

Original article

Patients with multimorbidity and their treatment burden in different daily life domains: a qualitative study in primary care in the Netherlands and Belgium

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Abstract

Background: Physicians and other healthcare professionals involved in the care of patients with multimorbidity should consider the problems these patients experience in managing their own conditions. However, treatment burden from the patient's perspective has been poorly explored, even though this might hamper treatment adherence. **Objective:** The present study examined the experiences of patients with multimorbidity in primary care in the Netherlands and Belgium using semi-structured interviews, with special attention to the daily life domains of treatment burden. **Design:** Individual interviews gathering qualitative data to explore the treatment burden experienced by patients with multimorbidity in primary care. Twenty-two patients agreed to participate: seven men and fifteen women. The recorded interviews were transcribed verbatim and evaluated using thematic content analysis. **Results:** The patients reported numerous aspects of treatment burden they experienced in various domains of their daily lives. These topics were categorized into four daily life domains of burden: organization of care, medication, patient's role, and impact on daily life (including the involvement of caregivers). **Conclusions:** The findings indicate that primary care patients with multimorbidity report treatment burden in several domains of their daily lives, not restricted to medical issues, such as side effects of medication. Some issues, such as those related to organization of care, seem easily modifiable. Further research is required focusing on special factors of treatment burden as experienced by patients with multimorbidity, and the implications for treatment adherence, especially in European settings, as little information is currently available.

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Introduction

Primary care in Europe is challenged by an ageing population and increasing demand for healthcare. People are

not only living longer, but increasing numbers of individuals are suffering from multiple (chronic) conditions, also called multimorbidity [1]. The prevalence estimates of multimorbidity vary: a European study found a self-reported prevalence of 37% in a population aged 50 years and older, increasing from 22.7% for those aged 50–59 years to 52.8% for those aged 70 years and older [2].

The organization of care for patients with multimorbidity in the Netherlands and Belgium is complex, and the referral systems vary. In the Netherlands, patients will first consult their general practitioner (GP) before being referred to a hospital specialist for their individual diseases, whilst in Belgium, patients can consult hospital

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specialists without a GP referral. GPs in the Netherlands usually have nurse-practitioners in their practice who care for patients with complex disorders, for example, for cardiovascular risk or diabetes management. There are no similar special care providers for patients with multimorbidity, but because of their symptoms and complaints, the GP will see patients regularly and probably knows them best. GPs in Belgium tend to work alone in single practices, and usually have no receptionists or practice nurses in their employment.

Multimorbidity often causes problems, such as functional limitations [3], reduced quality of life [4], visits to several medical specialists, care requirements, various (and possibly antagonistic) therapies and treatments, potentially resulting in complications and poor (medication) adherence [5]. It is generally accepted that multimorbidity represents a great burden both for the patients and their doctors and other caregivers [6–8]. A special aspect of this burden is treatment burden.

Treatment burden has been defined by Boyd *et al.* [9] as the patient's perception of the "aggregate weight of the actions and resources they devote to their healthcare, including difficulty, time, and out-of-pocket costs dedicated to the healthcare tasks such as adhering to medications, dietary recommendations, and self-monitoring". This definition already includes many domains of burden, indicating the complexity of the matter.

GPs and other healthcare professionals who are involved in the care for patients with multimorbidity will try to consider the problems these patients experience in managing their conditions as part of their daily lives. In practice, however, treatment burden from the patient's perspective, and the ability to sufficiently support patients with multimorbidity have not yet been widely explored, even after the concept of minimally disruptive medicine appeared in the scientific literature some time ago [10]. The burden of the treatment could lead to lower adherence to medical treatment [8] and to caregivers worrying about poorer outcomes [11]. Understanding patients' problems would probably result in provision of better care for them.

As yet, little is known about the domains of treatment burden experienced by patients with multimorbidity, and whether these domains differ from what is already known about patients with a single chronic disease.

