

*Master Thesis / Research Paper*

## *Reading Between the Lines*

An ethnographic field study on personalization in providing e-therapy

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# Reading between the lines

## An ethnographic field study on personalization in providing e-therapy

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*E-therapy is an important and increasing care practice in mental healthcare. This article explores possibilities and shortcomings of personalization in providing e-therapy for patients suffering from Cancer-Related Fatigue (CRF). The main question of this study is as follows: How do online therapists personalize their care to individual patients in providing e-therapy? To answer this question, an ethnographic field study was carried out on an online Mindfulness-Based Cognitive Therapy (MBCT) for CRF. In doing so, the work practices of online therapists were observed, online correspondence was studied, interviews were conducted, and a meeting of online therapists was recorded and studied. This study resulted in a better understanding of the structure, as well as the possibilities and the limitations of personalization in text-based e-therapy. The results show that the online MBCT potentially provides attuned, and also bodily attentive, care. However, in dealing with difficulties like asynchrony and invisibility, therapists also face limitations of personalization in their practices. Especially when patients fail to provide self-disclosure, the therapist may have insufficient information to act adequately and to prevent patients from dropping out.*

*E-therapy; Clinical practice; Standardization; Personalization; Ethnography;*

### Introduction

*Dear (...), I'm pleased to read your diary of last week. I have inserted a few notes in your diary. As for the helpful and unhelpful thoughts, I think you are also doing very well! In situations when you have quite persistent thoughts, writing these thoughts down on paper and then trying to reflect on them, could help you. This is also possible with thoughts that keep popping up. Reading them again when they pop up may help you. And as for the meditations, I get the impression that you are really into it! In week 9 it is important to answer all questions. So please continue with the exercises and I will check how you are doing. During the evaluation of the program a month later, we can focus on how you have experienced it, and see if we may have to update our plan. I wish you lots of luck for Week 9! Sincerely, (...)*

*(Online MBCT participant 12)*

The above message comes from an e-therapy for patients suffering from Cancer-Related Fatigue (CRF). Such e-therapies (Castelnuovo et al. 2003), or what in the 90s was called therap-e-mail (Murphy and Mitchell 1998), form a substantial part of current treatment for diverse psychological or somatic complaints. In these text-based

therapies, communication proceeds asynchronously, i.e., not in the same time. The asynchrony allows patients to interact at their own convenience, allowing the therapy to be more embedded in everyday life and allowing the therapists to take more time to interpret the patients' situations and struggles (Childress 2000).

Ethical objections on e-therapy mostly focus on the relationship between therapist and patient, emphasizing the risk of disembodiment and lack of personal presence (Bauer 2004; Tantam 2006). Not being able to see and meet the patient and his or her body may carry the risk of missing important individual details; patients may remain relatively anonymous to online therapists (Bauer 2004; Tantam 2006) and therapists may become disinterested in fulfilling their caring responses toward their unknown patients (Bauer 2004).

In empirical research, however, scholars in the field of Science, Technology, and Society (STS) determine more structural problems that relate to standardization of health care practices (Berg and Mol 1998; Knaapen 2014; Timmermans and Epstein 2010; Zuiderent-Jerak 2007). Under the influence of Evidence Based Medicine (EBM), regulatory guidelines are being established to ensure effectiveness of separate interventions, also referred to as cookbook-medicine (Knaapen 2014). Interventions and technologies often are developed according to a one-size-fits-all principle, focusing on ideal-typical or "normal patients", and often fail to deal with important differences between individual patients (Moser 2006). Likewise, patient knowledge is seen as of little relevance (Pols 2014) because EBM maintains a strict hierarchy of knowledge in which subjective or practical knowledge lacks relevance (Knaapen 2014; Zuiderent-Jerak 2007). Treatment procedures that have been shown effective in randomized controlled trials (RCTs) are translated into clinical guidelines. These guidelines, however, are rarely provided with observations of healthcare work in action (Zuiderent-Jerak 2007). Because care practices consists, in essence, of social practices that deal with subjectivity and particularity, standardization may form a serious threat to the quality of care (Knaapen 2014; Pols 2014; Rankin and Campbell 2014). In stark contrast to the rational logic of EBM in dealing with standardized interventions, online caregivers and technologies are constantly working to realize fits and to avoid misfits (Pols 2012), also referred to as tinkering practices (Mol, Moser, and Pols 2010).

What is missing in the understanding of e-therapy is precisely this empirical precision on actual e-therapy practices in realizing individual fits in their natural contexts. How do these text-based and standardized therapies deal with individual patients and their inherent differences? This study will focus on how online therapists, in the given textual setting, clinical guidelines, and standardized technologies, personalize their care to their individual patients. In doing this, an ethnographic field study will be performed. On the basis of the results, shortcomings, as well as possibilities of personalizing online psychological care, will be discussed.

## **Method**

### *Design*

In order to understand personalization in e-therapy, an ethnographic field study approach was applied. Ethnography requires the researcher to participate in people's daily lives, seeing what happens, listening to what is said, and asking questions. In other words, the research must collect all data available to throw light on the issue under study (Atkinson and Hammersley 1994).

The analysis was drawn from data generated in an ethnographic field study conducted in 2015 at the Helen Dowling Institute (HDI) in the Netherlands. The HDI conducted the pilot *less tired with cancer* (in Dutch: *Minder Moe bij Kanker*). In this pilot (Bruggeman-Everts, van der Lee, and de Jager Meezenbroek 2015), an e-therapy intervention was implemented following the protocol of Mindfulness-Based Cognitive Therapy (MBCT) (Segal, Williams, and Teasdale 2012), specifically designed for CRF (van der Lee and Garssen 2012).

During this field study, data was collected through participative observations, photographs, non-participative observations, natural documents, ethnographic interviewing, and an audio recording of a meeting among online therapists.

#### *Informed consent*

Informed consent was obtained with each therapist before conducting interviews and making observations. Also, all therapists participating in the recorded consultation meeting agreed with the recordings and usage for this research. Studied material and documents were part of an online psychological pilot program. This study included therapists' writings but did not include patients' writings. Because the therapists' messages often contained reactions to individual patients' personal situation, the messages were studied anonymously. Also, in the terms and conditions of the pilot project, patients had consented that correspondence may be used for the improvement of future programs of online care.

