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Patients have unwritten duties: experiences of patients with type 1 diabetes in health care

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Abstract

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Aim To describe the perceptions and experiences of patients with type 1 diabetes, examine their duties and responsibilities for their own care and increase our understanding of the value-based role of patients in the changing healthcare environment.

Background Current type 1 diabetes care highlights the importance of self-care and of patient involvement, which implies the need to evaluate the patients' role. Little is known about patients' views about their own role, and related responsibilities and duties for their own care. This is essential if we are to promote efficient patient involvement.

Design This study had a qualitative descriptive design.

Methods We conducted one-to-one themed interviews with 20 patients with type 1 diabetes during summer 2013 at a diabetes polyclinic in Finland. Data were analysed using inductive content analysis.

Findings Patients with type 1 diabetes believed that their well-being and self-care required them to consider their own responsibilities and their duties towards themselves, family members, society and healthcare professionals. These duties were seen to have implications for care outcomes, quality of life, and effectiveness and economy in health care. However, patients' background, motivation, relationships with healthcare staff and patient counselling influenced whether they fulfilled those duties, which are all crucial elements in type 1 diabetes care.

Conclusion Patient duties are significant for the well-being of patients with type 1 diabetes, but also for their successful involvement in their care. This study can be used to inform the development of individual care planning and support of patient involvement.

Background

Diabetes has become one of the major causes of premature illness and death in most countries.¹ Almost 400 million people are estimated to have diabetes, with dramatic increases seen in countries all over the world. So far, the most common diabetes is type 2, but type 1 diabetes is increasing in both rich and poor countries, and is most common among children and adolescents in high-income countries.^{2,3} Due to the onset of type 1 diabetes at a young age, lifestyle and self-care are crucial for preventing complications and early death. This makes self-care-related responsibilities lifelong and life-saving³ and requires understanding of the physical⁴ but also of the social and psychological ramifications of diabetes.^{4,5} It is worth noting that diabetes affects the lives of individuals as well as family members.^{6,7} The aim of diabetes care is to promote patients' well-being and quality of life and to prevent complications by supporting their involvement and self-care.^{5,8}

Patients' duties and responsibilities

Lifestyle-related diseases have raised the question of patients' duties and responsibilities. In previous studies, patients' duties have been described multidimensionally, using mainly theoretical methods. According to the current literature, patients have duties towards themselves, healthcare professionals and society,^{9–11} and they have a role as patients as well as citizens.¹¹ Patients' duties towards themselves include looking after their own health.^{10,12–17} They have a duty to seek health advice,^{10,15} follow given instructions^{12–15,18} and ensure they access healthcare provision.¹⁴

Patients' duties towards healthcare professionals include telling the truth,^{10,14,15,18} respecting staff^{10,14,15} and keeping appointments.^{15,18} Patients' duties have also been described from the point of view of society. This refers to their duties to respect other patients,^{10,14,15} to avoid spreading infections and to use health resources in the public sector appropriately.^{14,15} In their role as citizens, patients have duties towards

society that are linked to protecting the health of others, for example avoiding the spreading of infections.^{14,15} These duties also include being a responsible citizen such as paying relevant taxes¹⁴ and contributing to health services improvements, for example by providing feedback.^{10,14,15,19} In addition, patients' duties have been highlighted from an economical perspective.^{11,14}

Health promotion and patient involvement emphasizes duties

When a patient has diabetes, the earliest possible stages of health promotion should include the patient's involvement in planning, decision making and implementing their own care. It also raises the question of the patient's duties and responsibilities.^{8,20} In many Western countries, patients have a legal and ethical right to be involved in their own care.^{16,21,22} The understanding of patient involvement replaces the authoritarian and instructive care traditions¹⁶ and implies the need to re-evaluate the shared responsibility between patients and professionals.^{23,24}

However, the question of patients' duties also poses risks and limitations. Not allowing patients to carry moral responsibility for their avoidable errors is intended to protect individuals. Overemphasizing patients' duties carries a risk, as it can make people feel responsible for problems they have no control over.^{16,25} Recognizing that patients are morally responsible may increase the risks to their health and well-being. However, the idea of patient responsibilities also contributes to further thoughts about systems and practices that could help patients and healthcare professionals to understand and take a coordinated approach.^{11,14,18,26}

Despite the increased discussion on patients' duties, it is noteworthy that the methodology used has mainly been theoretical, and presents the perspectives of staff and experts, but the perspectives of clients and patients, and in particular of patients with diabetes, are little known.^{16,27} Thus, qualitative research methods are needed to achieve patients' individual views

of their needs and expectations regarding own duties and responsibilities.

