ICBT program for improving informal caregiver well-being: A qualitative study

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ABSTRACT

Background: Informal caregivers represent an important and vulnerable part of the society. They can experience negative psychological symptoms, such as depression and anxiety. Internet-based cognitive behavioural therapy (ICBT) is a promising psychological support option that could be effective in reducing informal caregiver burden as well as improving psychological well-being. Qualitative studies are valuable for gaining insights into participant experiences of using ICBT.
Objective: The main aim of this study was to explore informal caregiver experiences and hence acceptability and feasibility of the transdiagnostic ICBT program aimed at reducing informal caregiver burden and increasing the quality of life.
Methods: Following a strategic sampling procedure, 23 informal caregivers were recruited from previous randomized controlled trial for informal caregivers in Lithuania. Participants were interviewed over phone, using semi-structured interview questions. Interviews were analysed using a thematic analysis approach.
Results: Four themes and a total of 10 sub-themes were generated: I A program as a means of change (*Convenience and applicability of the format and materials; Ability to focus on own needs; Opportunity for communication*), II Suggestions for the program (*Including live support; Tailoring materials and format; Providing with more time and resources),* III Driving personal and situational forces *(Developing acceptance and adjustment over time; Being proactive and/or receiving support)* and Hindering situational factors *(Deterioration and unpredictability of the care-receivers health; Lacking external support and opportunities for respite).*
Conclusions: Most of the informal caregivers were found to be satisfied with the program's format and materials as well as the communication with the therapist via a message function in the program. Some suggestions were made regarding implementation of the live support option. Also, suggestions regarding possibility for tailoring the program's content. Lastly, several personal and situational factors were identified as important in affecting informal caregiver well-being. We conclude that ICBT has potential in reducing informal caregiver burden and improving psychological health. Further research trials are warranted for evaluating both, the effectiveness and the feasibility of the program.

1. Introduction

Cognitive behavioural therapy (CBT) is widely accepted and has been repeatedly found to be effective for a wide range of psychological problems (Hofmann et al., 2012). Due to wide spread of internet access and the use of the mobile phones, computers or other electronic devices, recent years have seen a rise in studies on internet-delivered cognitive behavioural therapy (ICBT). To this date, ICBT has been applied and tested in treating many different somatic and psychiatric conditions, such as tinnitus, anxiety, and depression among many other (Andersson, 2018). Comparative studies also suggest that ICBT can be as effective as traditional face-to-face CBT (Carlbring et al., 2018).

There are many ways in which ICBT programs can be structured. For example, some include video and audio materials, while others mostly rely on text (Andersson et al., 2019). The intervention programs are often presented in the form of modules (or lessons) that are spread out over a span of 5–12 weeks (Andersson, 2016). Some programs are self-guided, meaning that the clients complete them independently, while others are clinician guided. Lastly, ICBT can be targeted towards a specific disorder (or a problem) or it can be transdiagnostic. The latter targets several psychological symptoms and is broad enough to be applied for a range of clients. One example of a transdiagnostic treatment is an ICBT program for perfectionism, in which several problems in relation to the perfectionism are addressed (problem-solving, self-compassion, behavioural experiments and other) (Rozental et al., 2020). Overall, few qualitative studies have been conducted on internet intervention programs targeting transdiagnostic processes.

ICBT as well as other internet interventions have now been applied and tested for various populations (Etzelmueller et al., 2020; Hedman et al., 2012). One of the less studied groups is informal caregivers, which are individuals who provide care for chronically ill or otherwise dependent people in their close environment. It is currently well established that even though caregiving can bring satisfaction and fulfilment, informal caregivers often experience negative mental health outcomes, such as increase in depressive symptoms (see, for example Schulz and Sherwood, 2008). Hence, demand for support for informal caregivers is high.

Type of services that informal caregivers receive varies greatly from country to country. The use of the internet interventions for supporting this population in general is still new, but potentially promising alternative to other traditional services (Sherifali et al., 2018). As stated by Sherifali et al. (2018) to date, internet delivered interventions were found to display small to moderate beneficial effects in reducing caregiver stress, anxiety, and depression with interventions including education and information as well as peer and psychological support identified as more efficacious. However, findings across mental health outcomes are inconsistent. One explanation for this is the heterogeneity of the interventions as well as the heterogeneity of the outcome measures used (Ploeg et al., 2017). Consequently, it is not clear which types of internet interventions are the most effective as well as feasible for informal caregivers.

Qualitative methods can be very useful in gaining knowledge about client's views and perceptions. Because of this, qualitative studies have previously been conducted to investigate the feasibility as well as acceptability of internet interventions from the participant's point of view. Following the use of various internet interventions, current research literature suggest that informal caregivers appreciate the opportunity to receive knowledge and information (e.g., Ploeg et al., 2018), the convenience offered by the online format (e.g., Lewis et al., 2010), ability to reflect on one's experiences (e.g., Duggleby et al., 2018) as well as to share them with a professional involved in the program (e. g., Ducharme et al., 2011). On the other hand, studies have also identified that not all of the informal caregivers benefit from the internet intervention programs from in. To give an example, lack of time to use the intervention has been previously identified as a barrier to engage and benefit from the intervention (e.g., Ploeg et al., 2018) as well as the lack of individualization of treatment (e.g., Cristancho-Lacroix et al., 2015). It is important to mention that these findings have often been based on the studies targeting specific group of informal caregivers, such as, dementia caregivers. In addition, there is also a need to gain a better understanding of experiences of using internet interventions in languages and cultures that are targeted less often in research.

