrated in different set-ups. So far, there are no specific models for frequent flyers, but case management was put forward as the most promising intervention (34). This model would in fact reduce the number of hospital admissions and improve the patient satisfaction (35).

In case management, case managers play an essential role in the planning, processing and monitoring of the patient's care, involving the necessary healthcare services. Hence, communication and coordination are particularly important (36). In this way, the gaps in primary and transmural care, that our results have revealed, can be addressed. In addition, there is less miscommunication between patients and care providers since the case manager acts as an interpreter.

Our research identified death of a loved one, worrying about health, suppressing feelings and nervousness as specific forms of psychological distress. And as such, case management may have a positive effect on these forms of psychological distress and could lead to patient activation in the primary care setting. As mentioned in the research of Hudon et al case management increases the feeling of safety in patients and causes a decrease in psychological distress (34). This was achieved by simplifying the access to care via a single access point, but as well by creating close relationships between the patient and his or her case management nurse. This relationship will have a positive effect on the patient's well-being because it can compensate for the perceived consequences, such as missing social contacts and loneliness (35).

Although case management tackles a number of issues that also came up in our research, there is still room for improvement within this intervention. In our study, it was noticeable that there is often insufficient attention for the patient in his care process. There should be more dialogue between healthcare providers, patients and their families about the goals, wishes and preferred direction of care for the patient. This can be linked to the new definition of health formulated by the researcher Machteld Huber: "Health as the capacity to adapt and to take charge of your own affairs, and this with attention to physical, emotional and social challenges in life" (37). This definition outlines the ability to be and to become healthy, despite the presence of disease(s). By allowing space for these questions about the needs of patients and positive health, frequent flyers can experience more involvement, meaningfulness and a better quality of life (38). In addition to this, it is also important to be aware of the existential dimension of the patient (cfr. supra) and of the preventable or modifiable causes in our research when implementing case management for frequent flyers (see figure 1).

Limitations

This study also had some limitations. First, our participants were recruited in a single large academic hospital, while the patient population differs across hospitals. Furthermore, the participants were only recruited from the geriatric department. These factors limit the study's generalizability to patients admitted to community hospitals and other departments. The participants were also interviewed during their hospitalisation. This can have an impact on the answers as the participant was not fully healed yet.

Second, patients with poor hearing function, a known diagnosis of dementia, delirium, non-Dutch speaking, DNR3 and no speech were excluded. It is possible that patients with such characteristics have different background and perspectives that could have enriched the data.

Finally, interviews with a family member were incorporated and it provided additional insights and clarifications into healthcare experiences. This only happened when a family member was present at the time of the interview, but for the future, it is recommended to also examine the perspective of family members.

Conflict of interest

None.

Conclusion

This study offered an in-depth insight into the perceived causes of frequent hospital admissions and identified their experiences. Few qualitative studies have been published in this field of research, while they can provide added value for understanding and ultimately avoiding frequent hospital admissions. Therefore further research is crucial.

