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## Experiences of non-adherence to Internet-delivered cognitive behavior therapy: A qualitative study



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### ABSTRACT

Many trials on Internet-delivered psychological treatments have had problems with nonadherence, but not much is known about the subjective reasons for non-adhering. The aim of this study was to explore participants' experiences of non-adherence to Internet-delivered psychological treatment. Grounded theory was used to analyze data from seven in-depth interviews with persons who had non-adhered to a study on Internet-delivered cognitive behavioral therapy for generalized anxiety disorder. The process of non-adherence is described as an interaction between patient factors and treatment factors. A working model theory was generated to illustrate the experience of nonadherence. The model describes a process where treatment features such as workload, text-content complexity and treatment process don't match personal prerequisites regarding daily routines, perceived language skills and treatment expectations respectively, resulting in the decision to nonadhere. Negative effects were also stated as a reason for non-adherence. Several common strategies used for increasing adherence to Internet-delivered therapy in general are by these non-completers regarded as factors directly related to their reason for non-adherence.

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### 1. Introduction

Many published trials on Internet-delivered psychological treatments have had problems with a high degree of non-adherence, where a majority of study participants do not complete the entire treatment program (Christensen et al., 2009; Dunn et al., 2012; Eysenbach, 2005). Systematic reviews indicates that non-adherence to Internet interventions is comparable to other forms of treatment (Christensen et al., 2009; Kaltenthaler et al., 2008), although few studies have compared Internet and face-to-face interventions regarding variables such as adherence-rates (Andersson et al., 2014; van Ballegoijen et al., 2014). Web-based psychological treatments are effective, and as with psychological treatments in general, a challenge for further increasing effectiveness is to increase the proportion that completes the full treatment.

Providing participants with therapist contact for online guidance and support during the treatment period has been found to increase adherence and effect sizes (Andersson, 2009; Christensen et al., 2009; Spek et al., 2007). Even with added therapist support the proportion

of non-completers is still a crucial factor for web-based treatment programs. In addition to therapist guidance several strategies have been explored to further increase adherence to Internet-delivered treatment programs. For example adding telephone calls from the therapist (Clarke et al., 2005) increasing the frequency of e-mails from the therapist (Klein et al., 2009), allowing choice of treatment course and timing, adding clinician contact and varying the economic cost for the patients (Hilvert-Bruce et al., 2012). Overall, regular and more frequent therapist contact, reminders and more frequent intended usage seem to predict better adherence (Kelders et al., 2012). However, as noted by Postel et al. (2011) the success of specific initiatives seems in part to be related to the setting in which they are performed, e.g. adding telephone prompts yields different effects in different studies (Clarke et al., 2005; Farrer et al., 2011). As mentioned adding e-mail support from a therapist increases adherence but increasing therapist e-mail support (from one to three times a week) did not affect adherence significantly in the study by Klein et al. (2009).

Baseline predictors of adherence also vary between studies. A systematic review (Christensen et al., 2009) found that factors such as disease severity, treatment length and chronicity predicted adherence in Internet-delivered CBT. Clinical factors such as severity have also been related to adherence to web-based interventions targeting problematic drinking (Bewick et al., 2008). Other fields of online interventions have identified different predictors and no consistent pattern of

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predictors for non-adherence in online interventions is evident (Linke et al., 2007; Postel et al., 2011).

Even if there are previous studies that describe aspects of prematurely exiting a psychological treatment (Wierzbicki and Pekarik, 1993), few studies elaborates on why individuals choose to non-adhere. In a study on the reasons for non-adhering in an eating disorder treatment (Vandereycken and Devidt, 2010), the authors found that several patients did not complete treatment since they believed that they had achieved “sufficient progress”. Analogously lack of progress is in several studies not related to non-adherence (Christensen et al., 2009; Klein et al., 2009). When reasons for non-adherence are studied, common answers often concern personal reasons (Christensen et al., 2009).