Lithuania is one of the countries in which research regarding ICBT effectiveness and feasibility is scarce. Regarding caregiving, it is estimated that approximately 16% of total population in Lithuania are informal caregivers (Ahrendt et al., 2017). Even though several labor market as well as health sector related policy measures are available for informal caregivers in Lithuania, these measures can be described as

minimalistic and insufficient (Žalimienė et al., 2020). To give an example, respite and day care services for informal caregivers are only available in certain municipalities and offer a coverage for only a very small part of the population (Žalimienė et al., 2020). In addition, nursing services in the hospitals are also considered to be underdeveloped as it only offers coverage for a limited amount of days per year for given individual. Limited opportunities for support services as well as respite could put these caregivers in even higher likelihood of developing negative psychological symptoms. This, in turn, encourages further investigation into what psychological support options could be feasible in providing informal caregivers with psychological support.

In Lithuania, one of the first internet intervention studies was conducted for individuals suffering from an adjustment disorder (Skruibis et al., 2016). The intervention was a self-guided program based on CBT principles. Data analysis revealed promising findings – participants who engaged with the program at least once per 30-day period were found to experience reduction in their symptoms as well as increase in the quality of life (Eimontas et al., 2018). Regarding internet interventions for informal caregivers, to our knowledge, our previous pilot randomized controlled trial for evaluating the effectiveness of the ICBT program for informal caregivers was the first such attempt (Biliunaite et al., 2020). This ICBT program was aimed at improving caregiver psychological health, lasted eight weeks and was conducted online. Following quantitative data analysis program was found to be effective in reducing caregiver burden, anxiety, stress, and depressive symptoms as well as increasing the quality of life. Since this was the first ICBT program for informal caregivers in Lithuania, thorough investigation of the participant experiences of using the program could enrich the quantitative findings and provide with further insights regarding the feasibility and acceptability of such intervention.

The main aim of this research study was to evaluate Lithuanian informal caregiver experiences of using a transdiagnostic eight week-long ICBT intervention. More specifically, we wanted to obtain a deeper understanding of the participant experiences in relation to the acceptability and feasibility of the program. This study was conducted following a pilot randomized controlled trial for evaluation of the effectiveness of this intervention (Biliunaite et al., 2020).

2. Method

2.1. Participants

Participants were informal caregivers who had participated in the ICBT trial on Caregiver Burden (Biliunaite et al., 2020). In this study, 63 participants were recruited and randomly assigned to either an intervention group ($n = 31$) or a wait-list control group ($n = 32$). The only difference regarding the access and the use of the ICBT program for the participants in the two groups was the delay in time for the control group. That is, the control group participants first had to wait for eight weeks after which they received the access to the same ICBT program.

Out of the 63 participants who took part in the ICBT program, 25 participants in the intervention group and 23 participants in the wait-list control group filled in the post-assessment measures. These participants were contacted by either a phone call or email and requested to participate in the phone interview. Participants in the intervention group were contacted approximately two months after completion of the program, control group participants - straight after they finished using the program, during phone call for the post-assessment. Hence, participants from both groups were contacted at roughly the same time, between February and March of 2020. In total, 23 participants provided informed consent to participate in the qualitative study, 11 from the intervention group and 12 from the wait-list control group. These participants were mostly female (22) with an average age of 54 year, caring for either their mother or father (17) with an average age of 75 years. Characteristics of the included participants are presented in the Table 1. Informal caregivers in our study were providing care for family members

Table 1

Participant characteristics.

Nr	Age	Gender	Care duration (months)	Relation to the care-receiver	Group assignment
1	53	F	48+	Son	Intervention
2	54	F	48+	Sister-in-law	Intervention
3	59	F	24–48	Mother	Intervention
4	59	F	12–24	Mother	Intervention
5	47	F	24–48	Mother	Intervention
6	48	M	12<	Mother	Intervention
7	62	F	24–48	Mother	Intervention
8	67	F	48+	Mother	Intervention
9	47	F	12–24	Husband/Partner	Intervention
10	52	F	12–24	Mother	Intervention
11	56	F	24–48	Mother	Intervention
12	60	F	48+	Husband/Partner	Control
13	41	F	24–48	Mother	Control
14	56	F	48+	Father	Control
15	41	F	48+	Mother	Control
16	40	F	12<	Mother	Control
17	58	F	48+	Mother	Control
18	55	F	48+	Mother	Control
19	58	F	24–48	Brother	Control
20	58	F	24–48	Husband/Partner	Control
21	47	F	24–48	Father	Control
22	66	F	24–48	Mother	Control
23	54	F	12<	Mother	Control

suffering from various disorders, some of the more common ones being dementia and frailty due to old age. In addition, comorbid disorders were also observed to be very common with many care-receivers suffering from a range of medical complaints. The included 23 participants did not significantly differ from the whole sample of participants based on the demographic variables and caregiving duration as well as intensity (see Appendix A). For eight of these participants the interviewer served as a therapist throughout the duration of the ICBT program. We acknowledge this in the limitation section of the article.