#### *Data collection*

Data were collected between January 2015 and November 2015. Participative observations were carried out when therapists were giving online therapy, i.e., writing feedback. During these observations, clarifying questions were asked and photographs of the workplace were taken. Then, these field observations were documented in field notes with accompanying photographs. These field notes were then sent back for a member check. Non-participant observations concerned observing the online environment. Here, the researcher clicked through the online environment, listened to mp3 files, downloaded readers, and filled in textboxes for feedback messages. These observations were also documented in field notes with accompanying screenshots. The natural documents studied consisted of feedback messages of online therapists. These were no single feedback messages, but rather a series of feedback messages containing the therapist's messages from the whole nine-week therapy. Further, a consultation meeting of online therapists, in which five therapists participated, was recorded and transcribed. Finally, two formal interviews, following an interview

protocol based on earlier findings, were conducted with randomly chosen online therapists and then transcribed. These interviews both had durations of one hour.

**Table 1. Data collection methods**

Sites of study	Data collection method
<i>Site 1 “The therapists in their workplaces”</i>	Participative observations of one e-therapist
	Semi-structured interviews with two online therapists
<i>Site 2 “The digital environment”</i>	Non-participant observations of the online environment
	Analysing messages as Natural documents of 10 therapy sessions
<i>Site 3 “The consultation meeting”</i>	Recording and transcribing a consultation meeting with five therapists

### *Analysis*

Doing ethnography means that the researcher tries to treat the familiar world of “members”, i.e., online therapists, as anthropologically strange in order to expose its social and cultural construction. This task is especially demanding when the researcher is studying a practice or group with which he or she is familiar (Walsh 2012). In this study, the practice of the online therapy consisted of writing emails and using a computer. Using visual material, like photographs, which provided a static image of the practices, proved useful in exposing social constructions with regard to computing.

Analysis of the data began by writing analytic memos and field notes during the field studies. Field notes and transcripts were first coded by using open codes. With the issue of personalization in mind, important routines and aspects of e-therapy emerged from the data. Open codes then were presented and discussed in the monthly research meeting at the Helen Dowling Institute. When routines and features became clearer, axial coding and constant comparison were applied to understand their meaning and context. Also, formal interviews were carried out, which helped synthesize the different types of data and the aspects that diverged within different sites. Then, peer reviews were added by (a) an online therapist, (b) a colleague, and (c) a supervisor. Finally, preliminary findings were presented to online therapists in a consultation meeting. These findings were discussed, and peers were debriefed by all online therapists. In this consultation meeting, therapists asked critical questions on the findings, leading to minor changes in the manuscript.

### **Results**



**Figure 1. The online workplace.**

### *1. The e-therapy setting and its interactional structure*

Figure 1 shows a screenshot of the e-therapy program's online environment. This online environment is used both by patients and therapists. Here, the therapists can read notes in diaries from each of their patients and can respond through typed messages and add notes to these diaries. In this digital environment, the therapist and patient can find what exercises have to be completed each week and what themes are central.

The online environment is highly standardized. Figure 1 shows the nine weeks of the program lined up on the top of the page. Each week provides a different theme with a different exercise and a different reader. This online environment provides the script of the e-therapy and largely determines the actions and routines of both the therapist and the patient. In this way, the online therapy in the digital environment seems to be a fixed program, and its rules are determinant. In this online environment, the therapist's task is, therefore, limited to connecting with specific components of the patient's exercises and participating in the program. In doing this, the online therapist has both the task of reading notes and the task of responding to these notes by writing feedback. The patient, however, cannot see whether the therapist does or doesn't read his notes. Even when the therapist does not read all patient notes, he or she may still perform his or her observatory task. Therefore, the diary is not just a diary, but also a channel that enables the therapist to observe and intervene. This monitoring role of the online therapist is a consequence of the way in which the therapy is programmed and not, as in a face-to-face relationship, a result of personal choices made by the therapist.



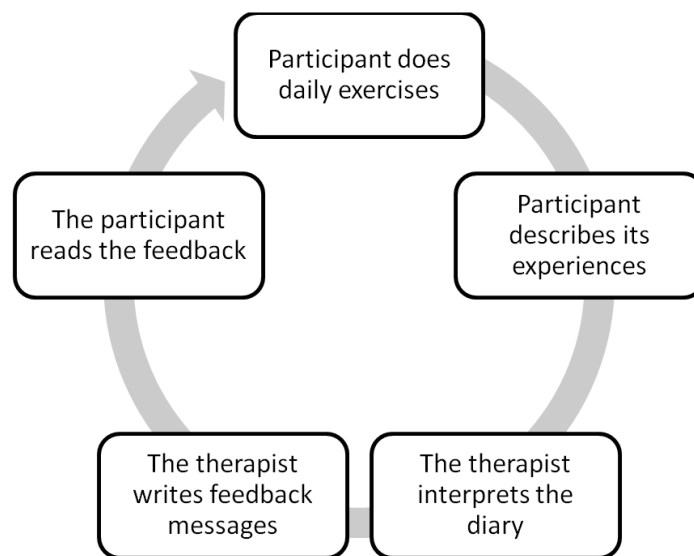
***Figure 2. The therapist at work***

Figure 2 shows the therapist providing care during the observations of the physical workplace. As shown in Figure 2, the interaction that occurred between the therapist and her patient consisted of typed text. According to the therapist, there may, in very rare exceptions, be telephone contact between the therapist and the patient. When the therapist in the observation wrote her feedback messages, she did so in a room in the care center, which was originally designed for giving face-to-face therapy. In some cases, the therapist may write feedback at home. However, according to the therapist, the location of writing feedback messages does not matter for the quality of the therapy. The only two requirements this therapist described are the presence of a computer connected to the Internet and a quiet place where the therapist will not be disturbed when reading notes and writing feedback messages. The therapist in the observations wrote her feedback messages by first carefully studying the patient's notes, then selecting the important topics from the notes and copying them to the text editor where she added responding messages to the chosen topics, and finally, deleting the patient's texts, leaving a complete feedback message. The important features of this approach seem to be the interpretation of, and response to, what patients write. When the therapist was asked what subjects were discussed in the feedback message, she described subjects that were currently playing a role in the patients' lives, for example, the death of a patient's dog or a current neighbors' quarrel. In choosing the important topics, she tried to write a personal comment as a reaction to this specific patient's notes. She also explained that she sometimes paused writing and started doing something else before finishing the comment later. She said this approach allowed her "to think about a reaction for a little longer".