Individuals who non-adhere to psychological treatment do not generally get better on their own without further treatment (Beumont et al., 1993; Fairburn et al., 1993), and considering the ambiguous results of research on predictors of adherence and strategies for improving adherence there seems to be a need to further investigate the reasons and circumstances surrounding non-adherence. Specifically there is a gap in the literature concerning in-depth exploration of the subjective reasons for non-adhering to online psychological treatments.

To our knowledge few studies, if any, have examined experiences of non-adhering to guided ICBT. In this study we focus on an Internet-delivered, guided self-help program for generalized anxiety disorder, with the aim to gain more knowledge about the factors that might play a role in the decision not to complete an ICBT treatment. By interviewing and qualitatively analyzing the participants' experiences of non-adherence we aim to generate a new theoretical working model on how non-adherence occurs in Internet-delivered treatments.

## 2. Method

The study was designed as part of a randomized controlled trial in a psychiatric setting in Sweden in 2010. The data were collected using semi-structured interviews with individual participants. The theory generating method grounded theory (GT), developed by (Glaser and Strauss, 1967), was used as an inspiration.

### 2.1. Definitions

Eysenbach (2005) formulated two aspects of non-adherence relevant to web-based interventions, dropout attrition and nonusage attrition, thereby differentiation between individuals who engages in the intervention but do not undergo follow-up and individuals who do not engage in the intervention but do undergo follow-up. In the present study we use the terms non-adherence and non-completers for participants who had started but not finished the treatment. The nonusage attrition/dropout attrition differentiation was not made in this study. Participants had ongoing online therapist guidance and all nonusage was followed up by the therapist encouraging the participant to continue treatment, if the participant still did not want to continue treatment he or she was defined as non-adherent thereby nonusage was equaled to dropout-attrition and is referred to as non-adherence. No participants completed treatment without undergoing follow-up.

### 2.2. Participants and recruitment

The participants in the study, six women and one man, were recruited from a psychiatric hospital in southern Sweden. Participants were contacted via letter and telephone and informed of the purpose of the study. All began the same ICBT treatment for generalized anxiety disorder but left the treatment prematurely. The treatment was given in the context of a randomized effectiveness trial at the hospital and was free of charge for the participants. The seven participants were between 21 and 69 years of age (mean = 39.3 years; SD = 17.1 years). Table 1 presents group characteristics including years with anxiety and pre-

**Table 1**

Descriptive characteristics of the sample and the adherent group.

	Sample n = 7 Mean (SD)	Adherent group n = 20 Mean (SD)
Age (years)	39.3 (17.1)	36.2 (10.0)
Years with anxiety	15.2 (6.6)	15.2 (10.8)
Education (years)	13.9 (2.8)	13.6 (3.1)
GAD-Q-IV pre	11.1 (1.5)	10.3 (1.8)
GAD-Q-IV post	9.3 (3.2)	7.3 (3.0)
PSWQ pre	70.5 (4.7)	62.8 (8.1)
PSWQ post	56.3 (7.6)	56.9 (8.1)
MADRS-S pre	26.8 (12.5)	18.0 (6.5)
MADRS-S post	21.8 (10.2)	16.6 (8.0)

and post-scores on self-report questionnaires regarding depressive symptoms, Montgomery-Åsberg Depression Rating Scale (Montgomery and Åsberg, 1979) and Anxiety, Generalized Anxiety Disorder Questionnaire-IV (Newman et al., 2002), and the Penn State Worry Questionnaire (Meyer et al., 1990). Scores in Table 1 are compared to the adherent group in the original trial. The inclusion criteria for the present study stated that the participants had completed at least one and no more than seven treatment modules (out of eight in total), thereby non-adhering to the treatment. 14 participants fulfilled the inclusion criteria (i.e. non-adhered between the 1st and the 7th module). Of these 14, 3 could not be reached and 4 declined whereby 7 participants were included. Informed consent was obtained from all included participants, and the study was approved by the Regional Ethical Review Board.

