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Experience of patients with chronic conditions with telemedicine in primary care: A focus group analysis

Izkušnje kronično obolelih pacientov s telemedicinsko obravnavo v ambulantah družinske medicine: analiza fokusnih skupin

Katja Prevodnik¹, Simona Hvalič-Touzery¹, Vesna Dolničar¹, Jelka Zaletel², Jerneja Laznik¹, Andraž Petrovčič^{1,*}

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¹ University of Ljubljana, Faculty of Social Sciences, Kardeljeva ploščad 5, 1000 Ljubljana, Slovenia

² University Clinical Centre Ljubljana, Zaloška cesta 2, 1000 Ljubljana, Slovenia

* Corresponding author/
Korespondenčni avtor:
andraz.petrovcic@fdv.uni-lj.si

ABSTRACT

Introduction: Telemedicine is becoming an increasingly important strategy for the management of chronic diseases, which cause a high proportion of deaths in Slovenia. The aim of this study was to investigate user experiences related to the use of telemedicine devices and experiences with telemedicine among patients diagnosed with chronic diseases in primary care.

Methods: We conducted four focus groups with 19 patients with type 2 diabetes and/or hypertension in July 2020 in a Slovenian primary health care centre. Transcripts were analysed according to the principles of inductive thematic analysis.

Results: Using inductive thematic analysis, seven themes were identified: advantages and disadvantages of telemedicine, ease of use of telemedicine, two-way communication with health professionals, impact of telemedicine on patients' health, desire to use telemedicine and its accessibility, influence and support from the environment, and concern for own health. The themes are composed of 10 subthemes and 29 factors.

Discussion and conclusion: Regular use of telemedicine is most strongly influenced by patients' perceived need to use it and instructions from health professionals. Despite patients' positive experiences of using telemedicine devices, an individual assessment of their suitability for each patient is needed, including an assessment of the patient's health status, attitude towards health, and level of digital literacy.

IZVLEČEK

Uvod: Telemedicinska obravnava stopa v ospredje kot strategija za obvladovanje kroničnih nenalezljivih bolezni, ki v Sloveniji povzročijo visok delež smrti. Namen raziskave je bil preučiti, kakšne izkušnje imajo pacienti z diagnozo kronične bolezni tako z uporabo telemedicinske opreme kot s telemedicinsko obravnavo v ambulantni družinski medicine.

Metode: Julija 2020 so bile v enem od slovenskih zdravstvenih domov izvedene štiri fokusne skupine z 19 pacienti s sladkorno boleznijo tipa 2 in/ali visokim krvnim tlakom. Prepisi skupinskih pogovorov so bili analizirani po načelih induktivne tematske analize.

Rezultati: S pomočjo induktivne tematske analize je bilo oblikovanih sedem tem: prednosti in slabosti telemedicinske obravnave, enostavnost uporabe telemedicinske opreme, dvosmerna komunikacija z zdravstvenim osebjem, učinki telemedicinske obravnave na zdravstveno stanje pacientov, želja po uporabi in dostopnosti telemedicinske obravnave, vpliv in opora okolja ter skrb za lastno zdravje. Teme vsebujejo 10 podtem in 29 dejavnikov.

Diskusija in zaključek: Na izvajanje telemedicinskih meritev najbolj vplivajo zaznana potreba pacientov in navodila zdravstvenega osebja. Kljub pozitivni izkušnji pacientov z uporabo telemedicinske opreme je potrebna strokovna presoja primernosti tovrstne obravnave na individualni ravni, ki ne vključuje le zdravstvenega stanja pacientov, marveč tudi oceno njihovega odnosa do zdravja in digitalnih veščin.



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Introduction

Chronic non-communicable diseases are responsible for 70% of all deaths in Slovenia (OECD, 2019), and we are seeing an increase in the number of people with diagnosed diabetes (Eržen, Zaletel, & Nadrag, 2020) and high blood pressure (Božič et al., 2020). At the same time, digital technologies now offer the possibility of using telemedicine in people with chronic diseases, which can significantly improve patients' medical treatment and have a positive impact on their overall quality of life (Gellis et al., 2012; van den Berg, Schumann, Kraft, & Hoffmann, 2012; Petrovčič, Peek, & Dolničar, 2019). Telemedicine refers to remote medical treatment by means of telemedicine devices, which eliminates the need for the patient to be physically present in the clinic (Snoswell et al., 2020). Telemedicine devices include monitoring devices (e.g. blood pressure and/or glucose monitors) and communication devices (e.g. tablets or smartphones running dedicated mobile applications) for the two-way exchange and transmission of data, forming a unified whole that allows health professionals to monitor and treat patients remotely (Goodwin, 2010).

The most common barriers to the adoption of telemedicine services by patients are related to the characteristics of the technology and supporting services (e.g. technical difficulties and inadequate support), telemedicine procedures (e.g., patients not using such devices regularly and seeing repetitive tasks as monotonous and tedious), users' attitudes towards technology (e.g., fear of technology, belief that telemedicine is unnecessary), and the desire for physical contact in medical treatment, expressed, for example, in patients' concerns that the use of telemedicine devices would lead to the loss of face-to-face contact with health professionals (Cimperman, Brenčič, Trkman, & Stanonik, 2013; Joo & Liu, 2021). Such barriers depend on patient characteristics, the type of technology used and the availability of support services for the operation of telemedicine devices, as well as their design and perceived usefulness in terms of their limited flexibility to accommodate patient preferences and needs, as well as in their opacity, imprecision and/or unreliability (Aberer, Hochfellner, & Mader, 2021; Joo & Liu, 2021). Appropriate app design is particularly important for older patients with lower levels of digital skills and who tend to be more reluctant to use health apps on mobile devices.

Barriers to the use of telemedicine are also related to the systemic use of telemedicine and telemedicine devices in health care (Joo & Liu, 2021). In this respect, Slovenia lags far behind the most advanced EU member states (European Commission, 2018; Oliveira Hashiguchi, 2020), as only few telemedicine pilot services have been implemented and researched here (Cimperman et al., 2013; Beštek & Brodnik, 2015; Rudel, Slemenik-Pušnik, Epšek-Lenart, Balorda,

& Lavre, 2016; Cimperman, Brenčič, & Trkman, 2016; Janković et al., 2020; Kaufman, Rudel, & Rudel, 2020). The first comprehensive description of existing telemedicine solutions in Slovenia was provided by Rant & Rudel (2021), who identified the problem of low national utilisation of such services and their integration into the national health and social care system. Existing telemedicine services in Slovenia focus on tertiary (e.g. CEZAR; Rudel et al., 2016), secondary (e.g. T-MED Gluco in diabetes clinics; Kaufman et al., 2020) and primary care (e.g. SOSTOP and E-Health Telekom; Rudel et al., 2016), which includes primary care outpatient clinics (Pečelin & Sočan, 2016). Research has shown positive impacts of telemedicine in terms of improved patient clinical outcomes (Aberer et al., 2021), financial benefits (Snoswell et al., 2020) and positive psychological impact on the user (Gellis et al., 2012; van den Berg et al., 2012). In Slovenia, research related to primary health care has mainly focused on the quality of care, patient outcomes (Petek & Mlakar, 2016) and health promotion (Janković et al., 2020), while there is a lack of comprehensive evaluation of telemedicine with user experience as a key aspect.

Aims and objectives

The aim of the study was to provide an in-depth evaluation of the experience of patients diagnosed with type 2 diabetes and/or hypertension with telemedicine and use of telemedicine devices in a primary care outpatient clinic. We addressed the following research question: What are the patients' experiences with the use of telemedicine equipment and the inclusion in telemedicine services?

Methods

We adopted a qualitative research approach and used the focus group method. This provided a comprehensive and in-depth insight into the factors that contribute to the experience of telemedicine in patients with chronic diseases at the primary level of health care in Slovenia. This is a widely used method of collecting information on the views of health service users and patients with chronic diseases (Lehoux, Poland, & Daudelin, 2006). The focus is on the interaction between focus group participants (Polit & Beck, 2014), who are more willing to share sensitive and personal information and views in group discussions, especially if the focus group has a common characteristic, which in our sample is experience with chronic diseases and participation in intervention research (Guest, Namey, Taylor, Eley, & McKenna, 2017).

Description of the research instrument

We developed a focus group guide that served as the basis for conducting the group discussions. The

topics of the guide were based on existing scientific publications and expanded based on the results of quantitative intervention research (Hvalič-Touzery, Dolničar, Prevodnik, Škafar, & Petrovčič, 2019). The guide was divided into seven thematic units/clusters, within which we asked respondents about their user experiences and expectations, their experiences with telemedicine and telemedicine devices, the impact of the use thereof on chronic disease management, and the desire for their further use. In addition to the key starting points, follow-up questions were prepared for the moderator to encourage reflections and responses from the focus group participants. The full text of the guide and the focus group guide are available from the corresponding author of the article. An example of a thematic question in one cluster: *Did you notice any changes in your life, perhaps in the way you think about your life and illness, while you were using the telemedicine devices? Is there a particular experience you can share? Examples of sub-questions: Were the telemedicine devices helpful? Please describe in what way. Did they give you relief? Did the use of the telemedicine devices represent an additional burden or stress? How did you perceive them yourself? What about your loved ones (family, relatives)? Did they also notice any changes? If yes, which ones?*

Description of the sample

A total of 103 patients who had participated in the intervention study in 2019 (Hvalič-Touzery et al., 2019) were invited to participate in this study. This was a purposive sample. The focus groups included 19 patients with type 2 diabetes and/or hypertension, representing almost one fifth of all participants in the intervention study. Their average age was 59.2 years (age range between 42 and 69 years). Nine patients had a secondary professional/technical qualification, four had vocational training or a lower qualification, and four had a tertiary degree (higher education or university education). Nine patients were retired, nine were currently employed, and one was unemployed. In total, nine men and ten women participated in the study. Twelve patients had hypertension, one had type 2 diabetes and six had both chronic diseases.