2.2. ICBT program

The intervention was a therapist supported ICBT self-help program. The content for the program was inspired by the informal caregiver literature (e.g., Revenson et al., 2016) as well as the materials used in previous ICBT trials (e.g., Andersson, 2015; Andersson et al., 2006; Andersson et al., 2012). The intervention was prepared in Lithuanian language and adapted to the cultural context, with Lithuanian users in mind. The intervention's content was divided across eight themes, each dedicated to a different topic. The eight themes were, respectively: Introduction, Thoughts, Stress and relaxation, Problem solving, Communication, Anxiety, Behavioural activation, and Maintenance. As indicated by the names, themes covered topics such as emotions and thinking processes, stress, problem solving, communication, anxiety, and behavioural activation. In each session participants were provided with psychoeducational information, examples and one or more exercises. Sessions varied in length. The average length of the written text for the session was 1711 words. As each of the sessions contained at least one or more exercises, it could be suggested that participants were required to spend at least a couple of hours for the completion of an individual session. Access to a new theme was given every week, starting from the theme one and finishing with the theme eight. At the end of the intervention, participants were offered tips of how to continue practising their knowledge once the program is finished. Apart from reading and conducting exercises, participants were also able to contact a designated therapist and ask questions. In addition, participants received weekly feedback on the completed exercises (homework) from the therapist. All communication with the therapist took place via a secure message function on the intervention's platform (Vlaescu et al., 2016).

2.3. Material and procedure

All 23 participants were interviewed by the main author of the paper (IB). A semi-structured interview guide was prepared and pilot-tested with two master-level psychology students familiar with the program. The two students participated in the pilot testing as interviewees and in this way helped to evaluate the interview protocol. Questions throughout the interview were open-ended and exploratory in nature. Each interview was started with requesting about the well-being of the participant. Later, participants were asked about their experiences of using the intervention, what they remember from using the intervention as well as what they appreciated or disliked about it. During the interviews, probes and clarifying questions were used for obtaining deeper, and more coherent story. Interview length varied between 8 and 32 min, with the mean length of approximately 16 min. Interviews were first recorded and then transcribed. Transcription was conducted by two authors of the paper IB and AD.

Upon initial invitation to participate in the study, participants were informed about the purpose of the interview. Also, that the interview will be recorded, that their information will be presented in an anonymous format and that if necessary, small adjustments will be made to anonymize the text. All participants provided with an oral consent for taking part in the study at the start of the phone call, before the interview. Vilnius University Psychology Research Ethics Committee approved the study as part of the intervention study, documented as 08-07-2019 No.26. Participants were offered no monetary compensation for participation.

2.4. Researcher characteristics

All interviews were conducted by the first author of the article (IB). The analysis of the qualitative data was performed by the first and the second author (IB and AD). Both authors are female clinical psychologists engaged in research. Both researchers are native Lithuanian speakers as the interviews were conducted with Lithuanian nationals in Lithuanian language. Both IB and AD were previously involved in the intervention trial and were familiar with the ICBT program. Due to this reason, researchers had an existing relationship with some of the interviewed participants. However, as opposed to face-to-face interaction, the ICBT setting provides participants with much more anonymity. For example, participants only new the name of their assigned therapist and did not have any real-life contact with researchers apart from messages in the platform and a couple of brief phone calls during the program. In addition, during the interviews, the interviewing researcher encouraged participants to express both positive and negative experiences when responding to the questions.

2.5. Analysis

An inductive reflexive thematic analysis was performed following guidelines proposed by Braun and Clarke (2006, 2020). This type of analysis was chosen as our main goal was to encapsulate the data rather than, for example, to produce a new theory. As our goal was to explore experiences of using the ICBT program, an essentialist/realist approach was adopted. The Atlas.ti program (Friese, 2019) was used for supporting initial coding process and forming of the code groups. The subsequent analyses were performed manually. To optimize the procedure, transcripts were coded by IB and AD independently. During this stage of the analysis, researchers discussed and continuously compared their codes in an iterative process. Once the initial coding was finished, researchers worked together to discuss occurring themes. By the end of this process, a summary of occurring themes was produced, resulting in five different themes and total of 16 sub-themes. These themes and sub-themes were then refined following a two-step process as suggested by Braun and Clarke (2006). At the end of this process, four main themes with a total of 10 sub-themes were generated. These themes and sub-

themes are presented in the result section.

The analysis process was constantly monitored and supported by the three experienced researchers with knowledge and experience of performing qualitative analyses. Such supervision assured that the analysing authors remained close to the data and that no aspects were overlooked during the analysis process. In addition, translation of the quotes and codes from Lithuanian language was done by the authors who conducted thematic analysis (IB and AD). IB has conducted the forward translation and AD the backward translation, both of which were then compared and adjusted.