References

1. Kesteloot K. (2018). *Financiering van de gezondheidszorg* (cursus). KU Leuven, departement Maatschappelijke Gezondheidszorg en Eerstelijnszorg.
2. OECD/European Observatory on Health Systems and Policies (2017), *België: Landenprofiel Gezondheid 2017*, OECD Publishing, Paris.
3. Capp R, Kelley L, Ellis P, Carmona J, Lofton A, Cobbs-Lomax D, D'Onofrio G. *Reasons for Frequent Emergency Department Use by Medicaid Enrollees: A Qualitative Study*. *Acad Emerg Med*. 2016 Apr;23(4):476-81.
4. Birmingham LE, Cochran T, Frey JA, Stiffler KA, Wilber ST. *Emergency department use and barriers to wellness: a survey of emergency department frequent users*. *BMC Emerg Med*. 2017 May 10;17(1):16.
5. Althaus F, Paroz S, Hugli O, Ghali WA, Daepfen JB, Peytremann-Bridevaux I, Bodenmann P. *Effectiveness of interventions targeting frequent users of emergency departments: a systematic review*. *Ann Emerg Med*. 2011 Jul;58(1):41-52.e42.
6. Fuda KK, Immekus R. *Frequent users of Massachusetts emergency departments: a statewide analysis*. *Ann Emerg Med* 2006;48:9–16.
7. Blumenthal D, Chernof B, Fulmer T, Lumpkin J, Selberg J. *Caring for high- need, high-cost patients-an urgent priority*. *N Engl J Med*. 2016;375(10):909- 911. doi: 10.1056/nejmp1608511.
8. Szekendi MK, Williams MV, Carrier D, Hensley L, Thomas S, Cerese J. *The characteristics of patients frequently admitted to academic medical centers in the United States*. *J Hosp Med*. 2015;10(9):563-568. doi: 10.1002/jhm.2375.
9. Braet A. *Unplanned readmissions in Belgian hospitals: importance of quality of in-hospital care and quality of care transitions. Ongeplande heropnames in Belgische ziekenhuizen: belang van kwaliteit van zorg in de ziekenhuizen en kwaliteit van zorgtransitie*. 2016.
10. Iglesias K, Baggio S, Moschetti K, et al. *Using case management in a universal health coverage system to improve quality of life of frequent Emergency Department users: a randomized controlled trial*. *Qual Life Res* 2018;27:503–13.
11. FOD Volksgezondheid (2017). *Evolutie van ziekenhuisverblijven*. Geraadpleegd op 15 december 2017, https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/multiyear-report-all-2006-2015-nl.pdf

12. Van der Heyden, J. (2013). *Gezondheidsenquête 2013*. Geraadpleegd op 17 december 2018, https://his.wiv-isp.be/nl/Gedeelde%20%20documenten/MA_NL_2013.pdf
13. Liu, T., Kiwak, E., Tinetti, M.E. *Perceptions of hospital-dependent patients on their needs for hospitalization* (2017) *Journal of Hospital Medicine*, 12 (6), pp. 450-453.<http://www.journalofhospitalmedicine.com/sites/default/files/Document/May-2017/jhm012060450.pdf> doi: 10.12788/jhm.2756
14. Zuckerman RB, Sheingold SH, Oraqv EJ, Ruther J, Epstein A. *Readmissions, observation, and the hospital readmissions reduction program*. *N Engl J Med* 2016; 374:1543–51.
15. Szekendi MK, Williams MV, Carrier D, Hensley L, Thomas S, Cerese J. *The characteristics of patients frequently admitted to academic medical centers in the United States*. *J Hosp Med*. 2015;10(9):563-568.
16. Fisher, K.A., Smith, K.M., Gallagher, T.H., Burns, L., Morales, C., Mazor, K.M. *We want to know: Eliciting hospitalized patients' perspectives on breakdowns in care* (2017) *Journal of Hospital Medicine*, 12 (8), pp. 1-7.
17. Allison Tong, Peter Sainsbury, Jonathan Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups*, *International Journal for Quality in Health Care*, Volume 19, Issue 6, December 2007, Pages 349–357, <https://doi.org/10.1093/intqhc/mzm042>
18. NIVEL. *Vragenlijst Ervaringen met ziekenhuiszorg Bestemd voor personen van 16 jaar en ouder die in de afgelopen 12 maanden zijn opgenomen in een ziekenhuis*. (2009).pdf
19. Drieskens S. *Gezondheidsenquête: Opname in het ziekenhuis*. (2008).pdf
20. Bos N., Zuidgeest M., Van Kessel P., De Boer D. *Handreiking Ontwikkelen van patiëntervarings- vragenlijsten om kwaliteit van zorg te meten*. (2015).pdf
21. Dierckx de Casterlé B, Gastmans C, Bryon E, Denier Y. *QUAGOL: a guide for qualitative data analysis*. *Int J Nurs Stud*. 2012 Mar;49(3):360-71.
22. Huber M. *The power of 'Positive Health'*.(2018).
https://www.mijnpositievegezondheid.be/media/Machteld%20Huber_tcm127-50265.pdf
23. O'Leary KJ, Chapman MM, Foster S, O'Hara L, Henschen BL, Cameron KA. *Frequently Hospitalized Patients' Perceptions of Factors Contributing to High Hospital Use*. *J Hosp Med*. 2019 Mar 20;14:E1-E6.
24. WHO, *Frequently asked questions*. Geraadpleegd op 5 mei 2019.
<https://www.who.int/about/who-we-are/frequently-asked-questions>