Description of the research procedure and data analysis

The focus groups were following the first intervention study in Slovenia, where telemedicine was utilised over a longer period of time and patients with chronic diseases were tested in the selected outpatient clinic in Slovenia. Thus, our participants had already had extensive experience with telemedicine during the three months of the intervention study, in which they had used monitoring devices (blood pressure and/or glucose monitors) and communication devices

(mobile apps on tablets or smartphones) to transfer data and communicate with health professionals. The telemedicine solution tested was developed by Telekom Slovenije (Hvalič-Touzery et al., 2019). The participants of the intervention study were recruited by health professionals in accordance with the protocols established for intervention research, under the supervision of nurses.

After obtaining approval from the Ethics Committee of the Faculty of Social Sciences, University of Ljubljana, we conducted four focus groups in July 2020. In determining the number of participants, we followed the guideline of smaller groups being more appropriate for topics that are relevant to participants and on which participants have an opinion (Nyumba, Wilson, Derrick, & Mukherjee, 2017). Our focus groups were therefore comprised of between three and seven participants. The group discussions, which lasted an average of 60 minutes, were led by a moderator and an assistant. All discussions were audio-recorded and transcribed (84 pages), and all the data obtained were anonymised.

The recorded discussions were analysed by an inductive form of thematic analysis (Braun & Clarke, 2012) using Atlas.ti software (Thomas Muhr – Atlas.ti Scientific Software Development GmbH, Germany). In consultation with the research team (consisting of three researchers), two researchers looked for the patterns (themes) that emerged directly from the data collected. Our coding book was formulated on four levels: Code – Factor – Sub-theme – Theme, where seven themes and ten sub-themes were identified based on 99 different codes (the total frequency of codes in all transcripts was 809). The frequencies reflect the frequency of the responses of focus group participants, but not the significance of the individual themes, which is why they were not interpreted separately.

Results

Using inductive thematic analysis, we identified seven themes and ten subthemes (Figure 1).

Advantages and disadvantages of telemedicine

The most frequently mentioned advantages of telemedicine were the ability to self-monitor blood pressure and/or blood glucose levels, and the ability to have the results of these measurements monitored by health professionals. The latter was seen by the participants as motivation to take these measurements regularly and thus monitor their health, which they would otherwise not do.

I was more encouraged and found it easier to do. To me, this was a kind of motivation. (F, 64)

Patients reported that they did not continue to perform these measurements regularly after the end of the study for lack of motivation. Patients also reported

a sense of safety knowing that health professionals were monitoring the results of their measurements. They also emphasised that they felt overwhelmed with health concerns (fear of the results of measurements, worry about health, feeling controlled by health professionals).

Well yes, I do occasionally, but not as often and not as regularly as I did when I had this device. Because it forces you a bit to do it, which is ok. It only takes a couple of minutes, and it feels ok, not bad, but we humans are just so wired that we need some encouragement. (F, 59)

An important benefit of telemedicine, according to patients, is the availability of measurement results over longer periods of time, which results in a more accurate identification of trends (elimination of the 'white coat syndrome' and familiarisation with the impact of daily

habits on one's health – in particular with the impact of physical activity and nutrition on blood glucose levels), which in turn can form the basis for a change in treatment (e.g. change/initiation of therapy, new diagnosis, referral to a specialist). The frequency of measurements did not contribute to patients feeling overburdened, as they became routine for most. Patients with diabetes took measurements more frequently. Some also felt more burdened at the beginning – especially those who had not been used to taking regular measurements before participating in the study.

Patients found the remote transmission of data to be the most useful feature of telemedicine devices, as it meant they no longer had to wait for a follow-up appointment and could avoid the 'white coat syndrome'. Patients rated communication via

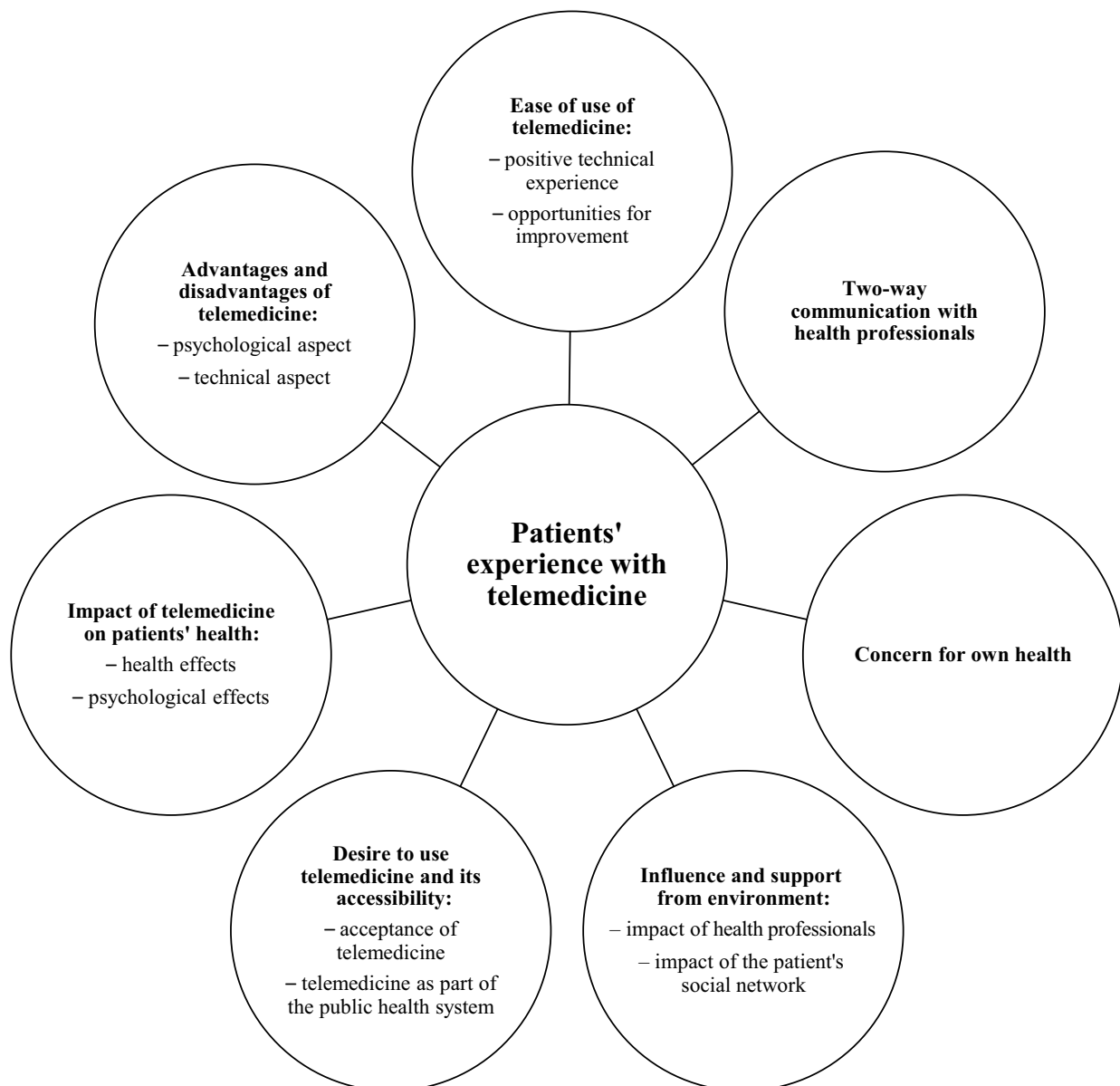


Figure 1: Themes and subthemes

messages in the mobile app as appropriate and time-saving. Communication via mobile devices was found to be more practical and faster than a personal visit to an outpatient clinic. It does not replace the need for a face-to-face visit, but it complements it well. Patients found that health professionals responded more to messages rather than calls.

Yes, and they found the solution faster. For example, if something was wrong, help was immediately available. And to be able to book an appointment and wait two or three days and avoid long queues is also in our favour. This way the doctors would also have a bit more time to talk. (F, 68)

Ease of use of telemedicine

Patients described the mobile app for entering measurements as simple and easy to understand. It was designed in a user-friendly way, with the user being guided through the user interface; using it required only basic knowledge of smartphone use.

I find that the tablet or phone and the software are so straightforward that you can't go wrong. It warns you: you have to do this and that, click here to send. Then it says, done, next time... So I think anyone who's not familiar with using a tablet or smartphone can learn it very quickly. Because it's not a complicated system, no. (F, 41)

Participants were mostly able to develop the necessary skills themselves or with the help of their family or friends. External assistance from health or technical staff was only needed in case of technical problems (e.g. password not working to unlock the mobile application). Such problems were very rare and did not negatively affect patients' confidence in their own digital skills or diminish their interest in telemedicine. On the contrary, some patients suggested additional functions and upgrades for the equipment and interface used: (1) alerts when to take measurements; (2) personalised limits for acceptable values and alerts when these limits are exceeded; (3) the ability to transfer readings to a computer; (4) integration of other smart devices (e.g. smartwatch); and (5) app connectivity with other monitoring devices and not only those used in the intervention study. Patients rated the monitoring devices they used as comparable or better than their own monitoring devices.