Publications about treatment burden in the scientific literature originate mostly from the USA and Australia [12–15], with only limited contributions from Europe [16]. However, cultural differences are deemed important [8,10] and the healthcare systems in individual countries differ, which might result in different problems, for instance, concerning financial issues [14,16]. In addition, patients participating in qualitative studies on

treatment burden are usually not recruited from primary care, and may have only a single chronic condition. Sav *et al.* [13] conducted semi-structured interviews with 96 patients with one or more chronic diseases, but recruited them from various settings, not only through primary care. Eton *et al.* [17] included medical outpatients newly enrolled in a medication therapy management program at a big hospital in the USA, all of whom were coping with one or more chronic conditions.

The tools developed to measure treatment burden [14,18] are not specifically aimed at patients in primary care or those with multimorbidity. In addition, these tools have not been linguistically validated for use in the Netherlands and Belgium.

The aim of the present study was to examine the experiences of patients with multimorbidity using semi-structured interviews with these patients in the Netherlands and Belgium, recruited from GP practices, focusing on treatment burden. The aspects of this treatment burden, as experienced by the patients, were clustered into daily life domains. The findings are expected to form the basis for further exploration of important problems experienced by patients. The reason why we chose the primary care setting to recruit patients with multimorbidity is that primary care is the setting where integrated care is delivered to most of these patients.

Methods

The study comprised individual in-depth interviews in which qualitative data were gathered to explore treatment burden experienced by patients with multimorbidity. The target population consisted of patients with multimorbidity in general practices in the Netherlands (Dutch province of Limburg) and in Belgium (provinces of Flemish Brabant and Flemish Limburg). These counties are geographically close to each other, and fairly similar in living conditions.

General practices from both sides of the border were approached to recruit eligible patients. Participating GPs were asked to invite patients who met the following inclusion criteria: have multimorbidity, i.e. two or more chronic diseases in at least two different organ systems, as documented in the GP's electronic medical records; live independently; have sufficient command of the Dutch language; and be at least 45 years old. Patients with dementia (as documented in the electronic medical records) were excluded. Both practices and patients were recruited using purposive sampling, aiming for an even distribution across urban and rural areas, and a mix of morbidity patterns.

The guiding principle was data saturation, which means sampling and interviewing was continued to

the point at which no new information was obtained and redundancy was achieved [19]. The key aim was to generate enough in-depth data to illustrate the categories, patterns, and dimensions of the treatment burden experienced by patients with multimorbidity. Participants for the study sample were selected using purposive sampling.

Three Dutch and seven Belgian general practices were approached to participate in this study. The reason for approaching more Belgian general practices was that it proved more difficult to find Belgian GPs willing to participate in this study. The most commonly mentioned reason for not participating was lack of time, as they had no opportunity to delegate tasks to staff, such as assistants or practice nurses.

The three Dutch general practices that were approached all agreed to participate and recruited a total of 12 patients with multimorbidity, resulting in 12 interviews. In addition, three Belgian general practices recruited a total of eight patients with multimorbidity. The interviewer (K.V.) found, through personal connections, two more Belgian patients who met the inclusion criteria and were willing to participate. Thus, 10 interviews were conducted in Belgium. Patients with a variety of characteristics were invited to ensure a wide range of ages, diversity of diseases and disease combinations, diversity of polypharmacy, diversity of the availability and use of family caregivers, diversity of mobility, and diversity of socioeconomic status.

All interviews were performed by K.V. in April to June 2016 and were conducted in a safe setting at the patients' homes or at their general practice. Patients were only included in the study sample after they gave written informed consent for participation. The medical ethics committee of Zuyderland Medical Center approved the study. The interviewer used an interview protocol, and a topic list, and the questions were formulated in such a way as to give the participants the opportunity to provide rich, detailed information [19].

Examples of topics discussed in the interviews were: a description of the background and state of health of the participant, the activities they had to perform to manage their diseases, whether they actually experienced difficulties doing what they had to do in managing their diseases, and what the impact was, for instance, on their daily lives. The topic list was tested on two independent patients with multimorbidity to find out whether all terms and questions were well understood and was also discussed with two medical students to define the best way of posing the questions. The interviewer's job was to encourage participants to talk freely about all the topics, and to tell their stories in their own words, giving them the freedom to provide as many illustrations and explanations as they wished [19]. The recorded interviews

were transcribed verbatim and analyzed using the NVivo software version 11. All data were anonymized.