Consequently, therapists connect to patients' experiences through interpretation of the patients' typed text. Through a routine of empathy and interpretation,



responding messages are typed to connect with what the patients reveal about experiences in everyday life and in performing the given therapeutic exercises.



**Figure 3. The interactional structure**

The online environment largely determines the structure of the program and, therefore, also determines the interactional structure between the therapist and the patient. As presented (Figure 3), the interactional structure begins with the patient doing that week’s mindfulness exercises. Also, the patient is expected to describe reflections after doing these exercises. This description enables the therapist to gain access to the patient’s experiences and to explore the patient’s struggles, worries, or goals. As a result, the therapist formulates feedback messages, which concern the specific patient’s specific situation. Then, the patient reads this feedback, which can be implemented or applied in the following exercises or during the next day.

The interactional structure wherein communication is practiced on the basis of notes and messages has three specific features. In contrast to interactions in face-to-face sessions or therapy through an online chat-room, telephone, or webcam connection, there is no real-time connection in this e-therapy. Therefore, the therapy is *asynchronous*, meaning the therapist and the patient are not simultaneously in contact with each other. This asynchrony in the online care relationship influences the structure of the interaction. Because of this feature, the therapist has more time to think about what patients write by interpreting the diaries and notes before responding to them, or as the therapist herself explained, “to think for a reaction a little longer”.

A second feature that is closely related to the asynchrony is the fact that the therapist and the patient cannot see or hear each other. The *invisibility* and *inaudibility* of this relationship implies that this care relationship differs from normal (e.g., bodily) relationships. This programmed online therapeutic setting ensures that both the therapist and the patient are invisible to each other; even when the therapist logs-in to the online environment, he or she cannot see whether the patient on the other side is

also logged-in, and vice versa. Thus, appearance and facial expressions do not play any role in the online situated care relationship.

A third important feature, which can be drawn from my observations, is the relative anonymity of the therapist caused by asynchrony and invisibility. The programmed online setting invites the patient to reveal much of his or her personal life regarding daily experiences, thoughts, feelings, and problems. The therapist, on the other hand, seems to remain fairly anonymous. After all, the therapist is not only invisible and inaudible, but may also inhibit his or her own experiences, thoughts, or feelings for the purpose of the therapeutic process.

Concluding, with a computer, the therapist and patient login to the online environment. There, they will find the script, their diary, their messages, and materials that are developed for the online therapy. These materials are the audio files of several mindfulness exercises, readers with instructions, exercises, and background information for every week of the program. The therapist and the patient not only interact with each other, but also with the material, the method, the online environment, mp3 recordings of guided exercises, and of course with their computers. An important notion here is that these materials are designed and developed. This development is completed partly by psychologists and partly by programmers. In this sense, developers of the material play a crucial part in the e-therapy. After all, the material, the weekly themes, the exercises, and the online environment with its colors, layout, structure, and scripts, all determine the activities and the practices of both the therapist and the patient. The e-therapy, in this sense, consists of a caring actor network in which the therapist has a relatively limited and executive, but still important, task.

## *2. Methods of personalization in feedback messages*

The therapists' feedback does not only show insight into important topics of patients, it also shows some kind of empathic or compassionate acknowledgment of worries, struggles, or achievements in patients' daily lives: "What a hard time you've experienced! It's impressive how you keep staying so energetic towards your recovery. Undoubtedly, that will cost you a lot of energy" (Session 8).

Despite the fact that this is online therapy without bodily or face-to-face contact, therapists still pay full attention to the physicality and the bodiliness of the patient and question it. This method means that, in this *bodiless therapy*, the body still receives considerable attention, possibly because of the bodiliness of fatigue and the methodological propositions of the MBCT in which attention to bodily sensations play an important role: "How nice to read that the body scan does you so much good, and that you experience much more space in your body. Are there also parts of your body that need more attention?" (Session 5).

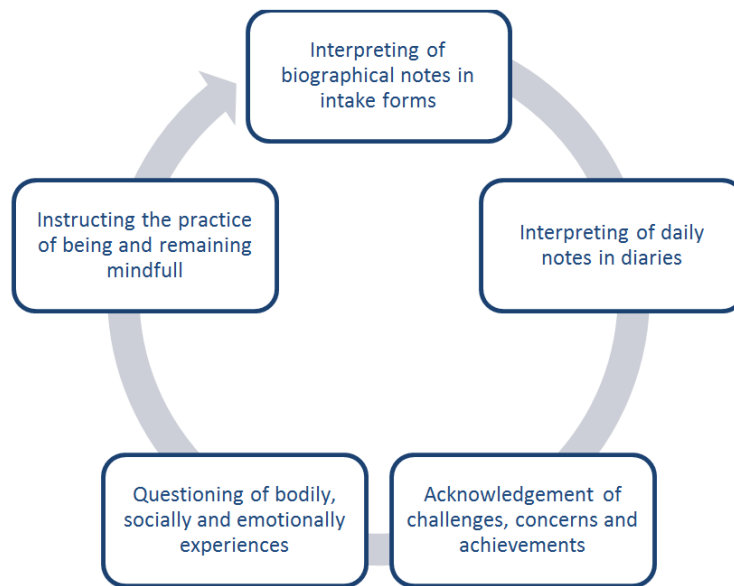
During this nine-week therapy, the therapist tries to stay engaged with understanding the patient's concrete situation. This engagement is also visible in the questions the therapist asks, "Do I understand you correctly? Do you mean this? How about the fact that...?" Although patients rarely give direct answers to these questions,

these questions still seem to play an important role. On the one hand, these questions show the therapist's attunement concerning the patient's experiences, concerns, and challenges. The therapist is actively working to understand what the patient writes down and shows engagement with and compassion for the patient. On the other hand, it encourages the patient to explore his or her own experiences and reflect on them. These questions stimulate the patient to a *questioning attitude* toward his or her own experiences. In these questions, the therapist also reiterates patient's goals, which were explicitly named or logically arose from the patient's statements. In naming goals, the therapist motivates the patient to remain hopeful and confident to the future: "How did it go last week? I really wish you the experience of quietness that you were looking for!" (Session 2). This, too, may be of importance for the therapeutic relationship because it seems to emphasize the purpose of the therapy and also confirms the goals of the therapeutic alliance.