3. Results

The main aim with this article was to evaluate participant experiences and hence investigate feasibility and acceptability of the eight-week-long, transdiagnostic ICBT program for reducing their psychological burden and increasing quality of life. Following thematic analysis, we have generated four main themes with a total of 10 sub-themes: I A program as a means of change (*Convenience and applicability of the format and materials; Ability to focus on own needs* and *Opportunity for communication*) and II Suggestions for the program (*Including live support; Tailoring materials and format* and *Providing with more time and resources*), III Driving personal and situational forces (*Developing acceptance and adjustment over time* and *Being proactive and/or receiving support*) and IV Hindering situational factors (*Deterioration and unpredictability of the care-receivers health* and *Lacking external support and opportunities for respite*). As it is evident from the generated themes, throughout the interviews participants did not only reflect on the program use, but also, on the several personal and situational factors affecting their well-being. We deem that indirectly, the third and the fourth themes (Driving personal and situational forces and Hindering situational factors) reflect important information that should be considered in evaluating the feasibility and acceptability of the program for informal caregivers.

A summary of the themes and sub-themes is presented in the Table 2. Selection of the participant (P) quotes to further illustrate our findings are presented below. Examples of codes and quotes for each of the themes and sub-themes are presented in the Table 3.

3.1. Theme I. A program as a means of change

This theme consists of three sub-themes: *Convenience and applicability of the format and materials, Ability to focus on own needs* and *Opportunity for communication*. Altogether theme and sub-themes represent components of the intervention that participants found to be the most useful. Important to reflect, that the interviewed participants almost collectively expressed appreciation for receiving support in general. Regarding the specific components of the program, online format of the program was often perceived as convenient and flexible. Transdiagnostic nature of the intervention was also evaluated positively, with most of the participants indicating to be successful in selecting those materials, that fitted their needs the best. Emphasis on oneself and

Table 2
Main themes and sub-themes.

I A program as a means of change	III Driving personal and situational forces
Convenience and applicability of the format and materials	Developing acceptance and adjustment over time
Ability to focus on own needs	Being proactive and/or receiving support
Opportunity for communication	
II Suggestions for the program	IV Hindering situational factors
Including live support	Deterioration and unpredictability of the care-receivers health
Tailoring materials and format	Lacking external support and opportunities for respite
Providing with more time and resources	

Table 3
Themes, subthemes, and examples of codes and quotes.

Themes and subthemes	Examples of codes	Examples of quotes
A program as a means of change		
		"Once you receive an exercise, you can choose when to conduct it: either straight away or towards the end of the week."
		[P 21 – female, 47, caregiver for a Father]
Convenience and applicability of the format and materials	Flexibility of online format, relevant themes, applying knowledge further	*"You know, straight away I decided, already at the begining when one had to log in, I did not manage to create a user, so straight away I got scared. I said 'This is bad, I will not be able to do this'. However, afterwards I got on the track; the program is provided in a really very easy, simple and very very comfortable way."*
		[P 22 – female, 66, caregiver for a Mother]
		"To leave your routine behind (...). That I liked a lot. It somehow obliges you to do something.'
		[P 18 – female, 55, caregiver for a Mother]
Ability to focus on own needs	Helps to stop, starting to care for myself, spending time for pleasurable activities	*"Taking care of oneself, this has been pointed out. And to be honest you do understand that that is very important, but when you are reminded about it from the scientific point of view, then you of course … after receiving that knowledge, then you yourself apply it to own situation somehow.'*
		[P 8 – female, 67, caregiver for a Mother]
Opportunity for communication	Opportunity to open-up, feeling understood, no judgement	*"It is needed, because you do not want to tell your close ones everything even more so to people at work… (…) So when you talk to a psychologist, you can be sure, at least I hope (laughs) that you can be sure, that no one will condemn you and get surprised and won't… won't… won't talk behind your back."*
		[P 4 – female, 59, caregiver for a Mother]
Suggestions for the program		
Including live support	Communicating online is not for everyone, talking is different, easier, would like to see and hear the therapist	*"Sometimes a person still needs a contact with a live person. I mean real, live, live conversation."*
		[P 6 – male, 48, caregiver for a Mother]
		(continued on next page)

Table 3 (*continued*)

Themes and subthemes	Examples of codes	Examples of quotes
Tailoring materials and format	Different people have different needs, some themes were not relevant, books or leaflets are better	*"I have mentioned this before, maybe you cannot divide it like that: person, who provides care for one year – one type of experience. For the second, for the third, fourth – you cannot divide it like that. You have some kind of common thing. Well, I think that maybe it is impossible from the technical point of view, but, but, the only thing, what I can say is about the experience of caregiving."* [P 7 – female, 62, caregiver for a Mother]
Providing with more time and resources	More time for processing, extend the program use, expand the themes	*"And so I don't know, if everything just happened at the same time, it was just before Christmas, and there were so many things happening and it seemed that you would still want to do that, well, exercise, or linger longer with those thoughts, but a new week has started and there are new exercises. So it seemed, that those exercises would have been enough for two weeks."* [P 10 – female, 52, caregiver for a Mother] *"More information; well there is a lack of such information. I cannot even find it anywhere, not even on the internet, some kind of advices, so that it would suit me, according to my situation."* [P 14 – female, 56, caregiver for a Father]
Driving personal and situational forces		*"Over time, a circle of people emerges around you, with whom you can share, you know who ... the ones who understand you (...)."* [P 5 – female, 47, caregiver for a Mother]
Developing acceptance and adjustment over time	Attitude changes over time, one adjusts, it came naturally	*"I calm down, yes, I calm down after work by praying, m... by rethinking."* [P 11 – female, 56, caregiver for a Mother]
Being proactive and/or receiving support	Having someone to go to, taking courses, using prayer	*"I am completely alone. And only with the help of my husband. If my husband would be different, I do not know*