A category scheme was developed based on the key themes and categories that emerged in the recorded interviews. The scheme could be further adjusted to include newly emerging concepts during coding and was discussed between the authors for errors or omissions (triangulation). The transcripts were then analyzed with the help of NVivo 11 using open coding, axial coding, and selective coding.

The coding process started with open coding, which involves comparison, conceptualization, examination, and categorization of data. This was followed by axial coding, which means that data were combined by linking the different categories. The third stage involved selective coding to define the core category, which was systematically related to the other categories.

The interviews were first independently coded by K.V. and either T.M. or M.A., after which the two authors tried to achieve consensus on the coding of all transcripts. In case of disagreement, the third author joined the discussion to obtain final agreement. This procedure was used to minimize the risk of biased decisions and idiosyncratic interpretations.

The results to be reported consisted of the selection and interpretation of data by the researchers [17]. In the final step, the findings were summarized based on the encoded transcripts and were illustrated with quotes in a qualitative content analysis [19].

Results

A total of 22 patients with multimorbidity agreed to participate: seven men and fifteen women. The characteristics of the participating patients are shown in Table 1. The demographic characteristics were varied. The age of the patients we interviewed ranged from 45 to 91 years. We included patients with different combinations of chronic conditions (see Table 2).

The participants mentioned various aspects of treatment burden they experienced in the different domains of their daily lives. The authors arranged the aspects of treatment burden into four daily life domains: organization of care, medication, patient's role, and impact on daily life (see Table 3).

Table 1 Patient characteristics (n=22).

Country	Men/women, n/n	Average age, years	
		Men	Women
Netherlands	3/9	75	70
Belgium	4/6	70	71
Total	7/15	72	70

Table 2 Characteristics of individual participants.

Participant	Sex	Country	Age	Marital status	Chronic diseases	Daily medication
1	F	Netherlands	73	Married	Vasoconstriction, cardiac arrest, type 2 diabetes, asthma, inoperable hernia	14 pills, 3 insulin injections
2	F	Netherlands	82	Married	Rheumatoid arthritis, pacemaker, leaking heart valve	9 pills
3	F	Belgium	81	Widow	Asthma, chronically depressed, chronic esophagitis	4 pills, asthma inhalers
4	F	Netherlands	74	Married	CVA, pacemaker, COPD	8 pills
5	M	Netherlands	74	Married	Diabetes*, stroke, COPD	12 pills, 1 insulin injection
6	M	Netherlands	79	Widower	COPD, chronic heart disease, cardiac arrest, diabetes*	6 pills, 2 insulin injections
7	F	Netherlands	69	Cohabiting	Rheumatoid arthritis, osteoarthritis, diabetes*, COPD	None
8	F	Netherlands	66	Divorced	CVA, epilepsy	1 pill
9	M	Netherlands	71	Married	Osteoarthritis, chronic heart disease, arrhythmia	7 pills
10	F	Netherlands	74	Married	Rheumatoid arthritis, chronic esophagitis	6 pills
11	F	Netherlands	55	Married	Heel spurs, osteoarthritis, repetitive strain injury	None
12	F	Netherlands	84	Married	Asthma, pacemaker, stroke	6 pills
13	M	Belgium	91	Widower	Chronic pneumonia, vasoconstriction, leaking heart valve	10 pills, asthma inhalers
14	F	Netherlands	55	Cohabiting	Asthma, COPD, stroke, vasoconstriction, rheumatoid arthritis	17 pills, asthma inhalers
15	F	Belgium	55	Married	CVA, pulmonary embolism	10 pills
16	F	Belgium	83	Married	Type 2 diabetes, cardiac arrest, sleep apnea, chronic kidney disease	13 pills
17	M	Belgium	45	Divorced	Fibromyalgia, diabetes*	2 pills, insulin injection
18	M	Belgium	79	Widower	CVA, blood vessel inflammation	2 pills
19	M	Belgium	65	Married	Type 2 diabetes, osteoarthritis, vasoconstriction	3 pills
20	F	Belgium	81	Widow	Osteoarthritis, asthma	10 pills
21	F	Belgium	62	Married	Asthma, arthrosis, milk allergy, plaster allergy	11 pills
22	F	Belgium	62	Cohabiting	COPD, pollen allergy	2 pills