The study

Aims

The aim of this study was to describe the perceptions and experiences of patients with type 1 diabetes of their health-related duties and responsibilities. The research questions were as follows: (i) How do patients with type 1 diabetes describe their duties? (ii) What are the implications of patient duties? and (iii) What issues influence fulfilling these patient duties? The ultimate aim was to increase understanding of the patients' value-based role in changing health care.

Design

The qualitative descriptive approach was selected to obtain new knowledge of a previously poorly studied subject by describing and understanding individual human experiences.²⁸

Participants

Purposeful sampling²⁹ was used to recruit participants among patients with scheduled appointments at the Internal Diseases Polyclinic of one public Finnish hospital. The inclusion criteria for purposeful sampling were that they had to have a diagnosis of type 1 diabetes and be willing to participate. The recruitment was conducted in summer 2013 by one of the researchers (MH) in collaboration with a diabetes nurse. At the beginning of the appointment, the diabetes nurse gave potential participants information and a recruitment letter and informed the researcher if they were willing to take part. At the end of the patient's appointment, the researcher interviewed them in a quiet room at the polyclinic for 10–45 min. During the recruitment period, 27 patients with diagnosed type 1 diabetes had scheduled appointments, but four did not turn up and three refused to participate. The remaining 20 gave their consent. All partici-

pants were Finnish with average age of 29.2 years, and they had been living with diabetes for an average of 14.3 years (Table 1).

Data collection

One-to-one interviews were chosen as the data collection method to gather individual knowledge and protect privacy when handling a sensitive subject.²⁹ Interviews with three main themes based on previous scientific knowledge about patient duties were used.²⁸ These themes were the patients' involvement in well-being and managing their disease, their perceptions and experiences of their health-related duties and the role of patients' duties in current health care. Saturation was achieved after 18 interviews, but two more interviews were carried out for verification.²⁸ Saturation was reached when concepts regarding the patients' duties were repeated multiple times without new concepts or themes emerging.³⁰

Ethical considerations

The guidelines of research ethics²⁸ and the current Medical Research Act 1999/488³¹ were

Table 1 Background information on the participants

Background information	<i>n</i>
Gender	
Woman	15
Man	5
Age (years, average age = 29.2 years)	
17–25	9
26–35	7
36–45	1
46–50 (average age = 29.2 years)	3
Living with diabetes for (average = 14.3 years)	
1–10 years	9
11–20 years	5
21–30 years	5
31–40 years (average = 14.3 years)	1
Medication	
Insulin	20
Reason for the polyclinic visit	
Routine control	15
Other	5

followed. Ethical approval (Dnr 15-2013) was obtained from the Ethical Committee of the University of Eastern Finland, and organizational approval was received from the hospital. The oral and written informed consent of participants were obtained and confirmed with a signature.

Data analysis

The data were analysed by inductive content analysis.^{28,32} The first phase of data analysis was to transcribe the interviews, which comprised 70 A4 pages, without the moderator’s statements. The second phase involved reading the data several times to provide an overview of the whole content and then coding according to the research questions. During the coding, original expressions were reduced to meaning units, and after that meaning units were allocated to subcategories and then categories. A total of three main categories and eleven subcategories were created.

Findings

The findings addressed three main categories. The first category, the type of patients’ duties, mostly confirmed previous studies, and the other two categories, the implications of their duties and the factors that influence fulfilling patients’ duties, represented new findings (Fig. 1).

The word ‘duty’ was linked to responsibilities and even interconnected with them. Duties were described as indisputable by nature, and health-care professionals were perceived as helpers and supporters. Patients’ duties aimed to uphold, preserve and promote health and well-being.

The type of patients’ duties

The first type of duties focused on patients’ duties towards themselves and included responsibility for their own life and in particular for self-care. Responsibilities included following a healthy lifestyle by taking sufficient physical activity, avoiding fatty food and not smoking.

