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RESEARCH ARTICLE

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Patients' experiences of a computerised self-help program for treating depression – a qualitative study of Internet mediated cognitive behavioural therapy in primary care

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ABSTRACT

Objective: The objective of this study was to explore primary care patients' experiences of Internet mediated cognitive behavioural therapy (iCBT) depression treatment.
Design: Qualitative study. Data were collected from focus group discussions and individual interviews.
Setting: Primary care.
Method: Data were analysed by systematic text condensation by Malterud.
Subjects: Thirteen patients having received iCBT for depression within the PRIM-NET study.
Main outcome measures: Analysis presented different aspects of patients' experiences of iCBT.
Results: The informants described a need for face-to-face meetings with a therapist. A therapist who performed check-ups and supported the iCBT process seemed important. iCBT implies that a responsibility for the treatment is taken by the patient, and some patients felt left alone, while others felt well and secure. This was a way to work in privacy and freedom with a smoothly working technology although there was a lack of confidence and a feeling of risk regarding iCBT.
Conclusion: iCBT is an attractive alternative to some patients with depression in primary care, but not to all. An individual treatment design seems to be preferred, and elements of iCBT could be included as a complement when treating depression in primary care. Such a procedure could relieve the overall treatment burden of depression.

KEY POINTS

Internet mediated cognitive behavioural therapy (iCBT) can be effective in treating depression in primary care, but patients' experiences of iCBT are rarely studied

- Most patients express a need for human contact, real-time interaction, dialogue and guidance when treated for depression.
- The patient's opportunity to influence the practical circumstances about iCBT is a success factor, though this freedom brings a large responsibility upon the receiver.
- An individual treatment design seems to be crucial, and elements of iCBT could be included as a complement to face-to-face meetings.

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Depression; primary care; Internet based treatment; iCBT; qualitative research; focus groups; general practice; Sweden

Introduction

Depression is a major source of human suffering and a great and growing challenge for societies worldwide [1]. In Sweden, approximately 15–20% of primary care patients suffer from depression or depression-like state [2]. Societal costs of depression are great; in 2006 the cost of depression corresponded to 1% of the total economy of Europe [3].

The treatment options for depression are many, and antidepressant medication is common. Only a third of patients with depression fully respond to antidepressants [4] and patients tend to favour psychotherapy compared with antidepressants [5]. Internet mediated cognitive behavioural therapy (iCBT) is an online alternative to face-to-face CBT. iCBT has been used as treatment for depression for

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many years, but patients' experiences of iCBT are not fully understood.

iCBT has been internationally studied as a treatment option for depression for more than 20 years [6]. Randomised controlled trials (RCT) of iCBT interventions have shown that iCBT may be effective in treating depression in community and secondary care [7–10]. As most of the patients with depression are diagnosed and treated within primary care [11], studies that target the primary care context are especially needed. Several studies show promising results of using iCBT as depression-treatment in primary care [12–14].

Patients increasingly request for online solutions for communication and treatment [15,16]. iCBT has the potential to enhance care for patients with such requests. In a systematic review, patients were more positive to computerised CBT than professionals were [17]. Hange et al. [18] also found that professionals believed that iCBT was too impersonal and thus would not meet the needs of the patients.

This study was carried out at primary care centers (PCCs) in the southwest of Sweden (Västra Götaland). Swedish PCCs are manned by GPs, nurses, psychotherapists and physiotherapists, who work in teams to support the patients and treat their conditions. Depressed patients treated in the PCCs are often, despite their condition, quite well-functioning and have capacity for work, unlike patients in secondary care. Limited access and unacceptably long waiting times to psychotherapy is a severe problem for patients suffering from depression. To be put on a waiting list to psychotherapy is a well-known disadvantage for recovery from depression.

Patients' experiences of iCBT as a treatment for depression in primary care context are important for gaining an understanding of the barriers and facilitators regarding successful treatment. Several studies have been conducted on patients' experiences of iCBT [19–23] showing both advantages and disadvantages of the treatment.

The aim of this qualitative study was to explore primary care patients' experiences of iCBT depression treatment.