Yes, it would be very good if when you take a measurement a signal would remind you that your optimal value has been exceeded. Perhaps with an asterisk or something similar. Some kind of symbol should appear. (M, 64)

Two-way communication with health professionals

Although communication via messages was considered effective, sufficient and desirable, it should be taken into account that no patient experienced a

significant deterioration in their medical condition or required a medical intervention during the study. Had this been the case, patients would have opted for a telephone call or a personal visit to the clinic. The messages were seen by patients as a supplement to, rather than a substitute for, telephone calls and face-to-face visits to the doctor's office. They strongly emphasized the need to receive feedback on whether the measurements have been reviewed. Some patients who had not received feedback questioned whether health professionals had in fact reviewed the results. At the same time, they also expressed an interest in further information about how the patient – nurse – doctor triangle worked (whether the measurements had also been reviewed by the doctor or only by the nurse, or whether they had consulted about the feedback).

It was great because there was a nurse behind it. You knew she was going through it because you could see when she called up the measurements and she would then let you know if there was anything wrong. She could tell you in advance, "Listen, you need to do this or come in early. For me, that was a plus." (F, 41)

Patients expressed understanding of the workload of nurses in outpatient clinics and had not expected an immediate feedback regarding the measurements submitted.

Impact of telemedicine on patients' health

According to the participants, the use of telemedicine led to changes in their medical treatment (e.g. adjustment of therapy, health examinations) and for some to an actual improvement in their health status.

Well, and then I was advised to stop taking pills except for the ones for my pulse, but even with those, the dosage is lower now, and now after I have stopped taking those medications, I feel pretty good. So it was beneficial and it felt good that they could now really see what I was saying. That my blood pressure is lower at home, that it's gone down. (F, 50)

The most significant changes perceived were related to psychological effects: in the course of using telemedicine, patients had developed a more serious concern for their medical condition and felt empowered by the feeling that they were successfully managing their health and were therefore less anxious about it.

I was more disciplined. In other words, I spent more time thinking about it. I paid more attention to really taking those 10,000 steps a day, going out and spending time in the fresh air. And I continue to do so. (F, 64)

Desire to use telemedicine and its accessibility

Most patients found telemedicine beneficial and would recommend it to other people with similar health problems, especially people with serious illnesses or physical impairments who find it difficult

to access the doctor's office.

And one more thing, let's say for the older ones among us – we can still move, which is much better. If someone has difficulty getting around or if it's difficult for them to get to a clinic or if they do not have a ride, this is a great way to just show them from a distance and they can see it immediately. (M, 64)

Patients who considered their physical health to be stable felt that daily data submission and additional monitoring were unnecessary. Therefore, some mentioned that it would have been better for them if the telemedical monitoring had lasted longer and the measurements had been taken less frequently or only occasionally (e.g. every first week of the month). They felt that their health status was changing slowly.

Well, that depends on if you just need it for monitoring purposes and you don't have any actual problems, then most people would not pay for this service, and I probably wouldn't pay for it either, no. Oh, but if there are more serious problems, whatever that might be, like if you're shaking or about to have a stroke or something like that, then it's probably not a question of money any more. (M, 55)

Patients' decision to opt for telemedicine is influenced not only by their specific medical condition and health professionals, but also by the price. They estimate that telemedicine would be more accessible if it were financed by insurance or integrated into the public health system. This would also increase patients' trust in telemedicine and reduce concerns about the protection of personal data. On the other hand, telemedicine marketed by a private company would be less trusted. Patients believe that such a service is more credible and reliable when provided within the public health system. Most patients believe that the primary objective of offering market services in telemedicine is to make a profit, not to promote well-being.

You see, it is most legitimate when it is offered within the health system. As soon as there are other providers, that is not it anymore. It's the same when they call you and say, "We are going to measure your cardiovascular health". But how can you measure cardiovascular health without medical analysis? That means you can only trust medicine and no one else. (F, 67)

Patients also mentioned the potential use of applications with other (own) monitoring devices, which would mean a financial relief for the health system.

Influence and support from the environment

Health professionals have the greatest influence on patients' willingness to engage in telemedicine. Most patients in our sample had made the decision to participate in the intervention study independently, without consulting their family members or loved ones. Patients even expressed doubts about the soundness of the advice given by their family members,

who (like themselves) had no professional or practical experience with telemedicine. The same view applies to the field of health management.

You see, the doctor is the first authority, he knows the most about medicine, while the family's opinion depends on the background of individual members. The people in your family may come from completely different professional backgrounds. And I have the most confidence in medicine. (F, 67)

Although the influence of family members on the decision to use telemedicine is relatively low, patients appreciate their encouragement and willingness to provide technical support in their daily use of telemedicine devices.

Concern for own health

Two patterns were prevalent regarding patients' attitudes towards their own health: (a) active patients who give considerable thought to their health or illness, are aware of the importance of regular health monitoring for the development of appropriate treatment approaches, and strictly follow the doctor's instructions, show initiative and strive to achieve their target blood pressure and/or glucose levels (e.g. by closely monitoring the effects of diet and physical activity); (b) less active patients who are less consistent and take their measurements spontaneously or when they feel unwell.

It is always worth doing something for your health /.../ For myself I can say that I'm active, I go for walks, I do yoga, I do physical work, I do mental work. In short, I have grandchildren around me. And I think I am constantly on the move. Device or no device, I know that I do these things just for me and that I have to do them. (F, 67)

Discussion

With the research question in mind, the authors identified seven main themes related to patients' experiences with telemedicine. Most themes ($n = 5$) relate to patients' experiences of using telemedicine devices and their inclusion in telemedicine treatment, while the remaining two themes relate to the role of health professionals in telemedicine use, and the desire for its continued use.

Similar to previous research (Vermeulen et al., 2013; Su et al., 2019), our study identified the usability of telemedicine and telemedicine devices as a critical aspect of user (patient) experience. The mobile application used was found to be easy to use, intuitive and user-friendly. The acceptance and use of telemedicine and telemedicine devices is most significantly influenced by the perceived need for their use (which depends mainly on the patient's health status) and the instructions given by the health professional, who also has the role of partner

and authority in the medical treatment. This is an important implication for the treatment of type 2 diabetes in primary health care, in which many patients do not have the ability to perform blood glucose measurements themselves. Currently, basic health insurance does not yet cover the cost of monitoring devices, and when they are purchased by patients themselves, systematic awareness of the importance of regular measurements is not yet available to all (Vermeulen et al., 2013). This was also confirmed by the finding that patients with diabetes were extremely enthusiastic to participate in the intervention study (device testing).

Despite patients' positive experiences with the use of telemedicine and telemedicine devices, it should be kept in mind that some patients do not have enough motivation or discipline to monitor their chronic disease by performing regular measurements without external control and encouragement. Such encouragement is mostly given by nurses and/or doctors. Studies conducted in Slovenia have already highlighted the role and influence of health professionals, but they have mainly focused on the process of medical treatment or care (Iljaz, Meglič, Petek, Kolšek, & Susič, 2014; Petek & Mlakar, 2016) and changes in patient outcomes (Petek & Mlakar, 2016), without considering the psychological or motivational aspects. Our study highlights the importance of a partnership relationship and patients' trust in the primary healthcare team (i.e., the nurse and the physician). Because of patient trust, health professionals play a central role not only in the decision to use telemedicine, but also in the selection of patients who would benefit most from this approach. Using health data, an outpatient nurse or doctor can also more easily assess whether a patient possesses the necessary digital skills and whether they are capable to participate in telemedicine without undue psychological distress (Joo & Liu, 2021). This is an important implication for the potential systemic implementation of telemedicine in primary care clinics and beyond.

Based on the results of the study, we can identify specific patient groups who are more or less suitable for participating in telemedicine at the primary care level. Telemedicine is more suitable for patients who feel more responsible for their health and take better care of their health; for younger patients who are more skilled in using new technologies; for 'managed' patients who need only occasional follow-up visits; for patients who have recently been diagnosed with a chronic disease and show a greater potential to learn about their health status; for patients who find it more difficult to attend medical treatment or who, for various reasons, find it more difficult to see a doctor. Telemedicine is less suitable for patients who are less health conscious; for those who would not be able to use the devices independently (family or social implications); for

those who need additional motivation; for those to whom the use of telemedicine would present an excessive psychological burden; for those who do not have sufficient digital skills or support to use the telemedicine devices. As telemedicine provides an integrative approach to medical treatment through direct two-way communication and the active role of patients, its utilisation is beneficial for a wide range of patients with various chronic conditions (Simblett et al., 2018; Donelan et al., 2019). The establishment of an integrated service which would automatically transmit patients' entire history of treatment (e.g. results of measurements and past therapies) from the personal physician to the specialist would also speed up treatment at the secondary level (specialist clinics).

The introduction of telemedicine into the public health or social care system would increase patient confidence and willingness to engage in telemedicine. We have found that patients trust the service more if it is part of the health system as opposed to being a commercial service. Reservations about the marketing of such services are not only tied to cost coverage, but are also affected by participants' view that the primary objective of market providers is to generate profit rather than to improve patients' health (Harris, Alfonso, Stewart, & Moore, 2021; Michaud, Hill, Estabrooks, & Su, 2021). However, this attitude depends on the severity of the patient's medical condition, which also affects the willingness to pay for telemedicine services (Steigenberger, Glatsher-Thoeni, Siebert, & Leiter, 2022). Patients who have a more serious attitude towards their health are also more willing to pay for such services. Given the widening gap between patients in terms of their financial situation, it is essential to include such services in the basket of health services covered by health insurance (Michaud et al., 2021), which is also part of the Diabetes Control Action Plan (Zaletel, 2020).