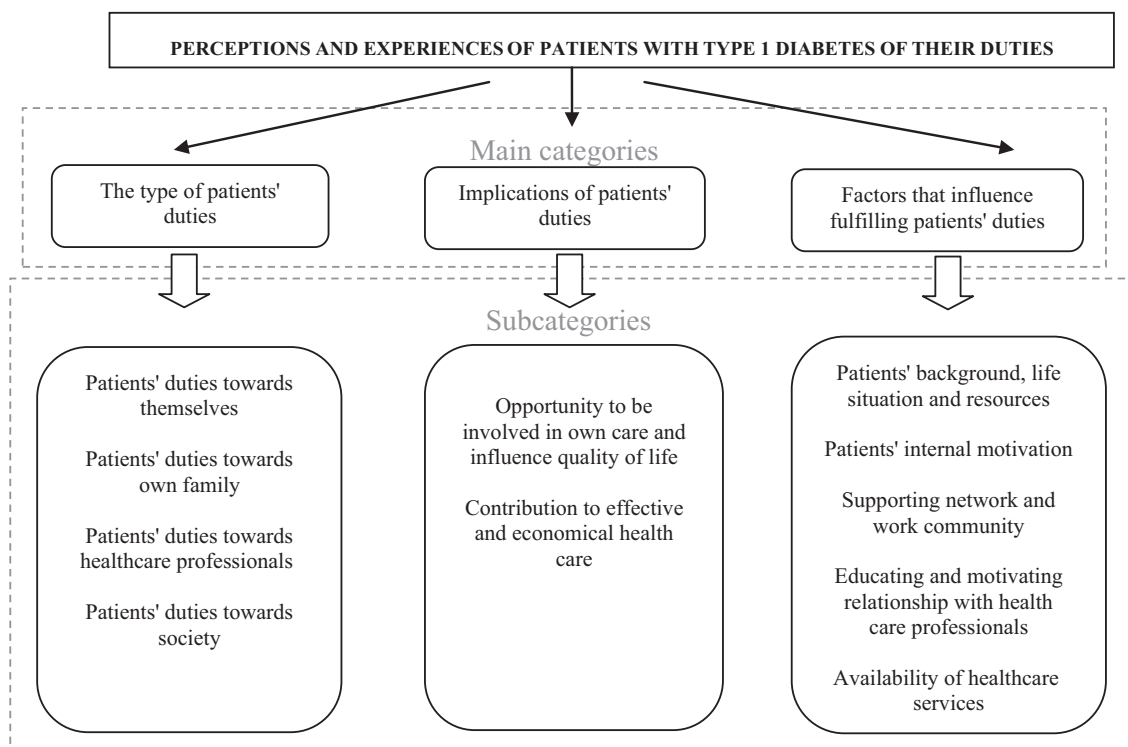


Figure 1 Perceptions and experiences of patients with type 1 diabetes of their duties.

A duty to follow given health advice was emphasized by most participants.

My duties are blood sugar monitoring, right insulin dosing and eating and a regular life rhythm, but also that I know how meal rhythm and exercising will affect my blood sugar levels throughout the day. (P4)

The second type of duties focused on social network, including family members, relatives, work and school colleagues, and other people. Duties towards family were about being honest regarding own condition and taking good care of themselves. These duties were mostly perceived through the effects that they could have on family members. Duties towards work and school colleagues referred to their duty to inform them about diabetes. Participants felt they were responsible for sharing information that would facilitate first aid procedures in case of an emergency, such as hypoglycaemia. This included using a diabetes tag or diabetes bracelet. They also reported a duty to protect the health of others.

I have a duty to upkeep myself. If I do not take care of myself, my family at home will suffer if I am not well. (P9)

I feel it is my duty to tell people about my diabetes, at least the people I often interact with, because if something happened to me, they would be able to help. (P2)

The third type of duties focused on health-care professionals. Patients had a duty to be truthful in terms of providing complete and correct information, such as reporting accurate glucose levels or possible new symptoms. Half of the participants felt they had a duty to respect professionals, and majority of participants emphasized a duty to co-operate with them and to attend appointments.

If I have an appointment, then of course I must attend or postpone it if I cannot attend. (P20)

The fourth type of duty concerned the role as a member of society. Participants perceived a duty to seek and access health care responsibly and to improve healthcare services through

feedback and by participating in research. A duty to be available for developing diabetes applications and devices was mentioned.

Implications of patients' duties

The findings offered new knowledge about the implications of the fulfilment of patients' duties. Implications concerned the opportunity to be involved in their own care and influence their quality of life, the workload of health professionals and the efficiency of the health-care system.

Opportunity to be involved in own care and influence quality of life

The most evident implication of patients' duties was the opportunity to be involved in their own care, in terms of planning, participating in and implementing disease treatments. That duty focused patients on the need to make independent decisions and manage their own care to become an expert on their own well-being.