### 2.3. Specifics of treatment protocol

The treatment protocol had previously been tested in two randomized controlled trials (Andersson et al., 2012; Paxling et al., 2011), and a description of treatment content can be found in Paxling et al. (2011). The treatment was delivered via the Internet with e-mail based, weekly support from a licensed clinical psychologist. The treatment consisted of 8 weekly self-help modules of text, audio and illustrations, averaging 21 pages per module. All modules contained a homework assignment that needed to be answered and sent to the guiding therapist for the participant to continue treatment. The following treatment related factors may also have influenced adherence: treatment was free of charge for the participants (Hilvert-Bruce et al., 2012), telephone reminders were carried out if participants did not finish their weekly module (Clarke et al., 2005).

### 2.4. Data collection

All interviews were performed by 2nd author T.M. during her last semester of the Master of clinical psychology program. T.M. was not a representative of the original study or of the psychiatric hospital, thus enhancing possibilities of participants speaking openly about experiences of the treatment and staff. Interviews were performed at the psychiatric hospital and no one besides interviewer and participant were present. No follow-up interviews were performed. Open questions such as “could you tell me about the treatment you received?” were asked and followed-up by probing questions. The probing questions included various possible aspects of Internet therapy such as “Could you tell me how the technical equipment was working for you?” or “How did you experienced your contact with the therapist?”. Interviews lasted for 25–50 min and were terminated when the participant conveyed she/he did not have more information on the topic. The different aspects of questioning had been broadly based on results from previous research studies on patient experiences of Internet-delivered therapy (Bendelin et al., 2011), from therapy in general (Barrett et al., 2008) as well as from discussions with experienced Internet therapy researchers. Examples of themes were personal characteristics and circumstances

related to the treatment and the non-adherence, environmental factors and the patient's experience of the therapeutic relationship.

### 2.5. Data analysis

An informed approach of grounded theory (GT) was used for the analyses. GT is an inductive qualitative method where the researcher searches for new theoretical models grounded in empirical data (Charmaz, 2006). The theory-generating process of GT is based on the conceptualisation of the current collected empirical data. The GT approach is suited for the purpose of the presented study which is to openly explore participants' experiences of non-adhering from Internet-delivered therapy.

The interviews were audiotaped, transcribed and coded line-by-line, with the emerging codes being clustered into categories which were labeled thematically. Subsequently a theoretical sampling was performed with the intention to develop a narrower and a more specific research and to explore variations in the data. This meant practically that themes emerging after the first interviews were formulated and could be explored further in later interviews. The next step of the analysis included finding relationships between the categories. Two core categories were identified. A core category in GT consists of one or a few categories that are central to the data and that reflect the main concern of the area studied. A new theory emerges through a constantly comparative process between raw data, categories and the emerging of theoretical concepts. All authors were involved in forming the concepts, participants however did not comment on transcripts or findings.

## 3. Results

The analysis generated a working model theory consisting of two core categories containing groups of underlying concepts, these concepts emerged as particularly relevant for the participants' decision to non-adhere. The theory indicates that the two core categories needs to be compatible, the experience of non-adherence to Internet-delivered therapy can be described as an incompatible relationship between any of the underlying concepts.

Quotations from the interviews are used to illustrate the different concepts originating in the raw data.

### 3.1. Concepts

The statements given by the participants were collated into categories and clustered in theoretical concepts. These concepts enabled the formation of two core categories: *Perception of the treatment* and

*Patients' situation*. The core categories and their connected concepts are presented in Fig. 1.

The basis of the theory is the relationship between the two core categories. The various concepts emerging from the interview data show which factors were present regarding *Perception of the treatment* and *Patient's situation* at the time of terminating the treatment. To enable clarity the concepts are firstly presented as pairs as they were connected in the interview statements.

#### 3.1.1. Extensive text content of the modules, fixed treatment arrangement and personal life factors

The participants' statements regarding non-adhering showed an incompatible relationship between the length of the weekly text modules and factors or conditions in the personal life of the participants, i.e. how well the effort required could be fitted into the daily life of the participants. The content of the treatment was perceived as a tiresome burden because of the length of the text modules and the time consuming effort to complete them in parallel with personal life circumstances.