*Type of diabetes not recorded. COPD, chronic obstructive pulmonary disease; CVA, cerebrovascular accident; F, female; M, male.

Table 3 Aspects of treatment burden in four daily life domains.

Daily life domain	Organization of care	Medication	Patient's role	Impact on daily life
Aspects	<ul style="list-style-type: none"> • Communication with healthcare providers • Waiting times and travel problems • Shortage of information • Attitude of care professionals • Medical failures • Absent or deficient aftercare 	<ul style="list-style-type: none"> • Interactions • Side effects • Change of brand or presentation form • Multiple medication and how to use them • No evaluation whether still relevant • Payment systems (shortage of information) 	<ul style="list-style-type: none"> • Acceptance of condition and necessary treatment ("routine") • Dependence on others (partner, doctors, paid help) • Being one's own doctor • Over-performing: wanting to do things too perfectly • Depression/hopelessness • Resistance to frequent visits to doctor, or to treatment as a whole • Joint medical decision-making with patients 	<ul style="list-style-type: none"> • Taking medication when traveling • Limits to traveling because of side effects of medication • Being on a special diet • Integrating rehabilitation/physiotherapy in daily life • Reimbursement procedures, e.g. for chairlifts

Organization of care

The communication with healthcare providers, for instance hospital based specialists, was sometimes confusing for patients, adding to their burden. Since patients with multimorbidity usually consult different specialists, they are more likely to be given a variety of, perhaps conflicting, medication or advice. Contacts between specialists and GPs concerning medical information about the patient were sometimes limited or delayed. Waiting times at the hospital were sometimes long, and

some participants had problems trying to find someone to drive them to the hospital and back. In addition, they had the possibility of high parking fees. These problems are more common when a patient has more frequent hospital appointments. Information on the diseases, and reasons for and use of medication and therapy were sometimes lacking or overwhelming, and the attitude of healthcare providers towards these complex patients with multimorbidity was not always empathic. If medical failures occurred and aftercare was absent or deficient, this augmented the sense of frustration and added to the

treatment burden. The organization of the care was not always patient-centered for patients with multimorbidity; for instance, because appointments were arranged on different days, instead of in more convenient consecutive timeslots.

“Yes, not everything is fed back to the general practitioner. There was this doctor at the hospital, I think I asked him 20 times, and that’s not a lie: ‘Did you send that to my general practitioner?’ Yes yes, he says, it’s always sent to the general practitioner, but then I visit my general practitioner and he hasn’t received anything” (Participant 20).

There appeared to be some differences between Belgian and Dutch participants, with Belgian participants being more positive about the perceived communication between hospital specialists and GPs than the Dutch participants. In addition, unlike the Dutch participants, Belgian participants mentioned being referred to a medical specialist when this was needed, in their opinion.

Belgian participants: *“Yes, it’s all rather well communicated. Nowadays it’s all in the computer. Most of the time they all know what happened on the same day”* (Participant 16). *“Well, at the start it is a kind of information overload, that needs time to sink in. But I feel information supply and guidance are always excellent here”* (Participant 15). *“It depends on the need. When you mention increased complaints or whatever, they react adequately. But when all is fine, you should go once a year”* (Participant 15).

Dutch participants: *“I don’t know. They’re not really collaborating, for example the lung specialist and the cardiologist are very much doing their own thing”* (Participant 1). *“I think, and I’ve told this to other people as well, that aftercare is omitted. Especially when you’re alone. It would be good if once or twice a week someone would be available for support. But I mean real support, not just asking how you’re doing. But actually, giving instructions like ‘you better handle it like this’”* (Participant 8).