Secondly, the messages also contain instructional content for the patient to actively relate to him- or herself, his or her body, his or her thoughts, his or her social relations, and his or her position in the world. This reflection is accomplished through exercises, e.g., guided meditations or self-research on which patients reflect in their diaries: "You already know the instruction: how am I really doing? What thoughts and feelings do I have? What is my body like? How does my body feel? I leave the thoughts and feelings and focus on my body" (Session 2).

A returning aspect in these instructions for patients is the ability not to judge and not to strive, but to practice *attentiveness and self-compassion*. These instructions are not so much focused on how to *be* attentive during the day, but rather on how to *practice* attentiveness during the day. The instructions seem to consist of actively doing: "I hope you will succeed to exercise regularly for the coming weeks. That is really needed to experience the impact of living with attentiveness in your daily life" (Session 2). In this sense, the patient receives training in a practice. Therefore, the therapist instructs and disciplines the patient on his or her faithfulness to the exercises and highlights the important propositions of the practice, such as *attentiveness* and *self-compassion*: "If you find yourself the next week losing your concentration once again, give yourself another compliment on that you have noticed and go back to the voice. Again and again, without punishing yourself" (Session 5).

Consequently, therapists emphasize that this practice needs practicing on a daily basis. This second routine of online therapists, *instructing a practice*, seems intertwined with the earlier routine of *acknowledging concerns and challenges* of patients. After all, to emphasize the necessity of *attentive self-care*, the therapist should also be attentive to the patient's concerns and challenges to which he or she can expose and make explicit. In this sense, the routine of acknowledgment may be part of learning the practice of attentive and compassionate self-care.



**Figure 4. Routines of the online therapist**

Therefore, when a therapist is assigned a new patient, he or she will start by reading the patient’s intake. The intake is an online form in which patient answer extensive questions about his or her illness, concerns, and other important parts of everyday life. Thus, the therapist becomes acquainted with this patient and his or her biographical or personal background so that therapist can write targeted and consistent feedback.

Then, before writing feedback messages, the therapist begins reading the patient’s diary. Thus, the therapist can adjust his or her feedback and instructions on the patient’s everyday experiences. The precise reading and interpretation of the intake, as well as the diaries, seem to be essential parts of the online care practice and of the personalization in the therapy. This is visible in the feedback messages since they often, though not always, contain specific and targeted information. In this therapy, a proper care relationship depends on a detailed attentive and empathetic reading of the patient’s writings. In this way, the therapist recognizes the patient’s concerns, as well as what challenges he or she experiences and what goals he or she sets. The therapist has studied the intake and shows insight into the patient’s everyday life, actively questioning him or her.

Last, the therapist will use this insight in instructing attentiveness and self-compassion. In this way, the act of the online therapist differs from the act of the instructions of programmed and nonhuman parts of the therapy. In contrast to, for example, the weekly readers or the online environment, the therapist is compassionate, human, and responsive to personal needs.

### *3. Limitations for personalization in the e-therapy setting*

In the online therapists’ consultation meeting, a much discussed topic was hitting the right notes or using the right tone, techniques, and strategies to motivate patients

and to promote and provoke behavioral change and active participation. An important notion repeatedly added was the therapist not being able to verify the direct response of patients to their writings. In this sense, therapists deal with a difficulty, which requires certain techniques.

For example, it is assumed that the first three weeks are crucial to build a successful therapeutic relationship. When the active attitude of the patient is not realized in these weeks, then the probability of dropping out is greatest. Techniques that were mentioned were *planting seeds*, *provoking*, *motivating*, and *confronting*. However, when confronting patients, therapists stated they created space for disapproval by using words like “maybe” (“maybe it’s better to explain this to your colleague”) or phrases like “could it be that” (“could it be that your job is taking you too much energy?”). According to therapists, this open-endedness is necessary because words can be interpreted wrongly, and if so, the therapist has no ability to verify and repair this interaction and, therefore, should not sound too strict: “Yes, I am very keen on not sounding too critical, because you don’t see if someone is shocked by my pointed writing style” (T3, p. 7).

Another concern discussed was the question *how to lower resistance and to prevent debate*. One of the techniques mentioned in preventing debate was “speaking in the name of the therapy”. For example, “in this therapy, we assume that practicing on a regular basis is necessary in order to achieve benefit (...)” (T1, p.5).

In the same way, the *tension between friendliness and discipline* is targeted. This tension was mentioned during a discussion about giving compliments. One of the therapists said he/she had considerable admiration for what patients have to encounter regarding their illnesses and limitations. Another therapist stated she often gave compliments to show her approval on how patients did in therapy. The question raised here was “Should we be kind or disciplining?” This tension also stresses the main role of the online therapist in the online intervention.

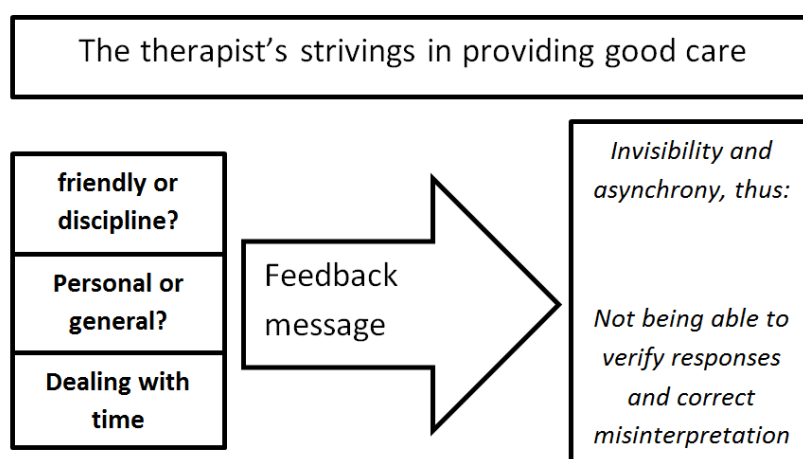
Another point of discussion was the reuse of messages, which implies sending messages, or parts of messages, that have earlier been sent to other patients. Therapists’ comments on this subject were that these messages must be checked thoroughly for congruency with that particular patient. According to the therapists, questions like “in what week is this patient?” and “does the subject of the message meet this specific patient?” should be addressed. Also, the risk of errors, such as accidentally using the wrong name, aspects that are not applicable to the specific patient, or addressing the wrong week’s topics, were discussed.