*...as a student you read so much already. I felt like I couldn't muster more energy or more time to spend by the computer and to read 10 or 20 more pages and also answer questions. It felt as if you were inclined to have a very structured life already to handle that (Informant 4).*

The fixed format consisting of one module each week being sent to the participants was also perceived as inflexible for some participants because of their personal life.

*...this treatment could have suited me if it would have been more flexible. The fixed format with one week per module, it feels as if you are so easily getting behind schedule (Informant 1).*

Some participants referred to the fixed study design as the immediate cause of their non-adherence. One aspect of this was participants' need for time to let the new knowledge sink in between reading parts of the text modules. Requests were made for a more flexible program in terms of time restraints.

#### 3.1.2. High demands on levels of concentration-, reading- and writing skills and individual capabilities

This concept relates to content complexity. The content of the treatment modules was perceived as difficult to understand and process by individuals who considered themselves as having attention problems or limited reading and writing skills.

*I thought that it was too much to read, and I cannot read anything at all that I need to remember or learn. It goes in here and out there (pointing at the ears) (Informant 6).*

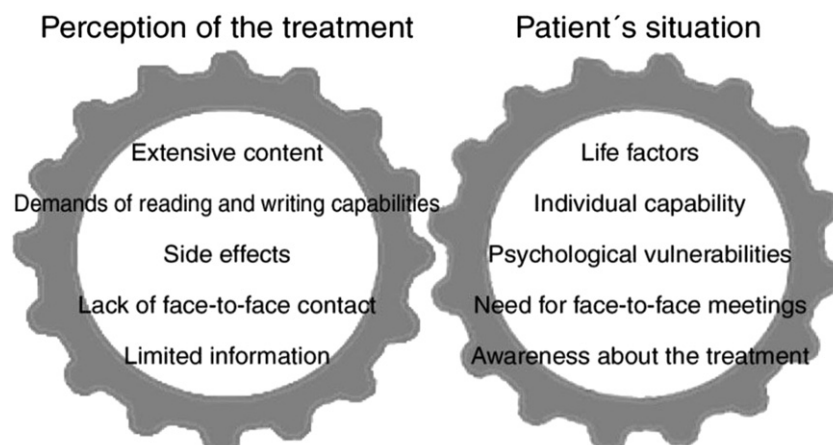


Fig. 1. Illustration of working model theory.

One critique was that information was difficult to understand because the content was perceived as complex and abstract. In some cases the participants felt unintelligent for their inability to understand.

### 3.1.3. Side effects and personal psychological vulnerabilities

Some participants viewed the ICBT as a trigger of anxiety symptoms. Other participants felt stressed by the content of the treatment program.

*I did not cope with the exercises. I did them at the start but it gradually became more difficult to complete them (...) particularly the breathing exercises, I got a bit dizzy and it increased my feelings of anxiety (Informant 3).*

The stress level caused by aspects of the treatment seemed to enhance or trigger participants' existing or prior psychiatric symptoms. This caused some participants to avoid the treatment and its exercises.

### 3.1.4. No face to face contact during treatment and perceived need for face to face meetings

Some participants perceived that the therapists did not really care about their personal issues. The therapists were sometimes considered only to have the task of checking that the participants read the text modules and completed their exercises. Some participants told us that they realized that they sought different aspects of having a face to face contact after they started the ICBT. Some participants felt a desire to share their problems in a face to face manner, to get support and being motivated by someone sitting in front of them. Some described a need for a face to face contact when sharing difficult issues such as anxiety and depression.

*I would have liked to have more of a personal contact, it became a little distant everything, to do this on the Internet, because it is so heavy stuff, it's nice to meet a real person when you're working with heavy things like this (Informant 7).*

Some participants changed to other treatment formats after terminating the Internet-delivered therapy. One participant explained that she had never prioritized her own personal development and that an individual therapy consisting of face to face meetings was needed to get away from home and focus on the therapy.

### 3.1.5. Limited information before starting the treatment and insufficient awareness or capability to grasp information about the treatment

Before the treatment started the participants received written information about the treatment. They were also encouraged to contact the staff for additional information if needed. The concept "insufficient awareness of the treatment" is based on statements from participants explaining they were offered and recommended to test a treatment but without getting or trying to find sufficient information about it.