Medication

Having to take multiple medications is a major aspect of the treatment burden. Interactions, side effects, and change of brands because of government policy added greatly to the burden patients experienced. Participants also said they felt that their medication was not reviewed regularly to check whether it was still necessary. This was especially important when a patient was using many different medications. Other comments concerned the reimbursement system, as insured persons in the Netherlands have to pay the first EUR 385 per year themselves, and in Belgium, they have to pay a small fee for each consultation. Another problem was the lack of information about why medication was prescribed.

“I do experience side effects of the medications. For example, I also have an allergy, wherever that comes from, and I get these

itches. My back, sometimes the itching drives me crazy and there are certain medications, I do not know which one it is, but when I take that medication in the morning then it starts and it’s always at the same spots on my back” (Participant 1).

“Look, I’ve got a pharmacy-filled pill container here with all the pills for each day and each time of the day in it. And it indicates these ones early in the morning at 7 am and then these at midday and then at 5 pm. Very handy, this pill container. It shows the hours when to take it, the names of the medications and what they look like. So you can’t make any mistakes anymore” (Participant 1).

“You know, I take hardly any medications at all, I’m not really a medication person. Because yesterday I watched TV again and I saw things about all the side effects and I said to my husband that’s why I don’t take them. Take the paracetamol that I had to take four times a day, 1,000 mg, I think that is way too much and so I said I won’t take that any longer” (Participant 7).

Patient’s role

Acceptance (or lack of it) of the treatment-related activities of chronic patients was mentioned as a key aspect of the treatment burden. Patients became dependent on their partner or relatives, needed paid help, and could not live their daily lives as they wished. Some patients were too eager to do everything correctly, and as a result, their lives centered around their diseases, without time for leisure and relaxation. This might result in depression or feelings of hopelessness, or in resistance to visiting doctors and complying with the treatment. Engaging patients in medical decision-making seemed to reduce the treatment burden in this respect.

“The first years were bad, really bad. I couldn’t accept the work I had to do and what I needed to take into account. Not being able to accept it, that is the worst. But if you can accept it, it gets a lot better right away, also in terms of organizing everything. You have to learn to live for the rest of your life with the fact that you have to take certain medications and have to see specialists. So learn to live with it. And I’m as stubborn as anything, at first I didn’t want to learn to live with it and so you fight it, which only makes it worse, but eventually you have to listen to your body” (Participant 17).

“I have a high burden of treatment. Because as I already said I do not want to do it anymore ... Yes, one of these days I will stop with everything because ... sometimes I get those days when it weighs so heavy on me, then yes ... I do not care anymore. What is bothering me is that I cannot help myself anymore, that is the worst actually; yes, that is what’s bothering me” (Participant 1).

“The same thing with the rheumatologist, I got big injections. And at some point, I said to the doctor it doesn’t help anymore, I don’t know what to do, I have this pain, I have that pain” (Participant 14).

“And I have someone to clean the house, but yes well if anything happens, they do not have a replacement. And then I want to do it myself but the doctor says I shouldn’t because then my health will worsen. The cleaning lady often doesn’t show up and then they do not send a replacement because they say we do not have anyone today. She’s supposed to be at my place at five to one and they’ll call me at twenty past twelve. Don’t tell me they didn’t know that earlier. This gives me extra stress and increases the burden for me because nothing is done or you start to clean yourself which is dangerous. [...] And I’m afraid to say that I am not satisfied. It’s difficult because when I then see them again I don’t feel comfortable” (Participant 20).

Impact on daily life

Having to be on a special diet was reported to disrupt daily life, as was the time investment for physiotherapy sessions. Having to go through reimbursement procedures to get money for necessary assistive devices, such as a chairlift or a wheelchair, not only costs money but also (emotional) energy. Traveling was said to be a complex matter for patients with multimorbidity, including problems regarding how and when to take the many necessary medications, or the limitations because of side effects (e.g. diarrhea) when traveling.