Table 3 (*continued*)

Themes and subthemes	Examples of codes	Examples of quotes
		what would happen." [P 8 – female, 67, caregiver for a Mother]
Hindering situational factors		
Deterioration and unpredictability of the care-receivers health	Intense and worsening situation, no solution for improving care-receivers well-being, well-being depends on the care-receiver	*"I can tell you, that the program did not have as much an effect on my well-being as... as the care-receivers health."* [P 23 – female, 54, caregiver for a Mother]
Lacking external support and opportunities for respite	No holidays from care-provision, accumulation of care-provision demands, limited opportunities in the province	*"It is great if you have some sisters, brothers or other relatives, that support you in some way, but sometimes... there are also women who are alone, providing care, as well as men."* [P 23 – female, 54, caregiver for a Mother]

spending the time for own needs (as opposed to only focusing on the care-receiver) was identified as one of the strong aspects of the program. In relation, being able to share own experiences and communicate with the therapist was also indicated to be much appreciated by most of the participants. At the same time, data analysis has outlined several controversies in relation to the participant experiences as well as perceptions regarding program's feasibility and acceptability that will be discussed in the following sections.

3.1.1. Convenience and applicability of the format and materials

Throughout the interviews it was observed that participants highly valued the flexibility of the online format of the program. There were two aspects that were appreciated: the ability to use the program in own time and from own home, and the ability to re-visit previous topics, exercises, and conversations:

> *"When I want, when I have time... You know, in the morning, at night, during days off."*
>
> [P 3 – female, 59, caregiver for a Mother]

The program's themes were also evaluated positively by the caregivers. To give an example, some participants appreciated behavioural aspects of the intervention, such as time scheduling, while others reflected on the usefulness of the cognitive aspects, such as the thought change record. Nevertheless, this does not mean that using the program and applying materials was always easy. Some participants reported that it required high concentration levels, or even re-living previous difficult experiences. Despite that, several caregivers indicated that being involved with the intervention and receiving psychological support was very beneficial for them. As these participants described, in their day-to-day life they found it much more difficult to manage psychological rather than physical caregiving demands.

3.1.2. Ability to focus on own needs

As one of the strongest benefits of the program, participants identified time for one-self. This was noted in two ways. First, using the program was a way to break the routine and spend time purely for one-self:

> *"It works for me. You receive a task, you do it, you organize yourself. All that time you dedicate to oneself. I would name it like that, that for reading and writing you must dedicate time, so I would dedicate that time for myself."*

[P 11 – female, 56, caregiver for a Mother]

In addition, throughout the duration of the program, participants practised scheduling time for engaging in pleasurable activities. Such activity scheduling further encouraged participants to break out from the daily routine and incorporate at least a small fraction of their time for engaging in own hobbies. This was found to be especially important for participants who described themselves as always being on the run. There were also participants for whom occasions of spending time for the pleasurable activities were accompanied by feelings of guilt. Some of the interviewed caregivers expressed that the program helped them to reduce such feeling:

"(...) I have especially found out about this this time for oneself. I would previously work and work and would even catch myself thinking, that if I sit down, drink coffee for too long, I will almost start scolding myself: So now you are not doing anything, you are being lazy, why are you not working? So many things are waiting to be done, so many things to do."

[P 22 – female, 66, caregiver for a Mother]

3.1.3. Opportunity for communication

Participants in the study found the possibility to communicate with the therapist and express own thoughts and feelings important for two main reasons: having limited amount of social contacts and not wanting to share care-related aspects of life with family or friends:

"Your social circle shrinks up quite sufficiently after such stuff, quite sufficiently. It is because not only others take their distance, but you yourself too. A lot, a lot. (...) And so maybe it is true, when a person you are not familiar with, maybe then it is easier (to communicate)."

[P 9 – female, 47, caregiver for a Husband/Partner]

Some participants reported that their emotions had been acknowledged and validated in the therapist feedback. Therapists were viewed as neutral and non-judgemental. Hence, the program provided these participants with an opportunity to share feelings that they were either not able or not comfortable with sharing with people in their close environment due to fear of being misunderstood. In addition, in some cases, sharing own feelings and emotions also helped to reduce the sense of guilt and other negative feelings.