*I had no idea at all really about what the treatment would be like; I was only interested in doing anything that might help me... (Informant 2).*

Participants explained that they were grateful for being offered the treatment, but not all of them seemed to be fully aware of the outline or the extent of the treatment.

Some participants did not remember what kind of information they had received and others had just entered the program out of curiosity. Insufficient awareness of content and outline of the treatment appeared to be an aspect that influenced participants' decision to terminate the treatment.

## 3.2. Working model theory

The current theory, visualized in Fig. 1, summarizes and explains patient experiences of non-adherence to Internet-delivered treatments.

Non-adherence emerged as a complex process made up of two core categories: *Perception of the treatment* and *Patients' situation*. The two core categories in turn were influenced by each other, the working model theory, grounded in interview data, visualize and highlight aspects of this complex process. The working model theory can be visualized as two cogwheels, where the underlying categories represent the cogs.

Five incompatible concepts describing the *Perception of the treatment* and *Patients' situation* emerged during the research process. It is important to note that an aspect of the treatment only caused problems if certain characteristics of the patient was present and vice versa. For instance the text modules were not necessarily always perceived as difficult, but it turned out to be so if the patients experienced themselves as having a lowered reading or writing capability. These different conditions and characteristics, presented in interplaying pairs, seem to play a role in non-adherence to Internet-delivered therapy.

## 4. Discussion

### 4.1. Discussion of main results

The aim of this qualitative study was to explore participants' experiences of non-adhering to an ICBT treatment. A working model theory was generated consisting of two core categories with five specific underlying concepts. Each concept was derived from participants' experiences of the treatment process. The participants' reported that the decision to non-adhere was taken when certain dimensions of the treatment process was perceived as incompatible with capabilities, constraints, or perceived needs.

Results from several studies suggest that participants' knowledge and expectations of the treatment process influence adherence (Beck et al., 1987; Bennett-Levy et al., 2010; Sledge et al., 1990). In this study the participants' need of prior information did not appear to match the way in which prior information was given to them (written information, informed consent). Due to this several participants expressed unfamiliarity with the treatment processes and demands, to which they relate their decision to non-adhere. This reflects the participants' experience of insufficient prior information, but potentially also reflects on the notion of the treatment as inflexible and extensive, and as demanding in terms of reading- and writing skills. These experiences could perhaps have been avoided using prior information with greater emphasis on these dimensions. It is also possible (since the participants did receive detailed written information of the treatment process), that different modalities of information presentations (e.g. video or oral presentations) would have generated more accurate expectation of the treatment process.

The notion of the treatment as inflexible and high in workload is a common experience among participants in Internet-delivered treatment (Halmetoja et al., 2014), though not regarded as a problem in itself it can lead to non-adherence when viewed as an obstacle to a participant's daily life. This is in line with previous research (Waller and Gilbody, 2009), where personal and practical circumstances appear to be related to adherence. Time constraints have also been given as a reason for non-completion in previous research (Christensen et al., 2009). In Internet-delivered treatment participants can usually, within certain boundaries, choose by themselves where and when to work with the treatment. Still, the treatment is largely considered inflexible which leads us to conclude that this type of treatment might be perceived as inflexible, specifically among non-adherers focusing on the fixed elements: module deadlines and homework assignments. Simultaneously the modular approach and frequent intended use have been related to adherence in the review by Kelders et al. (2012). Paradoxically this suggests that some of the general approaches aimed at increasing adherence are, by the individuals that do non-adhere, regarded as factors contributing to the decision to not complete the treatment. The presence of requirements during the treatment process

(e.g. due dates and intended usage) seems to assist a majority in completing a treatment but for some it appears to hamper adherence.