Material and methods

Qualitative methods were chosen in order to gain a deeper understanding of the patients' own perspectives regarding iCBT. Informants were recruited from the PRIM-NET RCT comparing iCBT to treatment as usual (TAU) as treatment for depression to primary care patients [12], conducted between 2010 and 2014. Patients aged 18 years or older, diagnosed with mild to moderate depression at their primary care centre were included in the study and randomised to iCBT or TAU. All patients met a psychologist or psychotherapist for initial assessment. Patients with substance abuse, suicidal tendencies, other severe psychiatric disorder, cognitive disability or insufficient knowledge of the Swedish language were excluded. The iCBT treatment consisted of a self-help program delivered via the Internet, including interactive elements online, a CD with acceptance and mindfulness exercises and a workbook. The minimal therapist contact was performed by e-mail once a week and by three telephone calls in total (additional contact was given if needed), with the aim of supporting the participant's work with the iCBT program. The iCBT treatment period was 12 weeks. The TAU could consist of visits to a general practitioner, nurse, antidepressants, face-to-face psychotherapy (or waiting list to), sickness certification or combinations of these. The participants were followed-up for 12 months from baseline. The results of the PRIM-NET RCT showed no significant differences in treatment effects between the iCBT and TAU groups [12]. After completion of the RCT, the iCBT participants were invited by telephone to participate in a focus group concerning their experiences of the iCBT. Of the 36 contacted, 17 were interested in participating. Two of the 17 subsequently withdrew. Reasons for non-participation were mainly lack of time. Fifteen patients received information about the study and signed a written consent. We conducted one focus group with four patients and one with two (two others cancelled immediately before the set appointment). For those where it was not possible to fit in an appointment for a focus group, individual interviews were offered. Seven patients were individually interviewed. In total, 13 patients were included in the study (Table 1).

Table 1. Data concerning gender, age, interview type, education and working status for the 13 patients.

Informant	Gender	Age	F/I[a]	Education	Working status
1	F	27	I	secondary school	employed
2	M	40	I	university	employed
3	F	42	I	university	employed
4	F	47	I	university	employed
5	M	58	I	university	employed
6	M	30	I	secondary school	–
7	F	28	I	secondary school	employed
8	F	43	F	university	employed
9	M	45	F	secondary school	employed
10	M	37	F	university	employed
11	M	37	F	university	employed
12	F	68	F	–	other
13	F	31	F	primary school	employed

[a]Focus group/individual interview.

Seven women (aged 27–68, mean 41 years) and six men (aged 30–58, mean 41 years) participated.

Data collection

The data were collected in March and April 2014 at the Research and Development Centre for Primary Health Care in Göteborg, Borås and Uddevalla by independent researchers who had not been involved in the patients' iCBT process. Time from end of treatment to interview varied between one and 36 months. A topic guide for both focus groups and interviews was developed based on the study's objective. An interview guide used in qualitative iCBT research by the Department of Psychology at Linköping University was used as inspiration [24]. A semi-structured interview guide was developed for the individual interviews [25].

The focus group discussions were led by one moderator and one observer (ELP and AH alternating), and the individual interviews by one interviewer (DH, ELP, CW or AH). Open-ended questions were used inviting the patients to talk about their own experiences of iCBT. Questions such as "how would you describe iCBT?", "how did you perceive Internet as treatment context?" and "what did you experience after the end of iCBT treatment?" served to enrich and deepen data collection. Each meeting lasted no longer than 1.5 hours. All sessions were audiotaped and transcribed verbatim.

Data analysis

Data were analysed by systematic text condensation (STC) according to Malterud [26], inspired by Giorgi [27], i.e. developing descriptions and concepts concerning experiences of iCBT. STC was chosen because it aims to describe the informant's experiences, as expressed by themselves, rather than to explore the possible underlying meaning of their statements. Authors AH, E-LP and SN performed the analysis. Before starting the analysis, they identified their preconceptions about depression treatment and iCBT to enable bracketing of previous ideas and knowledge. Neither AH, E-LP nor SN have clinical experience of patients using iCBT, but have worked with patients with depression. The main analyser AH (who is a General Practitioner (GP)) has, however, for many years worked closely together with CBT therapists in treating patients with depression. The process involved four steps: I. Reading all the material several times to obtain an overall impression. II. Identifying units of meaning, representing different aspects of the research question, and coding and sub-coding for these. III. Condensing and summarising the contents of each of the coded groups and IV. Generalising descriptions and concepts reflecting the informants' most important experiences of iCBT. The units of meaning in step II were systematically obtained by perusing the text line by line, looking for content that could shed light on the objective of the study. One of the focus groups discussions was coded by both AH and SN to enhance the dependability and the codes were set after thorough discussions between AH, E-LP and SN. Analysis was data-driven, but in the last step the relevance of our findings was assessed by comparing them to existing studies [20,22,28,29].