In resolving this problem, the distinction between *specific* and *general* was made. Specific was associated with the term *inquiry*, and *general* was associated with the term *psycho-educational*. For the reuse of messages, this distinction meant that general/psycho-educational parts could be reused, but specific targeted parts regarding inquiry were less suitable for reuse. Thus, if therapists reuse messages, general parts should be supplemented with specific parts. One of the therapists mentioned, however, that she felt uncomfortable reusing messages. She said she works *intuitively* and focuses on what a patient experiences in his or her daily life: “Ok, yes, I actually do

not do that. Because I work reasonably intuitively, I really focus on what is written, and I give psycho-education as well, but much more intuitive, concerning what someone is doing, and subjects I see repeating, for example, that someone feels very responsible for everyone, than that is what I address” (T3, p. 5).

The word intuitively was mentioned a number of times during the conversation and indicates how therapists *read between the lines* and connect to the patients’ concrete situations. In discussing the e-therapy, some of the therapists mentioned struggling with a high workload: “With a face-to-face patient, you have a fixed amount of time, which gives me calmness. If I must write a message, it often feels as a race against the clock, then it is really stressful to finish in time. But I really think it is very important what will eventually come down on paper” (T2, p.3).

As opposed to face-to-face therapies for which a fixed time is scheduled, online textual therapy is, because of its asynchronicity, subject to a variable time. Writing feedback is not a practice in which therapists can say, “Well, enough for today”. After all, feedback emails require consistency, a beginning and an end. As one of the therapists said, “writing these messages shouldn’t be rushed” (T2, p.2). In addition, therapists have to interpret patients’ writings, what they face in their daily lives, and how well they respond to therapy. This requires not only empathy, but also *self-discipline, time management, and motivation*. Therefore, giving online therapy requires different competencies with respect to dealing with time: “Sometimes I run out of time because something goes wrong with the secretariat, with a face-to-face appointment that is planned and then I run out again [...], agenda-technically it is really a bit confusing. And I'm very busy, even so with my face-to-face patients, and that means that sometimes I am not well organized. At the end of the day I have to rush and finish an online message that I just couldn’t finish in time” (T3, p. 4).



**Figure 5. Normative tensions**

Thus, personalizing care to individual patients in this e-therapy concerns providing accurate and proper responses to each patient. However, the therapist is not only challenged with providing proper responses for improving the patients’ situations, but also for convincing patients to engage in the program, which is necessary to

provide the insight into the daily lives of individual patients. Because of the invisibility, the therapist is not able to verify responses and, because of the asynchrony, the therapist is not able to correct misinterpretation. One mistake could do serious harm to the reasonably fragile therapeutic relationship. Therefore, formulating feedback messages needs to be done accurately and in a calm environment. The work should not be rushed, and the therapists should not be disturbed.

The text-based interactional structure and its asynchronicity and invisibility inherently form an important problem concerning personalization, especially when patients may fail to provide self-disclosure, which enables the therapist to attune the program to the individual patient. When patients, for example, have trouble engaging in the program, writing feedback, or understanding the point of it, therapists are simply not able to intervene adequately because of a lack of information.

## **Discussion**

The shift from face-to-face therapy to the Internet certainly has a major impact on what may be understood as providing care because new forms do not fit the old images. Therefore, opinions about this subject vary greatly but are rarely grounded in well-informed arguments (Pols 2012). In order to enhance our understanding of providing e-therapy, this paper studied shortcomings, as well as possibilities of personalization in an e-therapy called Mindfulness-Based Cognitive Therapy for patients suffering from cancer-related fatigue.

In this e-therapy, the computer was used as a tool for providing care and enabled the therapist to process, send, receive, or collect information from patients who were in a different location. The computer and online environment offered the therapist the possibility to make contact, carry out actions, share feelings, and acknowledge concerns, thus providing social care, which may otherwise not have been possible because of fatigue, the hindrance of travelling, or other physical limitations.

Nonetheless, how this care precisely appeared (asynchronous, bodily, invisible, attuned to specific aspects of patients' writing) was highly determined by its material and technological setting and its pre-programmed interactional structure. This paper furthers the understanding of what the shift from face-to-face therapy to the Internet entails. This shift might not just add accessibility of psychological care, but also has major impact on the way clinical practices are standardized and regulated.

### *How do online therapists personalize care to individual patients?*

In the studied MBCT, patients provided the therapists with individual insights through their biographical writings, as well as writings about daily experiences. These writings enabled the therapist to attune methods and feedback to the specific context of individual patients. Often, therapists had access to detailed biographical information on their patients and seemed very motivated to respond to challenges their patients faced. Ethical objections, like disembodiment and lack of professional presence (Bauer 2004; Tantam 2006) causing disinterest of health care professionals

(Bauer 2004), appeared only partly adequate. Therapists may indeed receive few details concerning the patients' appearances. Therefore, the therapist is not able to detect or correct misinterpretation or to give on-the-spot instructions to patients experiencing trouble with the program. In the text-based therapy, however, detailed daily experiences and bodily experiences likely garnered just as much attention to the challenges of patients, as in face-to-face therapy. Therefore, ethical objections claiming disinterested health care professionals because of disembodied presence (Bauer 2004) appeared inadequate.

The issue of standardization, much discussed in the field of STS (Berg and Mol 1998; Knaapen 2014; Timmermans and Epstein 2010; Zuiderent-Jerak 2007), may be more useful in understanding personalization and its limitations. Under the influence of EBM, clinical practices are being standardized and regulated in order to determine and guaranty their effectiveness. Shortcomings of EBM in evaluating and standardizing interventions imply its inability to include knowledge about clinical practices (Gkeredakis et al. 2011; Greenhalgh 1999; Zuiderent-Jerak 2007) and about patients and their perspectives (Greenhalgh 1999; Pols 2014) into regulatory guidelines.