Although research generally demonstrates patients' willingness to use telemedicine, matching telemedicine with patients' needs in the long term and motivating them to use telemedicine devices on a regular basis is still a major challenge. As has also been confirmed by this study, we can assume that the adoption of this technology is only successful provided that individuals are willing to continue using the technology after the initial usage phase (de Graaf, Ben Allouch, & van Dijk, 2018). The uptake of telemedicine and telemedicine devices seems to be particularly promoted by patients' recognition of their broader potential for health management and a more efficient access to health services, which is dependent on the user's personal characteristics such as perceptions of the usefulness of telemedicine, certainty about one's health, level of personal commitment to treatment, and personal initiative (Hibbard & Greene, 2013; Su et al., 2019; Joo & Liu, 2021). Patient enthusiasm for using telemedicine may also be positively influenced by

healthcare teams in outpatient clinics. The results of this study confirm that the acceptance of telemedicine depends on the positive attitude of patients as well as on the positive attitude of doctors and nurses towards this approach (Asua, Orruño, Reviriego, & Gagnon, 2012; Cimperman et al., 2013). With the introduction of telemedicine, we can successfully address some of the common barriers that negatively influence patient engagement in collaborative treatment of chronic diseases: asymptomatic nature of diseases, side effects of medications, discomfort, and lack of knowledge about the disease in question. One of the most important aims of primary care clinics is health empowerment (Pečelin & Sočan, 2016) so as to prevent the development or progression of chronic diseases by encouraging patient engagement in disease management (Govc Eržen, Vračko, Čuš, & Medved, 2017).

This study, which is one of the first in Slovenia to implement a functioning telemedicine service at the primary level of health care, provides important starting points for further research. In the future, it would be advisable to involve patients in telemedicine services for longer periods of time, to collect clinical data on their health status, and to monitor certain key aspects of their acceptance and effects through quantitative methods in a larger sample of participants. We also note that most initiatives and studies on the introduction of telemedicine in Slovenia have focused on the secondary or tertiary level of health care, while much less attention has been paid to the primary level, which also opens up opportunities for further research. The method of recruitment of participants in the intervention study and the sampling for the focus groups represents a certain limitation of this study. In the intervention study, recruitment was conducted in a single outpatient unit. Expanding the intervention research to include a larger number of outpatient units or clinics would result in a larger sample and thus a more diverse sample structure. This method of sampling (i.e. purposive sampling) does not allow for randomised controlled trials to be conducted, which would be possible in the case of random sampling.

Conclusion

This study has shown that telemedicine has an overall positive impact. This can be seen in the improvement of patients' quality of life and health status, health empowerment, motivation for disease management and an increased sense of safety. Remote access to health care and the ability to transmit data remotely are the most useful and frequently cited features of telemedicine devices, as they allow patients to avoid waiting for their medical examinations, reduce the frequency of doctor visits and eliminate the 'white coat syndrome'. The results of this study provide a solid basis for establishing the procedures for a wider

adoption of telemedicine at the primary level of health care. In future research, the use of telemedicine by the chronically ill should be conducted over longer periods of time and also include other target groups. To evaluate the impact of telemedicine, we recommend the use of mixed methods: in addition to qualitative research, quantitative monitoring (evaluation of user experience via questionnaires and assessment of the clinical condition of patients through an analysis of the measured values) should also be carried out.

Slovenian translation/Prevod v slovenščino

Uvod

Kronična nenalezljiva obolenja v Sloveniji povzročijo 70 % vseh smrti (OECD, 2019), pri čemer smo priča naraščanju števila oseb z znano sladkorno boleznijo (Eržen, Zaletel, & Nadrag, 2020) in oseb z visokim krvnim tlakom (Božič et al., 2020). Digitalne tehnologije ponujajo možnost razvoja telemedicinske obravnave kronično obolelih pacientov, ki lahko bistveno izboljša njihovo zdravstveno obravnavo in pozitivno vpliva na splošno kakovost njihovega življenja (Gellis et al., 2012; van den Berg, Schumann, Kraft, & Hoffmann, 2012; Petrovčič, Peek, & Dolničar, 2019). Telemedicinska obravnava zajema zdravstveno obravnavo na daljavo s pomočjo telemedicinske opreme, pri kateri ni fizične prisotnosti pacienta ob zdravstvenem delavcu (Snoswell et al., 2020). Telemedicinska oprema se nanaša na merilne naprave (npr. merilnik krvnega tlaka in/ali krvnega sladkorja) in komunikacijske pripomočke (npr. tablica z aplikacijo ali mobilna aplikacija na pametnem telefonu) za dvosmerno izmenjavo ter prenos podatkov, ki skupaj tvorijo celoto in zdravstvenemu osebju omogočajo spremljanje in zdravljenje pacientov na daljavo (Goodwin, 2010).

Najpogostejše ovire pri sprejemanju telemedicinske obravnave pri pacientih so povezane z značilnostmi tehnologije in podpornimi storitvami (npr. tehnične težave in podpora), postopkom vključenosti v telemedicinsko obravnavo (npr. pacienti pozabijo na redno uporabo ali se jim ponavljanje zdi monotono in dolgočasno), odnosom do tehnologije (npr. strah pred tehnologijo, prepričanje, da je telemedicinska obravnava nepotrebna) in željo po fizičnem stiku pri zdravstveni obravnavi, ki se odraža npr. v zaskrbljenosti pacientov, da bodo zaradi uporabe telemedicinske opreme izgubili osebni stik z zdravstvenim osebjem (Cimperman, Brenčič, Trkman, & Stanonik, 2013; Joo & Liu, 2021). Ovire temeljijo na značilnostih pacientov, tipu tehnologije in dostopnosti podpornih storitev za delovanje telemedicinske opreme, dizajnu slednje in njeni uporabnosti, ki se odraža v omejeni prilagodljivosti željam in potrebam pacientov, pa tudi v netransparentnosti, nenatančnosti

in/ali nezanesljivosti delovanja (Aberer, Hochfellner, & Mader, 2021; Joo & Liu, 2021). Ustrezen dizajn je pomemben zlasti za starejše paciente z manj razvitimi digitalnimi veščinami, ki so bolj zadržani do uporabe zdravstvenih aplikacij na mobilnih napravah.

Ovire so pogojene tudi s sistemsko razširjenostjo uporabe telemedicinske obravnave in telemedicinske opreme v zdravstvu (Joo & Liu, 2021). Pri tem Slovenija močno zaostaja v primerjavi z najrazvitejšimi članicami EU (European Commission, 2018; Oliveira Hashiguchi, 2020), saj pri nas obstaja le nekaj pilotnih storitev telemedicinske obravnave in z njimi povezanih raziskav (Cimperman et al., 2013; Beštek & Brodnik, 2015; Rudel, Slemenik-Pušnik, Epšek-Lenart, Balorda, & Lavre, 2016; Cimperman, Brenčič, & Trkman, 2016; Janković et al., 2020; Kaufman, Rudel, & Rudel, 2020). Prvi celovit opis obstoječih rešitev v Sloveniji sta pripravila Rant & Rudel (2021), ki sta prepoznala problematiko nizke nacionalne razširjenosti teh storitev in njihove vključenosti v nacionalni sistem zdravstvene ali socialne oskrbe. Obstoječe telemedicinske storitve v Sloveniji so osredotočene na terciarno (npr. CEZAR; Rudel et al., 2016), sekundarno (npr. T-MED Gluco v diabetoloških ambulantah; Kaufman et al., 2020) in primarno raven zdravstvenega varstva (npr. SOSTOP in E-Zdravje Telekom; Rudel et al., 2016), kamor uvrščamo tudi ambulante družinske medicine (Pečelin & Sočan, 2016). Raziskave ugotavljajo pozitivne učinke telemedicinske obravnave z vidika izboljšanja klinične slike pacientov (Aberer et al., 2021), finančnih prednosti (Snoswell et al., 2020) in pozitivnih psiholoških učinkov na uporabnika (Gellis et al., 2012; van den Berg et al., 2012). Raziskave v Sloveniji se na primarni ravni zdravstvenega varstva osredotočajo na zdravstveno oskrbo in spremembe v zdravstvenem stanju (Petek & Mlakar, 2016) ter na promocijo zdravja (Janković et al., 2020), manjka pa celovita evalvacija telemedicinske obravnave, pri čemer je uporabniški vidik eden ključnih.

Namen in cilji

Namen raziskave je bil poglobljeno ovrednotiti izkušnjo pacientov z diagnozo sladkorne bolezni tipa 2 in/ali visokega krvnega tlaka, ki so vodeni v ambulantni družinske medicine (primarna raven zdravstvenega varstva), s telemedicinsko obravnavo in uporabo telemedicinske opreme. V raziskavi smo postavili naslednje raziskovalno vprašanje: Kakšna je izkušnja pacientov z uporabo telemedicinske opreme in vključenostjo v telemedicinsko obravnavo?

Metode

Uporabili smo kvalitativni raziskovalni pristop z metodo fokusnih skupin. Ta nam je omogočil celovit in poglobljen vpogled v dejavnike, ki sooblikujejo

izkušnjo s telemedicinsko obravnavo pri pacientih s kroničnimi boleznimi na primarni ravni zdravstvenega varstva v Sloveniji. Gre za pogosto uporabljeno metodo zbiranja informacij o mnenju pri uporabnikih zdravstvenih storitev in pacientih s kroničnimi boleznimi (Lehoux, Poland, & Daudelin, 2006). Pri tem je v ospredju interakcija med udeleženci (Polit & Beck, 2014), ki v skupinskih pogovorih pogosteje delijo občutljive in osebne podatke ter mnenja, še posebej, ko ima skupina neko skupno značilnost – v našem vzorcu izkušnjo kronične bolezni in sodelovanje v intervencijski raziskavi (Guest, Namey, Taylor, Eley, & McKenna, 2017).