Results

The results showed that the patients were generous about sharing their experiences of iCBT. The patients described a need for face-to-face meetings with a therapist. A therapist who performed check-ups and supported the iCBT process seemed important. iCBT implies that a responsibility for the treatment is taken by the patient, and some patients felt left alone, while others felt well and secure. This was a way to work in privacy and freedom with a smoothly working technology although there was a lack of confidence and a feeling of risk regarding iCBT. These findings have been elaborated below with selected quotations.

Does it work without the face-to-face meeting?

Some patients appreciated iCBT because they would feel uncomfortable talking to a stranger in an unfamiliar place. They perceived that to write down thoughts by the computer was a good alternative to a personal relationship, although most informants lacked a regular human contact and lacked having a relationship to a therapist.

> You can easily fool your computer, you get no eye contact, no body contact, you get no pat on the back.

The opportunity to speak out and dwell on experiences, and the perception that someone listened were considered important aspects. Writing seemed less important. Many expressed a need for real-time interaction with the therapist to get instant feedback, to be able to make progress. The patients were aware of the large workload placed on the individual using iCBT, but the need for guidance and interpretation assistance was considered necessary, and to get that was a prerequisite for the therapy to work.

> Why do you do such a thing: replace the therapist with software?

Inter-process feedback

The regular e-mails and telephone calls from the therapist were considered as positive by most of the informants. They needed someone pushing them to continue the iCBT because they experienced impaired ability related to their depression. Some saw it as stressful and felt guilty when they were contacted; some felt controlled by the therapist.

> I got a bad conscience because I felt I betrayed her when I did not do what she asked me to do.

Some patients perceived the telephone conversations with the therapist as ventilation and support; some felt that they covered only technical problems and other practical issues. Sometimes the contact was too sporadic and fizzled out at the end. Someone felt left in the lurch. Most patients had wished for a more comprehensive introduction to the iCBT from the therapist; they lacked evaluation during iCBT and a closing meeting. Continuity was stressed by most informants as a very important factor.

> I had a therapist who called me and checked how I had proceeded and pushed me a bit and said 'come on, go through this chapter until tomorrow, I'll call you back then'. I needed someone to push me because I had a problem with sitting down and getting things done, to pursue things …

With freedom comes responsibility

iCBT was perceived as accessible and effective. Patients easily obtained access to the therapeutic tools by having the iCBT program in their own computer and could choose where to work. Someone was working outdoors and perceived this as a positive experience. Another person had a hard time finding suitable conditions, as the only available computer was a desktop inconveniently placed. Many patients experienced great freedom. They felt relaxed by not having scheduled appointments, since appointments can be stressful. Being able to choose the amount of time to spend on iCBT, to regulate the pace by oneself was appreciated. To be able to start working whenever they felt alert and concentrated was considered as valuable. Many patients felt stressed by the iCBT and that it required too much from them. They felt left alone, with a too heavy responsibility lying on them for the progress of the iCBT. It was easier to sneak out than to tackle the tasks. Maintaining the discipline was difficult. Some thought the tempo was too high to allow the new knowledge to fall into place. The self-responsibility felt stimulating, since it signified the ability to influence own health. The iCBT felt meaningful and was seen as an easy way to get into better mood.

> It felt like it was very, very smart to have it on the Internet, it is fast, it is easily accessible. You can get immediate help just when you feel like it. Just turn on the computer and go into the different exercises.

> I had a hard time those days I felt bad bringing myself to sit at the computer and start.

Is iCBT a suitable treatment?

The majority of the patients perceived that iCBT can be effective if given to the right patient. They stressed that deeply depressed patients should not be assigned this kind of treatment since there is a need for enough strength to pursue the iCBT process. It is important that the patient feels confidence in the choice of iCBT. For some, iCBT was perfect. Others perceived iCBT as superficial. It was a big step for many patients to ask for help from health care. Some felt offended by being offered iCBT and that it indicated that they were not a priority. The perception of not being taken seriously, as being one in a pile of depressed individuals offered a panacea, led to little confidence in iCBT. It was risky sending a person away with iCBT; they experienced a great risk that someone could crash in solitude, without healthcare taking notice.