Because online therapies, their online environments and their interactional structure are highly standardized, therapists are not able to personalize their care to patients that do not fit the expectations of the intervention. Patients that do not fully engage in the program, due to misinterpretation, misunderstanding or lack of writing, reading or computing skills, are likely to drop out of the program. Like most technologies, e-therapies are programmed for ideal-typical users and fall seriously short in dealing with differences like disabilities (Moser 2006), such as dyslexia or impairment. Therefore, online therapies require skilled and competent patients as well as therapists. Because the therapist is not able to act in real time, see the patients' struggles, understand misinterpretations, or provide on the spot instructions, the therapist's hands are simply tied when patients fail to live up to expectations. These limitations of e-therapy in personalizing care, may not only explain the therapist experiencing high workloads, but also the high rates of dropouts in e-therapies (Melville, Casey, and Kavanagh 2010).

## **Conclusion**

This study shows that personalization in e-therapy practice consists of therapists interpreting and adjusting to what individual patients share about their personal lives and daily experiences. This provides therapists with the ability to precisely attune the care they provide to what individual patients expose about themselves. However, although there are advantages to e-therapy, this type of therapy also contains serious problems for personalization.

Therapists in this e-therapy show lesser ability to fit the needs of patients that fail to share their experiences in written text or to engage in exercises, as well as those who are not able to engage in the program successfully. Because of the programmed



interactional structure, and its asynchrony and invisibility, the therapist may have insufficient information to act adequately and prevent patients from dropping out.

In discussing these results, these shortcomings were connected to STS literature about standardization in the health care sector. Under the influence of evidence-based medicine, effectiveness of interventions determined in RCT's gets translated into regulatory clinical guidelines. In order to assure evidence-based effectiveness, care practices are highly standardized, leading to one-size-fits-all interventions that may fail to deal with patients and their inherent differences.

### **Methodological limitations**

In performing this ethnographic case study, the focus was on the therapists' practice in attuning the program to individual patients. However, the scope could also have been on the practice of the patient, the developer, or even primarily on the material of the e-therapy. Obviously, in all three cases, the study would have shown other insights and understandings about psychological care in e-therapy, which means that these findings are not meaningful in regard to *patients' experiences* or *e-therapy designing*.

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### **Conflicts of interest**

The author declares that there is no conflict of interest.

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## **Appendix: Accompanying Reflection Paper**

### ***Introduction***

I wrote this reflection paper as an *accompanying reflection paper* to my research paper. The purpose of writing a master thesis, may not just be the product, because the learning and reflecting may be just as important. In this reflection paper I will try to articulate the lessons I have learned, and reflect on the credibility of the process.

In this paper I will start with *personal reflections*. In this part I will describe my own position and concern in doing research. Secondly, I will *reflect on the process*, on choices in designing my research project, on performing it and on lessons I have learned in performing it. Finally, in the *methodological reflections*, I will describe how I have tried to gain reliable results and to conduct valid qualitative research methods.

### ***Personal Reflection***

#### ***My position***

If I have learned one important thing from Carol Gilligan's book *In a different voice*, than it would be that knowledge is always gained by someone and therefore is always *someone's knowledge*.

The knowledge in this paper is gained by me as a researcher, so it may be useful to summarize who I am.

Firstly, I am a Dutch male of 30 years old. I am (or at least I am trying to be) a caring man, who is perfectly aware that he owes the world to the people he loves.

Secondly, I am a musician and a music therapist. I am educated as a professional guitar player in Amsterdam and as a Music Therapist in Utrecht.

Thirdly, I am becoming a researcher. In my job at the Helen Dowling Institute I am doing research on online interventions for psycho-oncological care. Also, I started my PhD at Maastricht University at the research programme for Science and Technology Studies. I really enjoy understanding the *concept of care* in all varieties and methods.

#### ***My concern: hierarchies in knowledge and practice***

If I have learned one important thing during my master *Zorgethiek en Beleid* (ZeB) at the University for Humanistic Studies, then it would be that knowledge is always gained from a concern. Or as Bruno Latour explains: Science is not about 'matters of fact', but about 'matters of concern' (Bruno Latour, 2004). The knowledge in this paper is gained by me as a researcher, so it may be useful to tell something about my own concerns.

As a musician and a music therapist I have learned that there are a million different ways to play a musical instrument. However, people always feel afraid to use musical instruments, to try how they sound or even to touch them. '*But I am not a musician*' they often explain. It often came down to me trying to convince them that everyone is a musician. Especially, in music therapy it always showed that everyone could express him or herself, that people can experience the joy of making music, but

also can comfort each other and can understand each other *within* making music. And so, there really are no universal standards for *true practice of music*.

I believe that these *hierarchies of true knowledge* and *practice* emerge within almost every practice, not just in making music, but also in solving moral problems (Gilligan, 1982) in tasting (Heuts & Mol, 2013; Annemarie Mol, 2008, 2009), in doing moral philosophy (Walker, 2007) or even in developing technologies (Bijker, Hughes, & Pinch, 2012). In hospitals, practices of physicians are valued above nursing practices and the practice of a lawyer is systematically considered as more important than the practice of a plumber.

However, no one really knows what all these practices really are about. It is the blind spot in our understanding of how we live together (Gkeredakis et al., 2011). In practices, exclusion and injustice are organized and maintained, and at the same time, lives are saved, care is given and meaning comes in to play. Some practices win over wisdom, humanity or animal welfare, some however create wisdom, humanity or animal welfare.

Therefore, I want to study and understand practices and find what goods consist within them. To articulate their strivings, to gain knowledge about normativity and materiality, about background understandings and to reorient on ‘goods’ within practices by, also articulating the ‘bads’ that should be avoided.