Opis instrumenta

Pripravljen je bil vodič za fokusne skupine, ki je osnova za vodenje skupinskega pogovora. Teme vodiča izhajajo iz obstoječih znanstvenih objav in so bile nadgrajene na podlagi rezultatov kvantitativnega dela intervencijske raziskave (Hvalič-Touzery, Dolničar, Prevodnik, Škafar, & Petrovčič, 2019). Vodič je bil razdeljen na sedem tematskih sklopov, v katerih smo povprašali po uporabniški izkušnji in pričakovanjih, izkušnji s telemedicinsko obravnavo in telemedicinsko opremo, učinkih uporabe na vodenje kronične bolezni ter želji po nadaljnji uporabi. Poleg osrednjih izhodišč smo za moderatorja pripravili podvprašanja za spodbujanje razmislekov in odzivov sodelujočih. Smernice in vodič za izvedbo fokusnih skupin so dostopni pri korespondenčnem avtorju članka, na tem mestu pa navajamo nekaj primerov. Izhodiščno tematsko vprašanje je bilo: *Če pomislite na obdobje uporabe telemedicinske opreme, ste opazili kakšne spremembe v vašem življenju, morda v tem, na kakšen način razmišljate o svojem življenju in bolezni? Imate kakšno posebno izkušnjo, ki bi jo lahko delili z nami?* Primeri podvprašanj: *Vam je telemedicinska oprema pomagala? Prosimo, opišite, kako. Ali vas je navedeno razbremenilo? Vam je uporaba telemedicinske opreme predstavljala dodatno breme, stres? Kako ste to dojemali sami? Kako pa vaši najbližji (družine)? So tudi oni zaznali kakšne spremembe? Če so jih, katere?*

Opis vzorca

K sodelovanju v raziskavi so bili povabljeni 103 pacienti, ki so v letu 2019 sodelovali v intervencijski raziskavi (Hvalič-Touzery et al., 2019). Gre za namenski vzorec. V fokusnih skupinah je sodelovalo 19 pacientov s sladkorno boleznijo tipa 2 in/ali visokim krvnim tlakom, kar predstavlja skoraj petino vseh udeležencev intervencijske raziskave. Njihova povprečna starost je 59,2 leta (starostni razpon 42–69 let). Devet pacientov je imelo srednjo strokovno/tehniško izobrazbo, štirje poklicno ali manj in štirje višjo ali visoko izobrazbo. Devet pacientov je bilo upokojenih, devet delovno aktivnih, en pacient je

bil brezposeln. Skupno je sodelovalo devet moških in deset žensk. Dvanajst pacientov je imelo visok krvni tlak, eden sladkorno bolezen tipa 2, šest pa obe omenjeni kronični bolezni.

Opis poteka raziskave in obdelave podatkov

Izvedba fokusnih skupin je sledila prvi intervencijski raziskavi v Sloveniji, ki je telemedicinsko obravnavo implementirala za daljše časovno obdobje in v testiranje vključila paciente s kroničnimi boleznimi izbranega zdravstvenega doma v Sloveniji. Pacienti so tako imeli celovito izkušnjo s sodelovanjem v telemedicinski obravnavi, saj so v okviru intervencijske raziskave tri mesece uporabljali merilne naprave (merilnik krvnega tlaka in/ali krvnega sladkorja) in komunikacijske pripomočke (tablica z aplikacijo ali mobilna aplikacija na pametnem telefonu) za prenos podatkov in komunikacijo z zdravstvenim osebjem. Testirano telemedicinsko rešitev je razvil Telekom Slovenije (Hvalič-Touzery et al., 2019). Pacienti so bili izbrani s strani zdravstvenega osebja in so opremo uporabljali v skladu s protokoli, določenimi za intervencijsko raziskavo, ki so jih nadzorovale medicinske sestre.

V juliju 2020 smo po pridobljenem soglasju Komisije za Etiko v raziskovanju Fakultete za družbene vede Univerze v Ljubljani izvedli štiri fokusne skupine. Pri določanju števila udeležencev smo sledili vodilu, da so za teme, ki so udeležencem blizu in imajo o njih izdelano mnenje, primernejše manjše skupine (Nyumba, Wilson, Derrick, & Mukherjee, 2017), zato so fokusne skupine vključevale od tri do sedem pacientov. Skupinske pogovore, ki so v povprečju trajali 60 minut, sta izvedla moderator in asistent. Vsi pogovori so bili zvočno posneti in dobesedno prepisani (84 strani), pri čemer so bili vsi pridobljeni podatki anonimizirani.

Zapisane pogovore smo analizirali z induktivno obliko tematske analize (Braun & Clarke, 2012) s programskim orodjem Atlas.ti (Thomas Muhr – Atlas.ti Scientific Software Development GmbH, Nemčija). Dve raziskovalki sta ob posvetovanju s širšo raziskovalno skupino (trije raziskovalci) poiskali vzorce (teme), ki izvirajo neposredno iz zbranih podatkov. Kodirna knjiga je bila zasnovana na štirih ravneh: koda – dejavnik – podtema – tema, pri čemer je bilo na osnovi 99 različnih kod (skupna frekvenca kod v vseh prepisih je 809) identificiranih sedem tem in deset podtem. Frekvence predstavljajo pogostnost odzivov udeležencev fokusnih skupin, ne pa tudi pomembnosti posamezne teme, zato niso interpretirane ločeno.

Rezultati

S pomočjo induktivne tematske analize smo identificirali sedem tem in deset podtem (Slika 1).

Prednosti in slabosti telemedicinske obravnave

Najpogosteje izpostavljeni prednosti uporabe telemedicinske obravnave med pacienti sta možnost samokontrole krvnega tlaka oziroma krvnega sladkorja in možnost spremljanja rezultatov meritev s strani zdravstvenega osebja. Pacienti so slednje izpostavili kot motivacijo za redno izvajanje meritev in spremljanje svojega zdravstvenega stanja, ki je sicer nimajo.

Jaz sem se bolj v pogon spravila, lažje, no. Mi je bila to ena motivacija. (Ž, 64)

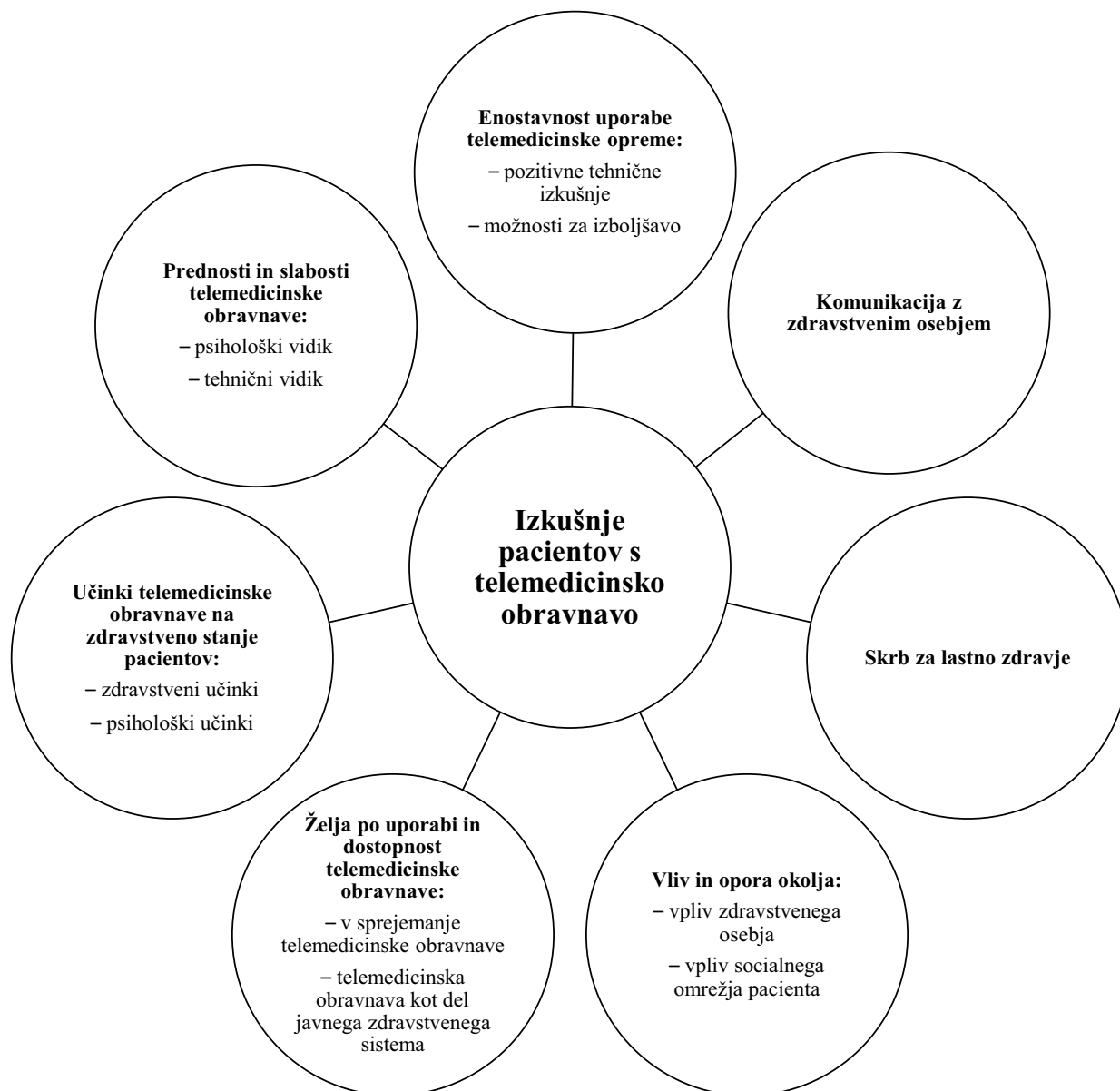
Povedali so, da so meritve po zaključku raziskave izvajali redkeje, saj niso imeli motivacije. Pacienti so poročali tudi o občutku varnosti ob zavedanju, da zdravstveno osebje spremlja rezultate meritev. Izpostavili so tudi preobremenjenost s skrbjo za zdravstveno stanje (strah zaradi rezultatov merjenja, obremenjenost z zdravjem, občutek nadzorovanosti s strani zdravstvenega osebja).