25. D'hoore T. (2008) *Doodsangst bij ouderen versus jongeren. Een vergelijking tussen de Multidimensional Fear of Death Scale en een Negative Affective Priming Task*. (Ongepubliceerd eindwerk). Ugent. Gent
https://lib.ugent.be/fulltxt/RUG01/001/289/674/RUG01-001289674_2010_0001_AC.pdf
26. Rush University Medical Center . *Purpose in life may protect against harmful changes in the brain associated with Alzheimer's disease*. 7 may 2012.
https://www.eurekalert.org/pub_releases/2012-05/rumc-pil050412.php
27. Boyle P. A., Barnes L. L., Buchman A. S., Bennett D. A. (2009) *Purpose in life is associated with mortality among community-dwelling older persons*. *Psychosomatic medicine*, 71, 574–9.
28. Pinquart M. Creating and maintaining purpose in life in old age: a meta-analysis. *Ageing Int* 2002; 27: 90–114.
29. Clarke PVM, Ryff C and Rosenthal C. *Well-being in Canadian seniors: findings from the Canadian study of health and aging*. *Can J Aging* 2000; 19: 139–159.
30. Krause N and Hayward D. *Religion, meaning in life, and change in physical functioning during late adulthood*. *J Adult Dev* 2012; 19: 158–169.
31. Hupkens S, Machielse A, Goumans M, Derkx P. Meaning in life of older persons: An integrative literature review. *Nurs Ethics*. 2018 Dec;25(8):973-991.
32. van der Vaart W, van Oudenaarden R. The practice of dealing with existential questions in long-term elderly care. *Int J Qual Stud Health Well-being*. 2018 Dec;13(1):1508197
33. Goossensen A, van Dijke J and Baart A. *Leren kennen, laten kennen': casus en probleemformulering* [Learning to know, allowing to know': case and problem definition]. In: Goossensen A (ed.) *Schetsen van mismatch: een zorgethische visie op evaluatieonderzoek* [Spiritual care: Dutch national guideline, vs 1.0]. Utrecht: Movisie/Universiteit voor Humanstiek, 2014, pp. 20–30
34. Hudon C, Chouinard MC, Dubois MF, Roberge P, Loignon C, Tchouaket É, Lambert M, Hudon É, Diadiou F, Bouliane D. *Case Management in Primary Care for Frequent Users of Health Care Services: A Mixed Methods Study*. *Ann Fam Med*. 2018 May;16(3):232-239.
35. WHO. *Integrated care models: overview*. (2016).
http://www.euro.who.int/__data/assets/pdf_file/0005/322475/Integrated-care-models-overview.pdf
36. Kagan J. *Case Management*. geraadpleegd op 5 mei 2019.
<https://www.investopedia.com/terms/c/case-management.asp>

37. Huber, M.A.S., Van Vliet, M., Giezenberg, M. en Knottnerus, J.A. (2013). *Towards a conceptual framework relating to 'Health as the ability to adapt and to self manage', Operationalisering gezondheidsconcept*. Rapport 2013-001 VG. Driebergen: Louis Bolk Instituut.
38. Zorg voor beter. Wat zijn levensvragen bij ouderen? Geraadpleegd op 10 mei 2019.
<https://www.zorgvoorbeter.nl/levensvragen-ouderen/levensvragen>