“I had problems getting everything straight, the bills and treatments and to sort out the paperwork. I had completely lost it. I just could not take it anymore. It was just a mess and then I turned to an agency. That’s an organization that helps and supports you with problems you have. It can be anything” (Participant 8).

“No, I do not really find it a burden. It is part of it, yes it is a part of it. It actually became a kind of routine of the day, it is part of life” (Participant 13).

“The hardest part still is to accept it. I’m sorry that I can’t go on vacation anymore and can’t ride a bike. Because it requires a lot of organization and a lot of work to be able to control your conditions” (Participant 6).

Discussion

The present study specifically looked at patients with multimorbidity in the primary care setting and the treatment burden they experienced in daily life, as part of their overall burden. The interviews with these patients showed that treatment burden covers several daily life domains, and is not restricted to medical issues, such as side effects of medication, as has been found in several other studies [13,14,18].

The patients’ attitudes and their acceptance of the difficulties in daily life caused by the various diseases and their treatment regimens were frequently mentioned as important issues. The impact of treatment on the daily

lives of the patients can hardly be overestimated. All of our findings should be viewed in perspective; however, as much of the care for patients with multimorbidity actually works well, and not all patients experience severe treatment burden. Patients with multimorbidity are most likely to experience treatment burden specific to their condition when the different diseases and treatments interact or necessitate more frequent check-ups. One could speculate that it is in domains such as medications (and the interactions between them), frequent hospital visits, and dependence on informal caregivers that the burden will probably be higher or different for them, compared with patients with single conditions. This implies that the meaning of treatment burden for these patients may be wider than, and perhaps different from, what is assumed by their doctors and caregivers, and different from that of single-disorder patients.

A look at these domains, and comparison with what is known about treatment burden in patients with single conditions, shows that it is especially the multitasking that patients have to perform to be a “successful” patient which seems relevant. Having multiple diseases naturally calls for multiple medications, multiple consultations with doctors, and multiple impacts on daily life. Hence, more things can go “wrong”, adding to the treatment burden, and drug interaction is more likely. Issues such as organization of care also appear to be more important aspects of the treatment burden for patients with multimorbidity.

The present study has some limitations. The participation of practices to recruit the patients in Belgium was difficult and might have resulted in a non-representative selection of participating GPs. Exclusion of patients with dementia was based on the GP’s electronic health records, and during the interviews, no obvious cognitive impairments were noticed by the interviewer. GPs received little other instruction about patient selection, which may have resulted in a selection of more fluent patients who might also be more capable of handling doctor–patient communication. Furthermore, we did not collect information about the number of patients who refused participation and their reasons for refusal. Finally, the limited number of patients, divided over two different countries, might limit the generalization of the results.

In order to throw some more light on these issues, and their importance in treatment adherence, it would be useful to conduct further qualitative research questioning patients with multimorbidity about the importance of the treatment burden they experience for their adherence to treatments for their various diseases. This could be compared with studies of single chronic-condition patients. Measurement tools for treatment burden should also be feasible for patients with multimorbidity in primary care. Primary care does not have the luxury of

treating only patients with one specific disease, as multimorbidity is the rule rather than the exception. Such a measurement tool specifically intended for patients with multimorbidity could be developed from existing tools [13,14,18], but might also need more domains.

A first step in improving the care of patients with multimorbidity would be for doctors and other care providers to be aware of the patient's perspective. This could help them to look beyond the purely medical frame, and to seek ways to improve the organization of care. Appointments with various doctors or for different examinations could be clustered in time to reduce the number of hospital visits. Sometimes even a multidisciplinary consultation might be relevant. Furthermore, more time and attention should be given to providing information about the disease and treatment aspects, and reasons for non-adherence should always be questioned from the patient's perspective. Decisions about new or altered therapy should explicitly involve patient preferences to encourage adherence and improve patient satisfaction, and to decrease treatment burden as experienced by patients. Furthermore, attention should be paid to enhancing the patient's acceptance of their health status.

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Conflicts of interest

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