3.2. Theme II. Suggestions for the program

This theme represents participant ideas regarding the development of the ICBT program. It consists of three sub-themes: *Including live support, Tailoring materials and format*, and *Providing with more time and resources*. In some respect, the first two sub-themes represent almost the opposite findings to the previously discussed theme I. More specifically, we have observed that communication with the therapist via the message function was not equally positively perceived by all of the participants. Instead, by some, it was observed as a non-naturalistic, artificial way for communication. The same regarding the program's format: even though majority of the participants did appreciate the flexibility of the online format, there were few participants, who did not find such format suitable. In addition, some participants also indicated that in certain circumstances it could be beneficial to have an option for tailoring the program's materials. On the other note, the last sub-theme communicates two slightly different aspects. Firstly, it represents participant need regarding the time for using the platform. Secondly, it represents participant need for receiving additional support once the program is finished. It is important to mention that even though there were a few participants who did have very strong preferences about changing program's format and tailoring the materials, most of the participants viewed it more as of an opportunity and less so as a necessity.

3.2.1. Including live support

Several participants indicated that they would have appreciated an opportunity to receive live support from the therapist during the program. Live support was suggested to take place either in person or via phone or other devices. Among these participants there were some who suggested that it should be added as a complementary option to the already existing messaging system whereas others suggested that the messaging should be replaced by the live support:

"I need live communication. I do not even like to speak on the phone. I like to meet a person, look into the persons eyes. But maybe this is how I am. But so, like this, internet is only for finding some kind of short information. For communication it is not."

[P 5 – female, 47, caregiver for a Mother].

For some talking was described as an easier, more acceptable, and natural way of communicating. It was also seen as an easier way to express one's thoughts as opposed to writing. Lastly, the ability to contact the therapist for live support was deemed important in urgent cases or when the person experienced deterioration in their well-being. Interestingly, few participants also expressed a wish to be able to communicate with other informal caregivers involved in the program, possibly in a group format, in which case the therapist would act as a moderator. In sum, all these suggestions potentially reflect participant need for more extensive and in demand support regarding the communication aspect.

3.2.2. Tailoring materials and format

Regarding program's format and materials, there were two main suggestions. First, some participants indicated, that the internet was not their preferred way to receive psychological support. Instead of being part of the ICBT program, some participants expressed a preference for reading books or any other printed materials, such as leaflets:

"Well, online format does not suit me. I prefer printed books or some leaflets. (...) O... o... sometimes I would even get annoyed, I could not make myself go to the computer."

[P 23 – female, 54, caregiver for a Mother]

There were also some suggestions for personalizing the program's content. For example, to tailor it according to the type of care-receivers illness or condition. Alternatively, to tailor materials based on the caregiving experience. Interestingly, despite these suggestions, participants seemed to be successful in selecting and applying materials suiting their needs. Moreover, they were very mindful about other caregivers using the program and the fact that even if something was not useful for themselves it might be useful for other caregivers. This was repeatedly observed throughout the interviews:

"In a sense, that this is only less useful for me, but it can be useful for others."

[P 6 – male, 48, caregiver for a Mother]

3.2.3. Providing with more time and resources

There were two main aspects regarding the concept of time. Firstly, some participants expressed the need to have more time for reading the materials and conducting exercises. Reasons for this included being busy, but also the need to linger with the materials and own thoughts longer. Secondly, some participants suggested that the program should be extended further and that more time for accessing the materials should be given. This last suggestion also relates to the following point of receiving more information:

"No, I think everything is fine, but well, there is a need for a next level. So, to extend more. To go even deeper into something. Yes, it would be good. I

feel so sorry that, that all this work, workmanship, all for only such a short amount of time and…. Well it does not have any continuation."

[P 18 – female, 55, caregiver for a Mother]

Regarding additional resources, participants presented different ideas about what type of information they would like to receive. For example, some had a need for knowledge in relation to the social services, others, practical information about how to conduct certain caregiving tasks. Despite the differences, it became clear that receiving relevant information via easy to access sources was very important, but unfortunately not always possible for these caregivers. Some participants also expressed the need to receive information on a regular basis. The need of information potentially reflects more general unmet need for accessible, condensed information sources for the informal caregivers in Lithuania.

3.3. Theme III. Driving personal and situational forces

This theme contains two main sub-themes: *Developing acceptance and adjustment over time* and *Being proactive and/or receiving support*. The first sub-theme represents a way in which participants individually maintain their well-being. That is, how they adapt to changed situation over time. The second sub-theme reflects partly individual and partly situational influences that supports caregivers in coping with various demands. It is important to emphasize that even though indirectly, this material provides with important information regarding the use as well as feasibility of the program for informal caregivers, based on their specific personal and situational circumstances.

3.3.1. Developing acceptance and adjustment over time
Regarding situational facilitators, participants mentioned that adjustment and acceptance develops over-time. Participants talked about how it was more difficult for them at the start of the caregiving and how eventually they adapted to the new situation:

"I do not know how much it is the merit of the program, and how much it is in general, that time passes by and a person adjusts. I mean… adapts to certain situations. But maybe this program made reconciliation a little easier."

[P 4 – female, 59, caregiver for a Mother]

On the other hand, the need for support seemed to remain even if it lessened for some due to successful adaptation to the changed situation.

3.3.2. Being proactive and/or receiving support
Other than the program, participants also mentioned that they had other various ways to maintain well-being. For example, some engaged in hobbies or activities, such as daily prayer. Other participants engaged in reading or taking courses. For some intervention was not necessarily useful for providing additional knowledge, but rather worked as a confirmation that they already were on the right path:

"So, as I say, I read something, something somewhere, I go somewhere. So, what I am saying, is that your program was only a confirmation for me, that I am doing everything well."