It would not be good if I was totally under the control of others and couldn't influence my own life and disease care. (P1)

Participants were willing to be involved in managing their care, including taking care of their treatment balance and making good health choices in life. This led to better physical and mental well-being. Physical well-being meant preventing complications associated with their diabetes and mental well-being included having a clear conscience, increased self-confidence and a feeling of success. Neglecting those duties was perceived to cause the deterioration of their own health care and family relationships.

When you manage your duties well, you avoid additional diseases and you are able to have a better life. (P15)

Contribution to effective and economical health care

Patients had duties on a personal, organizational and societal level, and those duties had implications for the effectiveness and economy

of health care. On a personal level, duties centred around responsibility sharing initiatives that could improve care between patients and healthcare professionals. In an organizational level, the patients' duties were seen as affecting healthcare professionals' workload and commitment to work.

The health care staff do not need to do extra work, if the patient is honest and trust works both ways. (P19)

A link between patients' duties and the effects on society was discussed in relation to the economy. Participants felt that a healthcare system could not work well in society if patients did not fulfil their own duties. Good management of patient duties was perceived to minimize healthcare expenses by decreasing the number of complications caused by the mismanagement of diabetes, but this was not just seen as relevant to people with diabetes. Neglecting general healthcare duties caused greater expenses for the healthcare system. Therefore, the well-being of society as a whole was seen as being affected by patient duties.

If everyone had a sense of duty for own health, we would have lower expenses. That is not just an issue for diabetes, but for other health issues such as being overweight. (P7)

Factors that influence fulfilling patient duties

Participants reported numerous factors that influenced how patient duties were fulfilled, including their background, life situation and resources, internal motivation and their support network. In addition, the influence of healthcare professionals and even the way that healthcare services were structured were also factors.

Patients' background, life situation and resources

Duties were not the same for all patients, but were connected to an individual's ability to manage their own duties. For instance, young children and older adults with diabetes, together with patients with mental health disor-

ders or substance abusers, were not seen as having the same duties and responsibilities as others. These ability-related duties included, for example blood sugar measurement, insulin dosage and managing the level of carbohydrates in their diet. Participants emphasized that a patient's life situation, as well as their limited personal or economical resources, could mean that they were less able to perform their duties. Therefore, it was unfair to expect everyone to fulfil their duties equally. However, if a patient was unable to fulfil their own duties, healthcare professionals were expected to recognize and understand the reasons for this.

Patients who cannot take care of themselves do not have same duties. For example older persons, people with memory disorders, alcoholics, and all this kind of groups. (P13)

Patients' internal motivation

Patients' own motivation was raised in the interviews as a significant factor affecting how they fulfilled their duties and managed diabetes. Personal motivation was perceived as an internal resource, independent of external influences and dependent of a patient's personality, character and sense of responsibility. The fear of consequences of a poor metabolic balance and complications of diabetes were motivating factors in self-care.

My own metabolic balance motivates me to fulfil my duties. If I want to feel well, then I must take care of myself and my duties. In a sense, it is not depending on others, I decide for myself whether to fulfil my duties or not. (P6)

Support networks and work communities

Support networks were a factor that enabled participants to fulfil their duties. They received help and shared their experiences and thoughts about managing diabetes. Their support network included their family, other patients with diabetes and the local Diabetes Union. In addition, their work environment was perceived as a factor that influenced the fulfilment of their duties. For example, a lack of time at work

prevented adequate diabetes care, such as registering glycaemia measurements.

Diabetes can cause difficult situations at work. For example, if I have problems with my blood sugar balance, I find it difficult to manage if work colleagues or my employer are not understanding and supportive. (P16)

Educating and motivating relationships with healthcare professionals

A good relationship with healthcare professionals, including physicians and nurses, had a positive influence on fulfilling patients' duties. The optimal relationship was achieved when there was collaboration with a permanent and dedicated physician or nurse with diabetes expertise. Knowledge-based patient counselling helped patients to carry out their duties. Good patient counselling comprised of them being given correct and clear information in comprehensible language, with advice, and counselling tailored to individual needs.

They (health care professionals) tell to me in an understandable way about what can happen and where we are going with the disease, without using difficult Latin terms. (P9)

In addition to counselling, the personal relationship with professionals was emphasized by all participants. A good relationship with patients was described as professional, having a positive, non-paternalistic attitude and being compassionate and friendly. It included truly listening and manifesting a real interest in the patient's physical and mental well-being. Communication was promoted by a feeling of safety, sincerity and trust in healthcare professionals.