## ***Reflections on the process***

### ***1.1 The method***

During my master’s degree, I also learned about practice approaches in understanding and researching care and health care applications. The classes of *Frans Vosman* about understanding the muddy and complex *doings* of care-practitioners introduced the *turn to practice* as a new way of thinking about care and studying it. In that same period, I attended a meeting of the Graduate School of the UvH in which  *Davide Nicolini* was one of the keynote speakers. After his lecture on practice approaches in doing social research, I started to read his book *practice theory, work and organization* (Nicolini, 2012a), which really inspired me in doing practice-based research in understanding care practices.

My attraction to practice wasn’t new. For me, as a music therapist, music therapy was all about practice. For example, in the *Analogue Process Theory* (Smeijsters, 1993), a theory about analogy between making music and everyday life, the creative process revolves around musical and social interactions, which contain analogy with problems or challenges in every day live. In music therapy it’s all about recognition, social alignment, interactional and emotional understanding. In this sense, music therapists already have a critical position towards regular and dominant forms of therapy (such as cognitive therapies) in which rationality and verbality (instead of feeling and doing) are central.

Also, in that same year, I started reading ethnographers from the field of Science and Technology Studies (STS) on social studies of science (Latour, 1987; Law, 2004) social studies of technology (Bijker et al., 2012) and social studies of hospitals and

health care practices (A. Mol, Moser, & Pols, 2010; Annemarie Mol, 2002; Jeanette Pols, 2014). For me the penny dropped reading an article of Jeannette Pols on *an empirical ethics in care* (Jeannette Pols, 2015). In my eyes she paves the way for an empirical ethics *in care* that is mostly based on STS roots like *praxiography* (Annemarie Mol, 2002) and *material semiotics* (Latour, 2007). The understanding that interactions with (not just musical) instruments and tools are a fact of care, and that non-humans like concepts and tools are important parts of the moral dimension of caring relationships, are key to how I conducted my research-thesis.

The problem I described in my final design was: *if good care always implicates same kind of closeness* (Vosman & Baart, 2008) *or presents* (Baart, 2001) *or even tele-presents* (Bauer, 2004), *what than is this online psycho-oncological care through e-mail which is physically not close nor present?* Therefore the main question I wanted to answer was: *In what way do distance and closeness emerge within this e-therapy?*

### 1.5 Doing ethnography

I believe that this paper really answers my main question, being: *'In what way do distance and closeness emerge in this e-therapy?'*. However, I am very well aware of the fact that I quite deviated my original research design. But also, I really enjoyed the pragmatic wandering around, doing fieldwork as a journey of discovery, not knowing what would be discovered.

Doing ethnography was a very informative process in which I had to engage in different sites to get to understand the practice. Choosing sites and investigating them was a puzzling but challenging process. The most difficult problem I confronted, was reducing the amount of information for answering my questions and the essence of the practice, and still being true to the complexity that surrounded the online MBCT. The problem of reduction really was a hurdle in all stages of my research process. How do I determine my problem/question without reducing it? How do I write down observations without reducing its appearance? And even now in presenting the results this problem of reduction plays a role.

I found my most fitting answer on this problem in the writings of practice theorists like Theodor Schatzki and Davide Nicolini who explained that practice research not imply reducing the practice, but lifting out aspects of the practice in order to answer a question (Nicolini, 2012b; Schatzki, Knorr Cetina, & Savigny, 2005).

### ***Methodological Reflections on the quality of the research project***

In this reflection I will describe (a) the credibility, (b) the transferability and (c) the reliability.

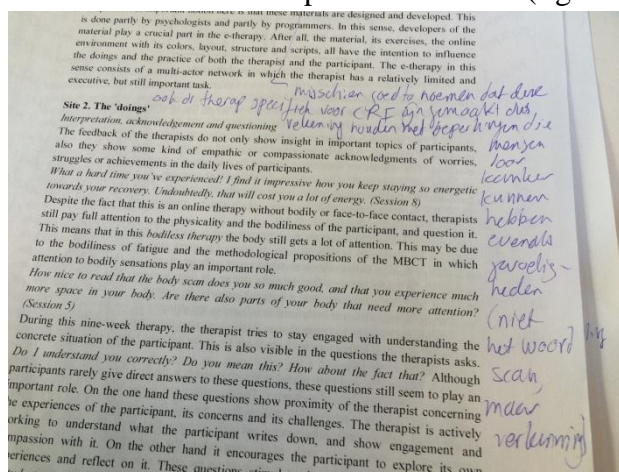
#### 1. *Credibility*

In doing praxiography different methods of data collection are used and different sites are studied. In synthesizing these sites, **triangulation of data and methods** was carried out. Subsequently, I checked the consistency of the findings that

were generated by different data collection methods. For example, (a) I observed the therapists actions in the physical workplace, (b) I analysed the actorship of the digital workplace which had consequences for the actions of the therapists (c) I studied the actual actions by analysing natural documents and (d) I studied what therapists said about their actions in the consultation meeting. Mostly, the aspects that diverged provided interesting insight. For example, how therapists explained their acting, and how the actions actually were carried out sometimes differed. Therefore, working with different sites was an informative method, which, I believe, contributed greatly to the credibility of the results.

Also, in a supervision meeting of online therapists in the study, held on the 29<sup>th</sup> of September 2015, I presented the findings, that were also discussed and so **peer debriefed**, by all online therapists. In this consultation meeting therapists asked critical questions on the findings and methods. This resulted for example in the change of the word *investing* of online therapist to the word *acknowledgement* in the manuscript of the research paper.

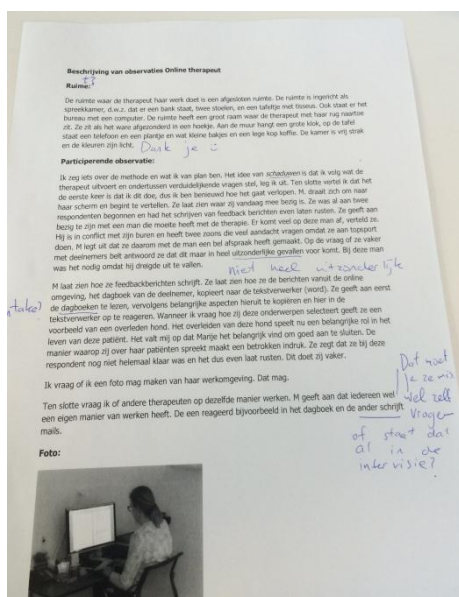
Also, **peer reviewing** is done by one of the therapists, who reviewed earlier drafts of the paper and provided the results with important feedback (figure 2).