[P 5 – female, 47, caregiver for a Mother]

Participants also differed in terms of the external support they were receiving. For example, some had relatives from whom they could receive emotional support. Others used social, medical, or other services to support them with the caregiving tasks. Even though such support seemed to buffer emotional or physical caregiving demands, same as regarding the adjustment or acceptance over time, participants still expressed the need to receive additional support.

3.4. Theme IV. Hindering situational factors

This last theme represents factors having a negative impact on caregiver well-being. The two main sub-themes are: *Deterioration and unpredictability of the care-receivers health* and *Lacking external support and opportunities for respite*. As it is evident from the names of these sub-themes, both represent situational factors that negatively affect informal caregiver's psychological health. Some of the factors discussed in this section, such as, lack of support, are representing the opposite to the previously discussed facilitators of the well-being.

3.4.1. Deterioration and unpredictability of the care-receivers health
There were caregivers who outlined the care-receiver's health as a core factor affecting their well-being:

" (…) he is feeling bad and so I am feeling bad too…"

[P 19 – female, 58, caregiver for a Brother]

In the interview's health of the care-receiver was mentioned as a central aspect impacting not only own well-being, but also other aspects, such as the relationships with other people. According to these caregivers, especially when the care-receiver was experiencing untreatable and deteriorating health problems, their own well-being could not be improved as there was no improvement for the care-receiver. The other way round, well-being seemed to be deteriorated due to deterioration of the health of the care-receiver. It was observed that these caregivers could possibly benefit more from more tailored approaches, targeting changes and specific demands that these caregivers were exposed to.

3.4.2. Lacking external support and opportunities for respite
Accumulation of the care-receiving demands, lack of support and lack of respite were other situational barriers impeding caregiver well-being. In some cases, participants expressed a physical need to distance themselves from the care-receiver to recover from the caregiving demands and improve own well-being. Inability to physically leave or 'escape' from the situation was sometimes an emotional strain for these caregivers:

"You know, here at home nothing changes. Everything is the same in here because there is this patient here and you have no, how to say it, you have no holidays from her."

[P 2 – female, 54, caregiver for a Sister-in-law]

Regarding the support need, larger cities and towns were described to be superior in this sense, as there are more opportunities for the support as opposed to smaller cities (in terms of support groups or social and health services). These participants, similarly, as in the *Providing with more time and resources* sub-group, expressed an overall unmet need regarding the support services for them as caregivers.

4. Discussion

The aim of this study was to investigate informal caregiver experiences of using an ICBT program for reducing their perceived burden and improving the quality of life. Following the data analysis and interpretation, four main themes and a total of 10 sub-themes were generated. Some of the obtained results communicate direct participant experiences of using the program. Specifically, in relation to the programs format, materials, and communication with the therapist. The other part of the findings informs about participant personal and situational factors, that either impede or help to maintain their well-being. We interpret the latter as indirect indication of factors that should be considered for program's evaluation and further development. We reflect on all these matters further.

4.1. Main findings

Even though most of the interviewed participants appreciated the flexibility offered by the online format of the program, there were also participants who have found it not fully suitable for their needs. These participants indicated, that, for example, written materials would benefit them more. Such finding has been previously observed in other internet intervention studies for informal caregivers (e.g., Duggleby et al., 2018) and could possibly be explained by different individual preferences. An alternative explanation could be that some of the informal caregivers were not only uncomfortable with the using the internet but also less skilled. Limited computer literacy has been previously observed to be one of the barriers for engaging with internet interventions (e.g., Chiu et al., 2009). Even though most of the population in Lithuania claim to have good computer skills (Augustinaitis et al., 2009), people above 55 years of age were previously found to display lower media literacy and hence lower internet use (Liubinienė and Thunqvist, 2015). Considering that the mean age of participants in our study was 54 years, this could be a plausible explanation. On the other hand, data analysis of the pilot randomized controlled trial for evaluating the effectiveness of the program (Biliunaite et al., 2020) has shown, that the majority of the informal caregivers in the trial have suggested the program to be either easy or very easy to use. Such positive evaluation could indicate the acceptance of the program's format and overall functionality.

Similar to the findings from the other ICBT trials (e.g., Beattie et al., 2009) we have found both, positive and less positive experiences regarding the communication aspect in the program. To start with, some of the participants have experienced the communication with the therapist via a message function useful as it gave them an opportunity to voice their emotions and share their caregiver experiences that they would not be able to do otherwise. This is in line with the findings form the pilot randomized controlled (Biliunaite et al., 2020) in which almost half of the participants indicated the communication aspect to be useful and almost one third – very useful. Also, in line with the previous findings showing that sharing care-provision related experiences can be useful for coping and even for preparing for the upcoming care-related demands (Ploeg et al., 2018). On the other hand, some of the informal caregivers were not satisified with communication via messaging. These participants were longing for a real contact. Overall, such differing experiences regarding communication aspect have been previously reported in other qualitative studies. For example, Rozental et al. (2015) has reported that for participants in the ICBT trial for procrastination it was not uncommon to desire for the face-to-face contact. One solution could be to tailor the treatment to include on demand or live support option. This could be done by, for example, requesting prospective participants about what preconceptions or expectations they have regarding the communication aspect for the online treatment program (Rozental et al., 2020). Alternatively, future research should aim at identifying participant groups for whom the current communication option would be suitable and who would benefit from different alternatives.