External motivation by healthcare professionals was felt to be a key feature of good patient relationships. According to participants, the support and encouragement they received from healthcare professionals motivated them to better self-care. Discouraging and accusing the patient was perceived to have a significant negative impact on their morale and led them to ignore their duties and decrease their commitment to self-care.

Accessibility of healthcare services

The accessibility of healthcare services was seen as a factor that gave patients the opportunity to fulfil their duties. This included travelling reasonable distances to the hospital or polyclinic, proper ambulance services and low-threshold access to healthcare appointments with physicians and nurses.

It is easier to see my own duties if the distribution service for treatment accessories works without heavy bureaucracy, and I know that I can get an ambulance if I need one, but also that someone is always answering the emergency number... and that I have the opportunity to receive insulin. All these things help me to commit to my care and take care of my duties. (P19)

Discussion

This study provides new findings regarding the implications of duties and factors that influence patients fulfilling their duties and confirms previous knowledge about the type of patients' duties. According to our findings, patients' duties were central to the care of patients with type 1 diabetes, but seldom discussed. Patients' duties aimed to uphold, preserve and promote the health and well-being of patients and were related to family members, social networks and healthcare professionals. Patients' duties consisted of responsibilities for self-care, telling the truth, being committed to their own care and respecting others and the healthcare system. New findings include the patients' duties to inform other people about diabetes as well as the implication that fulfilling patient duties led to improved involvement and better results in their own care. Fulfilling their duties as patients was linked to more effective and economical healthcare outcomes. However, patients' duties are not the same for each patient as they are related to individual life situations and resources. Fulfilling patients' duties was also linked to patients' individual motivation, the support they received from family members and social networks and accessibility to healthcare services. Healthcare

professionals play a key role in positively influencing patients to fulfil their duties by motivating and educating them. When patients are unable to fulfil their own duties, healthcare staff need to be aware and react to that.

Duties of the patient

Patients' duties are a highly topical subject in health care, particularly in relation to chronic diseases such as type 1 diabetes. Patients are currently willing to get involved, feel that they have a moral obligation to do so^{17,33} and take responsibility for actively achieving better health outcomes.²⁶ Our participants reported that carrying out their duties increased their commitment to their care and made them feel more independent. Commitment to duties was recognized as promoting successful self-care and physical and psychological well-being and preventing complications of diabetes. Previous studies have shown that individuals' motivational factors, such as autonomous motivation and perceived self-efficacy, are associated with better results in self-care.^{34–36} Participants felt that successfully managing their duties also brought the development of self-care, and this is reinforced by the literature findings.^{11,26,37} Previous studies have also highlighted that patients' duties, as a part of autonomy, are an ethical way to promote the purpose of care and provide the best care for the patient.¹¹

It is noteworthy that patients' duties are not the same for all patients. As our results proved, duties are affected by individual factors, such as the patient's background, life situation and resources. The surrounding culture, values and societal circumstances affect an individual's perceptions of their duties. Patients' duties differ significantly in different cultural and societal settings with diverse local legislation. In addition, some cultures are more family-orientated than others and family roles and responsibilities might differ from one ethnic group or culture to another.⁷ For example, the role of family members in diabetes care has been recognized as influencing patients' self-care and family life.^{6,7,38} Along with other

ethical values, patients' duties have to be looked at on an individual basis, by taking culture into account. In healthcare practice, this requires clinicians' maturity and knowledge to recognize patients as individuals and respect their human dignity. In particular, clinicians are required to pay special attention to the duties of vulnerable groups such as older adults and children³⁹. Healthcare professionals' understanding of patients' duties from the patients' perspective ensures more ethical and individual patient involvement in care.

Patients' duties play a key role in the care of current chronic diseases such as type 1 diabetes. Although there have been major developments in pharmacotherapy and the control of lifestyle risk factors, the early onset of type 1 diabetes highlights the major importance of patients' duties when it comes to making the right health choices. Understanding the right of patients to be involved in their care, the influence they have on their own health and well-being and the duty of healthcare providers to let them exercise these rights, is crucial for highlighting the consequences of healthy and unhealthy choices in people with chronic diseases. This has generated discussions in Western countries about guilt and blaming people for the consequences of unhealthy choices. In developed countries, people do tend to take responsibility and blame for developing or managing diseases and emphasize the role of their own lifestyle.⁴⁰ However, over-emphasizing patient responsibility can cause unnecessary feelings of guilt for issues that the patient has no control over.^{16,25}