Ja, tisto občasno no, ne tako pogosto in ne tako redno kot takrat, ko sem imela to napravo. Ker to te tudi malo prisili, kar pa ni nič narobe. Saj s tem zgubiš tistih par minut, pa je samo, aaa, ni slabo, ni slabo, ker smo ljudje pač tako naštimani, da rabiš nekaj vzpodbude. (Ž, 59)

Pomembna prednost telemedicinske obravnave je po mnenju pacientov razpolaganje z rezultati meritev v daljšem časovnem obdobju, ki vodi v natančnejšo identifikacijo trendov (izogonejo se učinku »bele halje« in se učijo o vplivu vsakdanjih navad na zdravstveno stanje – predvsem vplivu telesne dejavnosti in prehrane na raven krvnega sladkorja) in lahko predstavlja osnovo za spremenbo zdravljenja (npr. sprememba/ uvedba terapije, nova diagnoza, napotitev na specialistični pregled). Pogostnost opravljanja meritev večinoma ni prispevala k občutku obremenjenosti med pacienti, saj so za večino meritve postale del rutine. Pacienti s sladkorno boleznijo so meritve opravljali pogosteje. Nekateri so se na začetku počutili tudi bolj obremenjene – zlasti tisti, ki pred vključitvijo v raziskavo opravljanja rednih meritev niso bili vajeni.

Najkoristnejša funkcionalnost telemedicinske opreme je po mnenju pacientov posredovanje podatkov na daljavo, kar omogoča, da se izogonejo čakanju na pregled in učinku »bele halje«. Komunikacijo s sporočili v mobilni aplikaciji pacienti ocenjujejo kot ustrezno in časovno učinkovito. Komunikacija z uporabo mobilnih naprav je praktična in hitrejša kot osebni obisk ambulante. Tega sicer ne nadomešča, vendar ga dobro dopolnjuje. Po njihovi oceni se zdravstveno osebje na sporočila bolj odziva kot na klice.

Ja, lažje so rešitev našli, ne ... če je recimo bilo kaj narobe, ne ... takoj si imel pomoč, ne. To pa, da se naročiš pa čakaš dva, tri dni, recimo, da ni gužve, je tut nam v prid, ne. Pa zdravniki mislim, da bi imeli malo več časa za pogovor, ne. (Ž, 68)



Slika 1: Teme in podteme

Enostavnost uporabe telemedicinske opreme

Pacienti so mobilno aplikacijo za vnos meritev opisali kot enostavno in razumljivo: zasnovana je na uporabniku prijazen način; pri uporabi ga vodi in usmerja uporabniški vmesnik; za njeno uporabo zadostujejo osnovne veščine, potrebne za uporabo pametnih telefonov.

Se mi zdi, da je tut tablica oziroma telefon, program tako enostavno narejen, da nimaš kaj zgrešit. Te opozori: aha, še to in to moraš naredit, tukaj pošlji. Potem piše: aha, končano, naslednjič ... Tako da, mislim, da tudi vsak, ki ni navajen tablice al pa telefona, to zelo hitro osvoji. Ker ni kompliciran sistem, ne. (Ž, 41)

Veščine so večinoma lahko usvojili sami ali s pomočjo

bližnjih. Zunanja pomoč medicinskega ali tehničnega osebja je bila potrebna le pri tehničnih težavah (npr. nedelujoče geslo za odklepanje mobilne aplikacije). Ker so bile tovrstne težave zelo redke, niso vplivale na nižje zaupanje pacientov v lastne digitalne veščine ali zmanjšale zanimanja za telemedicinsko obravnavo. Nasprotno, nekaj pacientov je predlagalo dodatne funkcionalne in vmesniške nadgradnje uporabljene opreme: (1) opozorila, kdaj opraviti meritve; (2) personalizirane meje sprejemljivih vrednosti meritev in opozorila, ko so te meje presežene; (3) prenos meritev na računalnik; (4) integracijo drugih pametnih naprav (npr. pametna ura) ter (5) povezljivost aplikacije z drugimi merilnimi napravami in ne zgolj z merilniki, ki so jih uporabljali v intervencijski raziskavi. Pacienti

so uporabljene merilne naprave ocenili kot primerljive oziroma boljše od svojih.

Ja, zelo dobro bi bilo, če bi bilo zraven recimo, ko si izmeriš, ko gre čez tisto mero, ko je zate že mal vprašljiva, da ti da nek signal. Al zvezdico al, al, ne vem kaj. Nekaj bi ti moglo pokazat. (M, 64)

Komunikacija z zdravstvenim osebjem

Čeprav je komunikacija z uporabo sporočil ocenjena kot učinkovita, zadostna in zaželena, je treba upoštevati, da se med raziskavo noben pacient ni srečal z bistveno poslabšanim zdravstvenim stanjem ali zdravstveno intervencijo. V tem primeru bi se pacienti odločili za telefonski klic ali osebni obisk v ambulanti družinske medicine. Sporočila so pacienti dojeli kot dopolnilo in ne nadomestilo telefonskih stikov in osebnih obiskov v ordinaciji. Močno si želijo povratne informacije o tem, ali so bile meritve pregledane, pri čemer so nekateri, ki povratne informacije niso prejeli, izrazili dvom o resničnosti pregledovanja rezultatov. Hkrati so izrazili tudi zanimanje za dodatne informacije glede delovanja trikotnika pacient – medicinska sestra – zdravnik (ali so bile meritve posredovane v vpogled tudi zdravniku ali jih je pregledala le medicinska sestra, ali sta se o povratni informaciji posvetovala ...).

Dejansko je fajn, ker je zadaj stala sestra. Vedel si, da je ona pregledovala, ker se je, tako kot sem rekla, videlo, kdaj je ona pogledala te meritve, in ti je potem tut sporočila, če karkoli ni v redu. Ti je lahko predhodno povedala: »Lej, to pa to moraš naredit al pa tok prej se oglasi, ne. To je bil po eni strani meni plus.« (Ž, 41)

Pacienti so sicer izrazili razumevanje za obremenjenost medicinskih sester v ambulantah družinske medicine in niso pričakovali takojšnjega odziva na posredovane meritve.

Učinki telemedicinske obravnave na zdravstveno stanje pacientov

Po poročanju pacientov so rezultati vključenosti v telemedicinsko obravnavo opazni v spremembah pri njihovi zdravstveni obravnavi (npr. prilagoditev terapije, dodatni pregledi), pri nekaterih pa tudi v dejanskem izboljšanju zdravstvenega stanja.

No in pol smo, zdej smo stran dali tablete, ene pa samo še za pulz, ampak tud ta nizek odmerek, in zdej po teh, ukinitvi, se prav čisto dobro počutim. Tako da je to prav prišlo in čisto mi je bilo fajn, da sem rekla, no lej, zdej pa res vidijo, da je tako, ne. Da imam jaz doma nizek pritisk, da je dol šel, ne. (Ž, 50)

Največje spremembe so bile zaznane v psihološkem smislu: pacienti so v obdobju trajanja vključenosti v telemedicinsko obravnavo do skrbi za svoje zdravstveno stanje razvili resnejši odnos in se zaradi občutka, da uspešno upravljajo s svojim zdravjem, počutili opolnomočene in manj zaskrbljene.

Jaz sem bila bolj disciplinirana. Se pravi, da sem več

razmišljala o tem, ne. Bolj sem skrbela za to, da sem naredila tistih 10.000 korakov vsak dan, ane, da sem šla hodit, da sem bila na zraku. To sem bolj, skrbim tud zdej. (Ž, 64)

Želja po uporabi in dostopnost telemedicinske obravnave

Večina pacientov je telemedicinsko obravnavo ocenila kot koristno zanje in priporočljivo za druge osebe s podobnimi zdravstvenimi težavami, še posebej za osebe s slabšim zdravstvenim stanjem in gibalno ovirane posameznike z omejenimi možnostmi dostopa do zdravnika.

Pa še nekaj, recimo za starejše od nas – mi smo še kolker tok gibljiv, ne, je, to je velik boljše, ne. Tam recimo nekdo, ki je težko gibljiv al pa težko pride v zdravstveni dom, nima tega, nima unga, nima prevoza, pa ne vem kaj še vse, je to super, samo če zdej oni, če imajo ta program, da jim od daleč pokaže, da jim ni treba iskat, da vid. (M, 64)

Pacientom, ki so dojemali svoje zdravstveno stanje kot stabilno, se vsakodnevno posredovanje podatkov in dodatno spremljanje nista zdela potrebna. Zato so nekateri omenjali, da bi jim bolj ustrezalo, če bi telemedicinska obravnava trajala dlje časa in bi bile meritve manj pogoste oziroma občasne (npr. merjenje vsak prvi teden v mesecu). Zdi se jim namreč, da se njihovo zdravstveno stanje spreminja počasi.