Time for one-self was identified as one of the most beneficial aspects of the program. As our results indicate, interviewed informal caregivers have appreciated that the program encouraged them to focus on own needs. That is, to spend at least a bit of time for engaging in pleasurable activities. This finding is in accordance with the findings from the pilot randomized controlled trial (Biliunaite et al., 2020) in which the majority of the participants rated behavioural activation focused session of the program as the most useful. Disruption or interference in ones valued activities due to the care provision demands can be referred to as activity restriction (Revenson et al., 2016). Informal caregivers often find themselves in circumstances, were one must put own needs aside for meeting the caregiving demands as well as other obligations, such as taking care of the family or doing one's job. Very limited leisure time, loss of personal freedom and changes in the lifestyle in general are some

of the challenges faced by informal caregivers (Akgun-Citak et al., 2020). Hence, we deem it of a high importance that informal caregivers in our study found *the-time-for-oneself* as the most important benefit of the program. The finding that some participants suggested to extend the program or provide with more time for using the materials somehow comes in hand with this finding.

In relation to the program's content, our findings suggest that not all of the themes were rated as equally useful by the participants. Such differences were previously observed in a transdiagnostic intervention, as all participants received the same program (Rozental et al., 2015). Regarding this, personal circumstance is an important aspect to consider. Participants in our study provided care for individuals with various health problems. To name a few examples, there were individuals in need of care due to the mental health problems, dementia, and physical health impairments among many other. Due to the differences in the required care, participants experienced different care demands. The lack of individualization could act as a barrier to engage with the program (Fernández-Álvarez et al., 2017). Interestingly, even in cases where participants felt that their expectations were not met, they still expressed a gratitude for receiving support. This could indicate that receiving any support for these participants was still better than receiving none. This explanation is more likely given that psychological support services available for informal caregivers in Lithuania are limited (Žalimienė et al., 2020). Altogether, such finding could suggest, that current ICBT program could possibly be improved by adding an option for individualization of the content.

Lastly, several personal and situational factors affecting informal caregiver well-being were outlined. To start with, our findings shown that at least some of the caregivers tend to adapt to the situation over time. Also, that support network and opportunities for respite as well as care-receivers health play an important part in their well-being. One way to apply this knowledge in the future trials could be to offer caregivers an option to tailor the program. In this way, each given individual would be able to select the most relevant information. Another option could be to incorporate additional materials and edit existing program. To give an example, based on our findings, some of the participants could benefit from more information and suggestions about how to deal with uncertainty or deterioration of the care-receivers health. Adaptation of transition theory (Meleis, 2010) previously employed in development of internet interventions for informal caregivers (Duggleby et al., 2017), could inform development and inclusion of program's materials.

4.2. Limitations

Several limitations will be addressed. First, only approximately a third of the participants in the controlled trial (Biliunaite et al., 2020) expressed a wish to participate in the qualitative study. Those who decided to participate in the follow up qualitative interview might have been more positive about the program or the vice versa. Purposeful sampling procedure could have been a better alternative for obtaining experiences of participants who did benefit versus those who did not benefit from using the program. Secondly, the average duration of the interviews was around 16 min. That means that some of the information might have been lost due to short duration of the interview. Nevertheless, we consider the collected data sufficient as the data analysis resulted in various contradictions and complexities. Third, the interviewer was involved in the intervention trial including program's development, and this could have influenced the data analyses. Also, the interviewer's involvement in the trial could have impacted on the participants to express positive or negative views about the ICBT program. The latter especially for the eight of the interviewed participants, for whom the interviewer served as a therapist throughout the duration of the program. On the other hand, as the participants had never met nor seen the interviewer, their anonymity was preserved to a large extent. Moreover, the researcher's involvement in the program could have been

regarded as helpful in the interviews when evaluating responses as the researcher had an extensive understanding of the ICBT program. In addition, it could have helped to establish rapport with the participants and hence open the interview space for constructive reflections form the participant's side.

4.3. Conclusion

To our knowledge, this is the first qualitative study evaluating an ICBT program for the informal caregivers. Participants in the study mostly positively evaluated program's format and materials and communication with the therapist. Emphasis on spending time for own needs was found to be as one of the most positively evaluated aspects. Participant suggestions regarding intervention's development, such as to provide live support, provide participants with more time to use the program, or tailor content and program's format indicate some possibilities for further program's development. In addition, several participant personal and situation factors were identified that also should be considered for this purpose. Consequently, one of the future aims could be to further develop the current ICBT program to provide caregivers with more personalized treatment options. However, since most of the participants were positive about the current version of the program, further research trial is warranted for obtaining evaluations from a wider sample. Therefore, we conclude that an ICBT program can be a feasible and acceptable option for improving informal caregiver psychological well-being.

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Declaration of competing interest

None.

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