Patient duties in healthcare practice

Based on our findings, patients' duties were mentioned but little discussed and supported in healthcare practice. However, a good relationship with healthcare professionals was seen to positively influence how patients fulfilled their duties, by increasing their motivation for better self-care of their diabetes. According to previous studies, people with diabetes who have had good experiences of communication with clinicians have better self-management practices.^{41,42} The

need for collaborative relationships with health professionals has also been highlighted by a number of studies that found that collaborative ways of working were an essential part of people taking on the responsibility for self-care.^{38,41–43} Patient satisfaction is linked to feelings of autonomy and equality, worthiness as a person, being listened to and feelings of safety and confidence.⁴⁴ In healthcare practice, clinicians should have sufficient skills and expertise regarding patients' duties to recognize them and thus support and promote responsible self-care.

Patients with type 1 diabetes reported that good counselling helped them to fulfil their duties. This consisted of practical issues as well as personal, emotional and psychological support.⁴ In clinical practice, expertise, sufficient time and continuity⁴⁵ and taking account of patients' individual skills and competences⁴⁶ guide clinicians to provide counselling practices where patients have the opportunity to learn, involve, empower³⁸ and create their own routines.²⁷ Thus, staff need to be educated in ethical and effective counselling methods. Healthcare professionals' understanding of the patients' role and duties leads to better counselling and goals being achieved.⁴⁷

To support patients to fulfil their duties, professionals can use strategies like finding out what knowledge they already have,^{38,48} their values, motivation,³⁸ emotions⁴⁸ and goals and linking these to actions. Larsson *et al.*⁴⁵ found that patients experience obstructions to being involved in their care, like their own inability, being confronted with a lack of empathy or paternalistic attitudes and sensing structural barriers. Close co-operation, together with confidence, respect, listening and reinforcing self-care capacity by generating accountability and encouragement, all contribute to increasing patients' involvement in their care.⁴⁹ The quality of the relationship between clinicians and patients is also influenced by the degree of responsibility they perceive the patient has for the clinical situation.⁵⁰ Many physicians and nurses consider that a patient's unwillingness to change is always, or nearly always, a key barrier to treatment.⁵¹

In addition to care outcomes, good management of patients' duties has been linked to positive effects at a national level and may also have a financial impact on public health care by maximizing the effectiveness of limited healthcare resources.^{11,14,25} Patients' duties also promote efficient research, aimed at making healthcare work effectively and efficiently for all patients.^{11,14} Participants in this study also mentioned the duty to provide feedback and to participate in research and they saw this as a way to improve healthcare services.

Limitations

A limitation of this study was that participants did not receive interview themes beforehand, and thus, the time for pre-orientation was short. However, they had the opportunity to ask the researcher questions before starting the interviews. Pre-testing of the literature-based themed interview did not suggest any changes, and the first interview was included in the data. The quantity of the transcribed interview data was relatively low, but the content of the interviews was clearly focused on the patients' duties and saturation was achieved.^{28,30} The interviews were conducted by a researcher with extensive clinical experience of patients with type 1 diabetes. Before the interviews, the researcher reflected critically on her own preconceptions. The atmosphere during the interviews was open and confidential.²⁸ The analysis of the data was conducted until the subthemes were identified by one researcher (MH) and completed and confirmed in collaboration with the other authors.

Conclusion

Patients' duties are a topical, but less discussed and complicated area of healthcare ethics. The views expressed by patients make it easier to understand how they feel about their duties and roles and how these can achieve better results in their own care. Along with patient rights, patient duties are a part of healthcare ethical values and need to be considered and supported in healthcare practice. Patients'

duties are linked to self-care, efficacy and cost to the healthcare system and they have a positive impact on the quality of patients' lives and may promote health. How these duties are fulfilled is influenced by many factors and these have to be emphasized to provide individual and efficient healthcare and health promotion. More conceptual research is needed in the future to clarify the definition of patients' duties and their relationship to other concepts. Cultural, societal and economical differences between countries or regions can be seen within healthcare practices and influence patients' but also clinicians' attitudes towards health and patients' duties. Thus, we need empirical studies among different target groups, to gather more views on the subject. A possible comparative study could provide valuable findings. In addition, there is an obvious need to develop instruments to measure patients' duties in practice and to find additional factors that influence these duties being fulfilled. Future research should include an exploration of clinicians' perspectives about patient duties and how to support these in clinical practice.

Conflict of interest

No conflict of interest has been declared by the authors.

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