Non-completers in this study reported a mismatch between demands of the treatment (with regard to content complexity) and their capability. However research examining the role of verbal fluency and education level on adherence did not find these factors to influence adherence (Melville et al., 2010; Spek et al., 2008), also no significant differences in education length between the sample in this study and the adherent group were found. This experience could therefore be related to some other variable than actual verbal fluency or education level such as perhaps the ability to cope with stress or treatment requirements as mentioned above.

The perceived need for face to face contact during the treatment process is probably difficult to predict and influence. Several participants felt at ease with working without face to face contact before the treatment began, but changed their mind during treatment. Some research (Iacoviello et al., 2007) suggests that treatment preference among participants affects efficiency in trials, whereas other research does not (Glass et al., 2001).

Perceived negative effects, for example relaxation exercises leading to elevated stress levels, were provided as a reason for non-adherence. Although temporarily heightened levels of anxiety are to be expected from CBT interventions (e.g. during in-vivo exposure), negative effects that lead to non-adherence should be taken seriously (Rozenal et al., 2015). Especially since many clinicians are unaware how to monitor and report negative effects (Bystedt et al., 2014; Rozenal et al., 2014). Also negative effects have implications on to which extent adherence is desirable for all individuals. Ethically it may very well be questionable to promote adherence at all times. Several of the reasons stated in this study for non-adherence such as the treatment interfering with daily routines or the treatment leading to negative effects could arguably be handled differently (e.g. exploring alternate types of treatment delivery modalities) than providing incentives for the participants to continue the treatment at hand in spite of these obstacles.

#### 4.2. Limitations of the present study

The present study has several limitations that will be discussed here in turn. The sample size was limited; a larger number of participants would have been preferred, as it would have increased the theoretical selection and led to additional and clearer defined concepts to describe participants' experiences in relation to their decision to terminate the treatment, thereby increasing both internal and external validity.

Time from treatment to interview; the interviews took place three to six months after the treatment had ended, meaning that the results rely on participants' memories of their treatment. This might make it difficult to draw any firm conclusions about reasons for non-adherence because clients might have constructed new memories about treatment content, their situation, and stress levels during treatment.

Another limitation is the interviewer's role as a part of the research project initiated by the psychiatric hospital and thus to some extent, a representative of that party. The participants were patients in a subordinate position of power vis-à-vis the caregiver and this may have influenced patients' responses. It is possible, due to fear of jeopardizing their future contact with psychiatric services, that some types of criticism were withheld when providing their answers. On the other hand, interviews conducted in a psychiatric setting are a familiar situation for the participants, signaling to some that they are in a serious and reliable context. Also the interviewer formally did not represent the psychiatric hospital.

#### 5. Conclusions

This study contributes with perspectives on experiences of non-adherence to Internet-delivered therapy. A working model theory is

used to illustrate the experience of non-adherence. The model describes a process where treatment features such as workload, text-content complexity and treatment process don't match personal prerequisites such as daily routines, language skills and treatment expectations respectively. Negative effects were also salient as a reason for non-adherence, along with a wish for face-to-face contact. Several of the strategies used for increasing general adherence in Internet-delivered therapy (e.g. modular approach, high intended use) is by these non-completers regarded as factors directly related to their reason for non-adherence. A discrepancy between participants' expectations of the treatment process and the actual experiences of the therapy was related to the participants' non-adherence. This discrepancy could potentially be avoided by beforehand better preparing and educating the participant of the treatment process.

#### 5.1. Future research

Based on the results of this study it is important to further investigate the relationships between access to prior information before commencing treatment and its relationship to non-adherence and experiences during treatment.

Considering the role of negative treatment effects on adherence among several participants, it would be relevant to explore potential disadvantages of adherence-increasing initiatives. Possibly, providing strong incentives for continuing treatment could be hazardous in regard to those with negative treatment effects.

Building upon the results from this study it would be interesting to further investigate why so many of the non-completers experienced a limitation in their own ability related to the demands of the treatment. Previous studies have not indicated that constraints such as reading and writing difficulties are related to non-adherence. However, it is evident from this study that non-completers on occasion experience the demands from the treatment as overwhelming, and further knowledge about this factor could lead to better treatments with improved adherence.

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#### Appendix A. Supplementary data

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