> I think it would have suited a great number of people well, but it does not suit those who do like me and dig down into their own thoughts and can't come out of it.

> I strongly believe in this and I definitely think this is a good option.

> How dare they do this? They do not know how bad I feel, I would perhaps have thrown this book on the table and said 'damn healthcare, to hell with this!'

Privacy and well-functioning technology

Most patients wanted to work with iCBT in privacy. It was important not to show the world that they had depression or received treatment for depression. Some had feelings of shame. Some told people around them, and completed the iCBT during working hours while others needed time alone at home in privacy, which was sometimes difficult to achieve. Most patients experienced Internet as safe from the point of integrity. Someone thought that the technology worked perfectly while most had some kind of technical problems with either headphones, passwords to the program or that they could not work in the

application on a mobile device. Several described the importance of the smoothly working technology since depression means low tolerance for adversity.

> It was a bit difficult in practical terms, in that I did not want the whole world to know that I was on iCBT for depression.

Discussion

This study showed that patients had diverse experiences of iCBT. Most informants expressed a need for a face-to-face contact with a therapist, when treated for depression. They valued human contact, real-time interaction, dialogue and guidance. All informants liked the freedom of being able to work anywhere, any time, and as much as they wanted. Many felt lonely and left with a responsibility that required too much from them. Easily used and high functioning technology was crucial. iCBT was described as a good alternative to common depression treatment by most patients. Some thought it was a risky way to handle depressed people and felt offended when offered iCBT, e.g. not being treated as an individual, but being served in a fast checkout.

Strengths and weaknesses of the study

A key strength of this study was that the patients were exclusively primary care patients. Only a few similar studies conducted in primary care context have to date been carried out [28,29]. All iCBT patients from the PRIM-NET were invited to this study. The ones who agreed to participate were acceptably diversified in age and gender, enabling a broad description of iCBT experiences. Our informants presented their experiences openly. Our impression was that they did not try to meet any expectations, but expressed themselves honestly. Moderators had different occupations (GP, occupational therapist and nurse), creating wide analytic space, which increased the validity of the results. Data collection was made in neutral surroundings. The number of patients was considered sufficient given that STC rather serves to gain new understanding than to create evidence [26]. The results cannot be regarded as generalizable for all people receiving iCBT, or even for all participants in the PRIM-NET study. The analysis was made in cooperation between AH, ELP and SN seeking to adhere strictly to guidelines of the STC research method. Preconceptions were identified prior to conducting the focus groups, interviewing and analysing, but the risk of a bracketing deficit affecting the results could not be totally eliminated.

A weakness of the study was the relative homogeneity of the study sample with regard to cultural background; informants were with one exception native Swedes. Results may therefore not be transferable to patients with other cultural backgrounds. Also, for some of the patients, a considerable amount of time had passed between their iCBT treatment and the present study. However, the patients were very informative and had a clear view of their experiences of iCBT. One of the focus groups contained only two patients, which generally is too few to create a wide discussion, but since these two patients were very eloquent and helped each other to remember their experiences, the discussion became very informative.

Findings in relation to other studies

Our study sheds light upon iCBT as a treatment for depression "in the real world" [30], which in Sweden most often is primary care. As the patients were asked to describe their experiences of iCBT, it is not entirely clear whether their experiences reflected the Internet- or the CBT-part of iCBT.

Our results showed that many of the patients experienced a longing for a relationship with a therapist. They expressed a need for someone they knew and trusted who could understand them and provide a helping hand throughout iCBT. Many expressed that the feedback and help they received from the therapist during iCBT gave support and push when needed, but as they had only met the therapist once at the start of the treatment, they perceived the feedback as not deep and personal enough. Increased patient–therapist contact might, however, not relieve patients from experiencing this. Patients receiving extensive contact with their therapist in live online CBT (10 hours) have expressed similar feelings [28].