To je zdej odvisno, če si samo takole v ... kako bi rekel, v kontrolne namene, da nimaš nobenih problemov, pol si jih večina pomoje ne bi odločila, al pa tut zase bi lahko rekel, da najbrž ne bi plačeval, ne. Aa, če pa pride bolj do resnih težav, ne vem ... Kakšnih sicer, ampak da se to izpostavi, da se včasih, ne vem, tresiš al pa da si na meji kakšne kapi al kej tazga, pol pa verjetno ni več vprašanje denarja. (M, 55)

Na odločitev pacienta za telemedicinsko obravnavo poleg zdravstvenega osebjem in njegovega zdravstvenega stanja vpliva tudi cena. Ocenjujejo, da bi bila telemedicinska obravnava dostopnejša, če bi bila financirana s strani zavarovalnice oziroma integrirana v javni zdravstveni sistem. Pacienti bi tako imeli tudi večje zaupanje v telemedicinsko obravnavo in manj skrbi glede varovanja osebnih podatkov. Telemedicinska obravnava, ki bi jo tržilo zasebno podjetje, bi uživala nižje zaupanje, saj so prepričani, da je takšna storitev v okviru javnega zdravstvenega sistema bolj verodostojna in zanesljiva. Med pacienti prevladuje mnenje, da je primarni cilj ponujanja tržnih storitev na področju telemedicinske obravnave dobiček in ne blaginja pacienta.

Lejte, verodostojno je najbolj, če je prek zdravstvenega. Čim so drugi, recimo, nisi več to. To je isto recimo, ko te pokličejo, pa pravijo, ti bomo zmerili ne vem koga vse, ožilje pa to. Ja kako boš meril ožilje brez analiz pa brez skrbi, ne. To pomeni, da zaupaš samo tam zdravstvenemu nivoju, onemu drugemu pa ne. (Ž, 67)

Pacienti so omenjali tudi potencialno uporabo aplikacij z drugimi (lastnimi) merilnimi napravami, s čimer bi finančno razbremenili zdravstveni sistem.

Vpliv in opora okolja

Največji vpliv na pripravljenost pacientov za vključitev v telemedicinsko obravnavo ima zdravstveno osebje. Večina pacientov je odločitev za sodelovanje v intervencijski raziskavi sprejela samostojno in se o tem ni posvetovala z družinskimi člani ali bližnjimi. Pacienti so izrazili celo dvom glede tehtnosti nasvetov svojcev, ki so (podobno kot oni sami) brez strokovnih in praktičnih izkušenj s telemedicinsko obravnavo. To prepričanje tudi sicer velja za področje upravljanja z zdravjem.

Lejte, prvo je zdravnik avtoriteta, on o zdravstvu največ ve, domači krog zavis, kakšen imaš okoli sebe. Maš lahko čist drug krog. In sigurno je to, da ti zdravstvo reče največ, ne. (Ž, 67)

Kljub temu da je vpliv družinskih članov na odločitev za vključitev v telemedicinsko obravnavo razmeroma majhen, pa pacienti kot pomembno ocenjujejo njihovo spodbudo in pripravljenost nudenja tehnične podpore pri vsakdanji uporabi telemedicinske opreme.

Skrb za lastno zdravje

Prevladujeta dva vzorca odnosa pacientov do lastnega zdravja: (a) dejavni pacienti, ki imajo do svojega zdravja oziroma bolezni resen odnos, zavedajo se pomembnosti izvajanja rednih meritev za oblikovanje ustreznega pristopa k zdravljenju in dosledno upoštevajo navodila zdravnikov, so samoiniciativni in si prizadevajo za doseganje ciljnih vrednosti krvnega tlaka in/ali sladkorja (npr. s podrobnim spremljanjem vpliva prehrane in fizične dejavnosti na ravni parametrov); (b) manj dejavni pacienti, ki so pri meritvah manj dosledni in jih opravljajo »po občutku« oziroma ob slabem počutju.

Vedno je vredno narest nekaj, kar je v povezavi z zdravjem /.../ Ker jaz tako, za sebe, lahko rečem, jaz sem aktivna, hodim, na jogo hodim, hodim aktivno, fizično delam, miselno delam. Skratka, okoli sebe imam vnuke. In mislim, da sem skoz v pogonu. Še tako da ... Če bi bila aparatura al pa ne, vem, da pač te stvari delam zase in jih moram delat. (Ž, 67)

Diskusija

Ob upoštevanju raziskovalnega vprašanja so avtorji oblikovali sedem glavnih tem, ki naslavljajo izkušnjo pacientov. Največ tem ($n = 5$) se nanaša na izkušnjo pacientov z vidika uporabe telemedicinske opreme in vključenosti v telemedicinsko obravnavo, po dve temi pa sta vezani na vlogo zdravstvenih delavcev pri sprejemanju telemedicinske obravnave in na željo po njihovi nadaljnji uporabi.

Podobno kot v preteklih raziskavah (Vermeulen et al., 2013; Su et al., 2019) je bila tudi v tej uporabnost telemedicinske opreme in obravnave prepoznana kot kritični vidik izkušnje uporabnikov (pacientov) s kroničnimi boleznimi. Uporabljena mobilna aplikacija je bila ocenjena kot enostavna za uporabo, intuitivna in uporabnikom prijazna. Na prisvojitve in uporabo telemedicinske opreme in telemedicinske obravnave med pacienti najbolj vplivajo zaznana potreba po uporabi (odvisna predvsem od zdravstvenega stanja pacienta) in navodila zdravstvenega osebja, ki ima hkrati vlogo partnerja in avtoritete v zdravstveni obravnavi. To predstavlja pomembno implikacijo za pristop k zdravljenju sladkorne bolezni tipa 2 na primarni ravni zdravstvenega varstva, kjer so večinoma vodeni tisti pacienti, ki pogosto nimajo možnosti izvajanja meritev krvnega sladkorja. Za zdaj predpis pripomočkov v breme osnovnega zdravstvenega zavarovanja še ni možen, če pa si jih kupijo sami, sistematično osveščanje o pomenu meritev še ni na voljo vsem (Vermeulen et al., 2013). To potrjuje tudi ugotovitev, da so bili sodelovanju v intervencijski raziskavi (testiranju opreme) izjemno naklonjeni pacienti s sladkorno boleznijo.

Kljub pozitivni izkušnji z uporabo telemedicinske opreme in telemedicinsko obravnavo se je treba zavedati, da nekateri pacienti sami ne premorejo zadostne motivacije ali discipline, da bi kronično bolezen z rednimi meritvami spremljali tudi brez zunanje kontrole in spodbude. Slednjo najpogosteje predstavljajo medicinske sestre in/ali zdravnik. Nekatero raziskavo v Sloveniji so že izpostavile vlogo in vpliv zdravstvenega osebja, vendar so se osredotočile na proces zdravstvene obravnave oziroma oskrbe (Iljaz, Meglič, Petek, Kolšek, & Susič, 2014; Petek & Mlakar, 2016) in spremembe v zdravstvenem stanju (Petek & Mlakar, 2016), manjkal pa je psihološki oziroma motivacijski vidik. V naši raziskavi ugotavljamo pomen partnerskega odnosa in zaupanja pacienta v tim ambulante družinske medicine (tj. medicinske sestre in zdravnika). Zaradi zaupanja pacientov zavzema zdravstveno osebje osrednjo vlogo ne le pri odločitvi za izvajanje telemedicinske obravnave, pač pa tudi pri izboru pacientov, ki bi imeli od slednje največjo korist oziroma bi jim takšna obravnava ustrezala. Medicinska sestra oziroma osebni zdravnik v ambulanti družinske medicine namreč ob zdravstvenih informacijah lažje oceni tudi to, ali ima pacient potrebne digitalne veščine in ali je sposoben vključitve v telemedicinsko obravnavo brez večjih psihičnih obremenitev (Joo & Liu, 2021). To je pomembno sporočilo za morebitno sistemsko implementacijo telemedicinske obravnave v ambulante družinske medicine in širše.

Na osnovi izsledkov raziskave lahko identificiramo skupine pacientov, ki so za vključitev v telemedicinsko obravnavo na primarni ravni zdravstvenega varstva bolj oziroma manj primerne. Primernejši so pacienti, ki čutijo večjo odgovornost za svoje zdravje in bolj

skrbijo zanj; mlajši in večji uporabe novih tehnologij; »urejeni« pacienti, ki potrebujejo občasne kontrole; tisti, ki so nedavno prejeli diagnozo kronične bolezni in imajo večji potencial za učenje o svojem zdravstvenem stanju; tisti, ki se težje udeležijo zdravstvene obravnave oziroma iz različnih razlogov težje obiščejo zdravnika. Telemedicinska obravnava je manj primerna za paciente, ki so manj ozaveščeni glede svojega zdravja; se za uporabo ne bi odločili samostojno (vpliv družine ali socialnega okolja); potrebujejo dodatno motivacijo; bi jim uporaba telemedicinske obravnave predstavljala preveliko psihično obremenitev; nimajo digitalnih veščin ali zadostne podpore za uporabo telemedicinske opreme. Vključevanje v telemedicinsko obravnavo je smiselno za širok krog pacientov tudi pri drugih kroničnih boleznih, saj telemedicinska obravnava predpostavlja vključujoč pristop k zdravstveni obravnavi z neposredno dvosmerno komunikacijo in dejavno vlogo pacientov (Simblett et al., 2018; Donelan et al., 2019). Z vzpostavitvijo integrirane storitve, s katero bi celotno telemedicinsko obravnavo pacienta (npr. rezultate meritev in pretekle terapije) samodejno prenesli od osebnega zdravnika do specialista, pa bi bila olajšana implementacija tudi na sekundarni ravni (specialistične ambulante).