**Figure 2. Peer reviewing of the findings**

**Other peer reviewers** were (a) Merel Visse, who reviewed the paper in supervising my thesis research, and (b) my colleague researcher Fieke Everts at the Helen Dowling Insitute, who also reviewed some of the data.

Also, to assure the credibility of the participative observations, I sent the thick descriptions to the observed online therapist who provided them with notes and questions, and finally agreed with the observations. This provided a **member check** of the participant observations (figure 3.).



**Figuur 3. Member check of participative observations**

Finally, one **final interview** of 1 hour was carried out which helped me greatly with **synthesizing** the different sides into one consistent paper. This was done pragmatically because it showed difficult to synthesize different sites, which sometimes diverged. Using the semi-structured interview helped me to understand how the sites and actions were related to one another.

## 2. Transferability

Firstly, as I mentioned in the methodological reflections in the research paper, in performing this praxiographic case study, the scope was on the therapists practice in providing good care in the online MBCT at the Helen Dowling Institute. However, the scope could also have been on the practice of *the patient* or on that of *the developer*, or even primarily on *the material* of the e-therapy. Obviously, in all three cases, the study would have shown other insights and understandings about good care in the e-therapy. This means that these findings don't say anything about *patients' experiences* or *e-therapy designing*.

For this case of the online MBCT, case-to-case transferability can be determined on the basis of similarities and differences. However, it shouldn't be done too hasty or easily. As I explained in the introduction, the results of this study do not contain objective and universal truths but locally interpretations of specific sites in a particular practice.

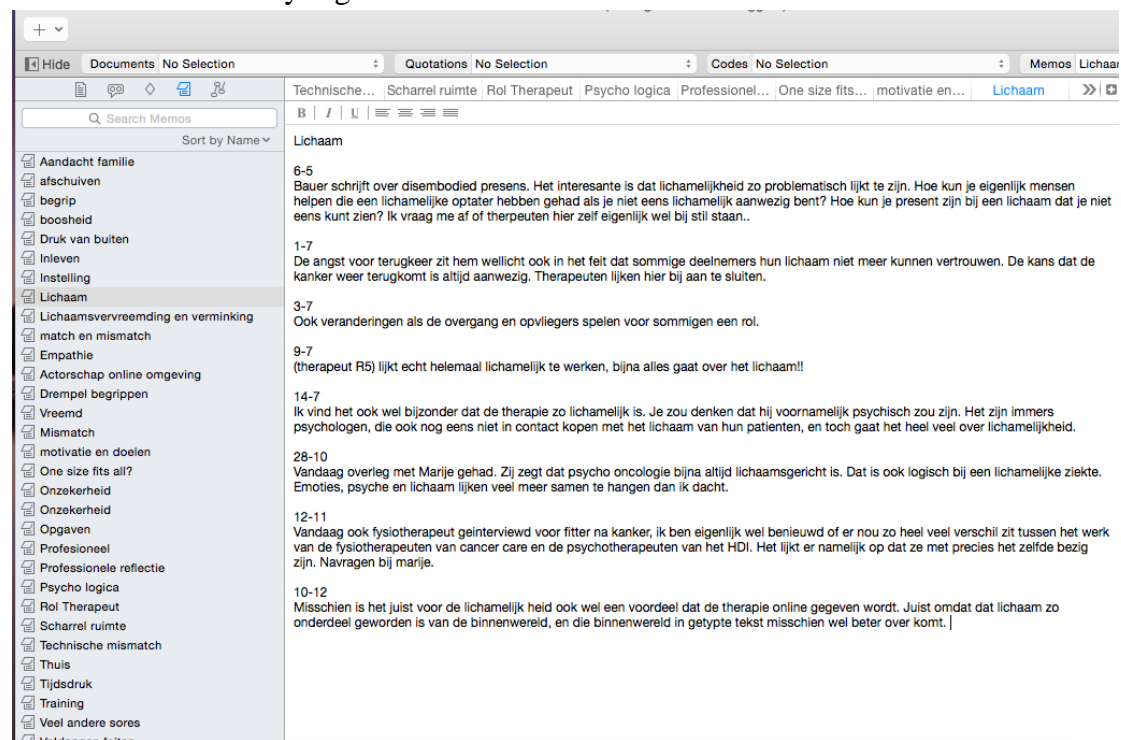
To give insight in the possibility for transferability it may be useful to describe some of the most important characteristics. There may be just little transferability in online interventions in which communication methods are used, other than typed texts. Also there may be just very little transferability in telemedicine or healthcare interventions that are not designed for psychotherapy and psychological treatment.

There may be more transferability in cases of online therapy like online cognitive behavioural therapy (eCBT) in which its communication is done exclusively

by typed messages. Most transferability will occur in other cases of online MBCT treatment on diverse complains like for example depression or anxiety.

### 3. Reliability

In the process (from the beginning until now) I have done a lot of **memo writing**. These memos were organized thematically. Each theme contains memos and the date of each memo (See figure 4.). The memos were organized in Atlas.ti software. However, not all memos were written in Atlas.ti. Memos were also written on my mobile phone, in field notes, on my tablet and on my laptop. All memos however were finally organized in Atlas.ti.



**Figure 4. Memo writing**

The memo writing also helped me with **preventing bias**. Because all of the themes in memos contain early thoughts, which evolved during the process, preoccupations have been changed because they were proven to be wrong. A nice example of proving a preoccupation wrong shows the memo about the body in figure 4. The first memo of the body problematized the fact that the online therapy is a bodiless therapy, however the last memo explains that the bodilessness can also be a benefit in providing bodily care because the *inner world* may get more in to picture. In this particular case, the potential bias of disembodied presence was articulated and proven wrong. However, I also believe that not all biases can be articulated because they are so implicit and cultural that they will never get caught. However, it didn't prevent me from trying.

Finally, a view words on the possibility for replication. I do believe that when my research process would be replicated by using the same method, the same sites and the same research question, the same themes and findings would occur. However, the



question is if the replicating researcher would make the same choices in prioritizing, or as Schatzki calls it, if he would lift up the same aspects of the practice.

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