Waller et al. [17] found that therapists were usually more negative to iCBT than clients. A study by Kivi et al [31] of the iCBT therapists' experiences showed that therapists considered that iCBT could serve as a complementary part of face-to-face therapy. There is evidence that blending care, where iCBT is combined with face-to-face therapist support, is more effective than iCBT without face-to-face support in community and secondary care [32,33]. In our study, many patients suggested iCBT to be a part of a therapeutic intervention. When starting the intervention with face-to-face meetings to develop a relationship and a therapeutic alliance, an iCBT treatment may become more effective by the patient feeling more secure and individually treated.

Some patients perceived that the responsibility that iCBT placed on them for their own recovery was too heavy, and they could not maintain the discipline to carry out the treatment. Depression is known to affect motivation and executive abilities [13], which may partially explain these experiences. Wilhelmsen et al. showed that the patients' motivation to persist iCBT is an important consideration for the treatment to be completed and that motivation is closely linked to a feeling of relatedness which is enhanced by a social relationship with the therapist, suggesting that face-to-face support during iCBT is preferred [34].

Some patients believed that the feedback process would have been more helpful in a chat- rather than mail-design; the immediate response seemed important. This mode of delivering CBT has been successfully tested [28], but live chat CBT requires as much therapist time as face-to-face therapy, which of course is a drawback. An overall well-functioning and accessible technology seems to be crucial, and both hardware options and software could be developed to make iCBT even more accessible.

Bargh et al. [35] found that some people feel more able of expressing their "true selves" on the Internet than in face-to-face interaction. In our results, we found few such opinions. However, some patients valued getting treatment without talking to a stranger. The opportunity of getting treatment in the privacy that iCBT provides was considered as a beneficial factor. Stressed as positive by our patients was also the freedom in the possibility to choose time and place to get treatment that iCBT offers. No-one worried about the online integrity. Most patients had some kind of technical problems. They described the importance of the smoothly working technology since depression means low tolerance for adversity. Depressed elderly patients might not perceive iCBT as a suitable treatment as they according to Aakhus et al might lack computer skills to use web-based resources [36].

Many patients perceived themselves as too ill to benefit from iCBT, even though none had a more severe degree of depression than mild to moderate, according to MADRS-S [37].

Patients expressed a feeling that iCBT patients were being left unguarded by healthcare in comparison to those treated by face-to-face therapy, and thought this could be hazardous for deeply depressed patients. To make patients feel secure and not left alone seems to be very important [18].

In a similar study, Bendelin et al. [24] explored patients recruited via advertisement. This study showed that iCBT was perceived in different ways depending on personality traits; persons with a practical "hands-on" approach were more positive about iCBT than those with more of an uncertain and doubtful personality. This phenomenon is, however, described even in face-to-face CBT. In the present study, personality traits were not investigated.

Meaning of the study

The current study sheds light on the complexity of primary care patients' perspective on iCBT for depression. This knowledge is important for health care providers to keep in mind when implementing iCBT as a treatment option in primary care, to understand the diversification of experiences of iCBT to achieve good treatment results and healthy satisfied patients. The prerequisites of treatment differ between primary and secondary care levels in several ways. In primary care, continuity, accessibility, and care adjusted to the individual patient's preferences and needs constitutes the basis for treatment carried out in close cooperation between patient and doctor/therapist, guided by the notions of continuity, accessibility, and person-centered consultation methods. It is influenced not only by diagnosis and symptoms, but also by such aspects as the patient's concerns, expectations, ideas and social as well as educational and psychological background.

Patients desire human contact, dialogue and guidance. The patient's opportunity to influence the practical circumstances surrounding iCBT is a beneficial factor, although this freedom confers a large responsibility upon the recipient. iCBT may be perceived as a risky treatment for depression. Some may not develop a therapeutic alliance online, and some may be too ill to fully participate.

Further studies should investigate iCBT delivered via other forms of technology, such as tablet computers and smart phones. Therapist-support by chatting or Internet mediated video calls is also a development that could provide better outcomes and should be further investigated in the primary care setting.

Conclusions

iCBT is an attractive alternative to some patients with depression in primary care, but not to all. The patients seem to need different amounts of support by the therapist. An individual treatment design seems to be preferred, and elements of iCBT could be included as a complement to face-to-face meetings. Such a procedure could relieve the overall treatment burden of depression.

Ethical approval

All informants received written and oral information before entering the study. The study was approved by the regional committee for medical research ethics of Gothenburg.

Disclosure statement

There are no conflicts of interest in connection with the paper. The authors alone are responsible for the content and writing of the paper.

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