Zaupanje in s tem pripravljenost za sodelovanje v telemedicinski obravnavi bi bila višja pri njeni implementaciji v javni sistem zdravstvene ali socialne oskrbe. Ugotovili smo, da pacienti storitvi bolj zaupajo, če je ta del zdravstvenega sistema in ne gre za tržno storitev. Zadržki do trženja tovrstnih storitev niso vezani le na kritje stroškov, temveč nanje vpliva tudi mnenje sodelujočih, da je primarni cilj tržnih ponudnikov želja po dobičku in ne skrb za zdravje pacientov (Harris, Alfonso, Stewart, & Moore, 2021; Michaud, Hill, Estabrooks, & Su, 2021). Obenem je to stališče pogojeno z resnostjo njihovega zdravstvenega stanja, ki vpliva tudi na pripravljenost plačila telemedicinske obravnave (Steigenberger, Glatscher-Thoeni, Siebert, & Leiter, 2022). Plačilo so bolj naklonjeni pacienti, ki skrb za zdravje pripisujejo večji pomen. Zaradi povečanja razkoraka med pacienti glede na njihov ekonomski položaj je ključno, da se tovrstne storitve vključijo v košarico zdravstvenih storitev, ki jih krije zdravstvena zavarovalnica (Michaud et al., 2021), kar je tudi del akcijskega načrta za obvladovanje sladkorne bolezni (Zaletel, 2020).

Kljub temu da raziskave splošno kažejo pripravljenost pacientov na vključenost v telemedicinsko obravnavo, velik izziv predstavljata skrb za dolgoročno skladnost telemedicinske obravnave s potrebami pacientov in njihova motivacija za redno uporabo telemedicinske opreme. Le če so posamezniki po začetnem obdobju uporabe pripravljeni še naprej uporabljati tehnologijo, lahko domnevamo, da je bila prisvojitve te tehnologije uspešna (de Graaf, Ben Allouch, & van Dijk, 2018), kar je potrdila tudi ta raziskava. Zdi se, da v kontekstu telemedicinske obravnave in

opreme prisvojitve spodbujajo predvsem pacientova zaznava širših možnosti oziroma potenciala za upravljanje z lastnim zdravjem in učinkovitejšega dostopa do zdravstvenih storitev, ki so pogojene z njegovimi osebnimi značilnostmi, kot so dojetje uporabnosti telemedicinske opreme, pomirjenost glede zdravstvenega stanja, zavzetost za zdravljenje in lastno aktivacijo (Hibbard & Greene, 2013; Su et al., 2019; Joo & Liu, 2021). Na povečanje zavzetosti pacientov za uporabo telemedicinske obravnave lahko vplivajo tudi zdravstveni timi v ambulantah. Predstavljeni rezultati so potrdili pomen pacientove zaznave pozitivnega odnosa in dojetanja telemedicinske obravnave med zdravniki in medicinskimi sestrami, kar vpliva na njeno sprejemanje (Asua, Orruño, Reviriego, & Gagnon, 2012; Cimperman et al., 2013). Z vpeljavo telemedicinske obravnave lahko uspešno naslovimo tudi nekatere splošne ovire, ki zmanjšujejo zavzetost pacientov za sodelovanje pri zdravljenju kroničnih boleznih: asimptomatičnost bolezni, nezaželeni učinki zdravil in slabo počutje ter pomanjkljivo ozaveščanje o bolezni. Prav opolnomočenje na področju zdravja predstavlja pomembno dejavnost ambulant družinske medicine (Pečelin & Sočan, 2016), katerih cilj je preprečevanje razvoja oziroma napredovanja kroničnih boleznih in s tem tudi povečanje pacientove zavzetosti za obvladovanje bolezni (Govc Eržen, Vračko, Čuš, & Medved, 2017).

Raziskava, ki je kot ena izmed prvih v Sloveniji implementirala delujočo telemedicinsko storitev na primarno raven zdravstvenega varstva, postavlja pomembna izhodišča za nadaljnje raziskave. V prihodnje bi bilo paciente smiselno vključiti v tovrstno storitev za daljše časovno obdobje, pridobiti tudi klinične podatke o njihovem zdravstvenem stanju in v primeru večjega vzorca udeležencev spremljati nekatere ključne vidike sprejemanja in učinkov s kvantitativnimi metodami. Prav tako opazamo, da je večina iniciativ in raziskav, ki si prizadevajo za vzpostavitev telemedicinske obravnave v Sloveniji, osredotočenih na sekundarno ali terciarno raven zdravstvenega varstva, precej manj pozornosti pa je namenjene primarni ravni, ki tako ponuja priložnost za nadaljnje raziskovanje. Ne nazadnje pa omejitev raziskave predstavlja način rekrutacije sodelujočih v intervencijski študiji in vzorčenje za fokusne skupine. V okviru intervencijske raziskave je bila rekrutacija namreč izvedena v enem zdravstvenem domu. Z razširitvijo intervencijske raziskave, ki bi potekala v večjem številu zdravstvenih domov oziroma bi vključevala več ambulant družinske medicine, bi zagotovili večji vzorčni okvir in s tem bolj raznoliko strukturo vzorca. Izvedeni način vzorčenja (tj. namensko vzorčenje) ne omogoča izvedbe randomiziranih kontroliranih kliničnih študij (ang. *Randomized Controlled Trials*), ki bi bile mogoče v primeru slučajnega vzorca.

Zaključek

Z raziskavo ugotavljamo pozitivne učinke telemedicinske obravnave, ki se kažejo v boljši kakovosti življenja pacientov, izboljšanju njihovega zdravja, opolnomočenju, večji motivaciji za upravljanje z boleznijo in povečanem občutku varnosti. Dostop do zdravstvene oskrbe na daljavo in možnost posredovanja podatkov na daljavo sta najuporabnejši in najpogosteje izpostavljeni funkcionalnosti telemedicinske opreme, saj pacientom omogočata, da se izognejo čakanju na pregled, manj pogoste obiske zdravnika in izničenje učinka »bele halje«. Ugotovitve raziskave so ustrezna osnova za oblikovanje postopkov širše implementacije telemedicinske obravnave na primarno raven zdravstvenega varstva. V prihodnjih raziskavah bi veljalo uporabo telemedicinske obravnave s strani kroničnih pacientov spremljati dlje časa in vključiti tudi druge ciljne skupine. Za oceno učinka telemedicinske obravnave priporočamo uporabo kombiniranih metod: poleg kvalitativnega tudi kvantitativno spremljanje (ocena uporabniške izkušnje z anketnimi vprašalniki in ocena klinične slike z analizo izmerjenih vrednosti).

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Conflict of interest/Nasprotje interesov

The authors declare that there is no conflict of interest./Avtorji izjavljajo, da ni nasprotja interesov.

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Ethical approval/Etika raziskovanja

On 28 November 2018, we obtained the approval from the Research Ethics Committee of the Faculty of Social Sciences of the University of Ljubljana (No.801-2018-040/JG), and the patients gave their informed consent to participate in the study, to the recording of the interview, and to the publication of the results./Za izvedbo raziskave smo 28. 11. 2018 pridobili soglasje Komisije za etiko v raziskovanju Fakultete za družbene vede Univerze v Ljubljani (št. 801-2018-040/JG), pacienti pa so podali obveščeno soglasje k sodelovanju v raziskavi, snemanju pogovora in objavi rezultatov.

Author contributions/Prispevek avtorjev

Katja Prevodnik contributed to the Introduction, Methods, Results and Discussion sections, as well as the preparation of the manuscript for submission. Her contribution includes the preparation of the theoretical background and literature review, the preparation of the research instrument, data collection, data processing and interpretation, and the coordination of the work of the other authors. Simona Hvalič-Touzery contributed to the Introduction, Methods, Results and Discussion sections, as well as the linguistic revision of the text. She prepared the theoretical background, participated in outlining the starting points of the research instrument and provided an expert review of the interpretation of the data processing. Vesna Dolničar contributed to the Introduction, Methods, Results and Discussion sections. Her contribution includes the conceptual design of the research, expert review of the research instrument and analysis design, and final review of the text. Jelka Zaletel contributed to the Introduction, Results and Discussion sections. She provided expert guidance of the research from a medical perspective, the expert review of the analysis and the implications of the results. Jerneja Laznik contributed to the Methods, Results and Discussion sections. Her contribution is an overview of the research instrument, data processing and interpretation and translation of the abstract. Andraž Petrovčič contributed to the Introduction, Methods, Results and Discussion sections. His contribution is the conceptual design of the research, the management of the data collection and processing, and the interpretation of the results./Katja Prevodnik je sodelovala pri poglavjih Uvod, Metode, Rezultati in Diskusija, vključno s pripravo besedila za oddajo. Njen prispevek je priprava teoretskih izhodišč in pregleda literature, priprava raziskovalnega inštrumenta, zbiranje in obdelava podatkov in njihova interpretacija ter koordinacija dela ostalih avtorjev. Simona Hvalič-Touzery je sodelovala pri poglavjih Uvod, Metode, Rezultati in Diskusija, vključno z jezikovnim pregledom besedila. Njen prispevek je priprava teoretičnih izhodišč, sodelovanje pri izhodiščih

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