Using smartphone-based ecological momentary assessment and personalized feedback for patients with chronic cancer-related fatigue

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Using smartphone-based ecological momentary assessment and personalized feedback for patients with chronic cancer-related fatigue: A proof-of-concept study
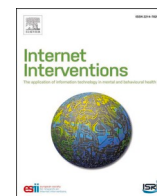
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ABSTRACT

Introduction: Chronic cancer-related fatigue (CCRF) is a complex multidimensional problem warranting person-centered care. Providing patients and therapists personalized feedback based on network analysis applied to ecological momentary assessment (EMA) data could facilitate case conceptualization in psycho-oncological care. The aim was to explore patients' and therapists' experiences of using an EMA app and personalized feedback based on network theory to aid case conceptualization in psycho-oncological care.
Methods: A n = 5 proof-of-concept study was implemented in routine psycho-oncological care. We purposively selected adult cancer patients suffering from severe CCRF who were on the waitlist for psycho-oncological care. During a 3-week period participants filled out the EMA app *Energy InSight* (fatigue, mood, activity, responding, and context) five times a day. Participants received a descriptive and network feedback report, which they reflected upon during the first therapy sessions. Thematic analysis was used to analyze user experiences.
Results: Patients experienced that filling out the *Energy InSight* app, as well as receiving descriptive and network-based personalized feedback provided them with insight into their CCRF. Although therapists experienced the discussion of network feedback as challenging, it facilitated the case conceptualization.
Discussion: Using EMA during waitlist for psychological care seemed feasible. Patients experienced beneficial effects from filling out the EMA app and talking over the personalized feedback reports, which in turn aided case conceptualization and personalized care. Based on this evaluation, an improved version of the *Energy InSight* app and a therapist training for providing network feedback is developed for implementation in psycho-oncological care.

1. Introduction

1.1. Chronic cancer-related fatigue

Fatigue is experienced as the most disruptive side effect of cancer and its treatment (National Comprehensive Cancer Center, 2020).

Approximately 25 % of cancer patients suffer from chronic cancer-related fatigue (CCRF) months to years after cancer treatment is completed (Bruggeman-Everts, 2019; Thong et al., 2020b). From the patient perspective, CCRF is an embodied experience with different interrelated dimensions (e.g., physical sensations, limited daily functioning, invisibility of fatigue) that vary across social situations, and

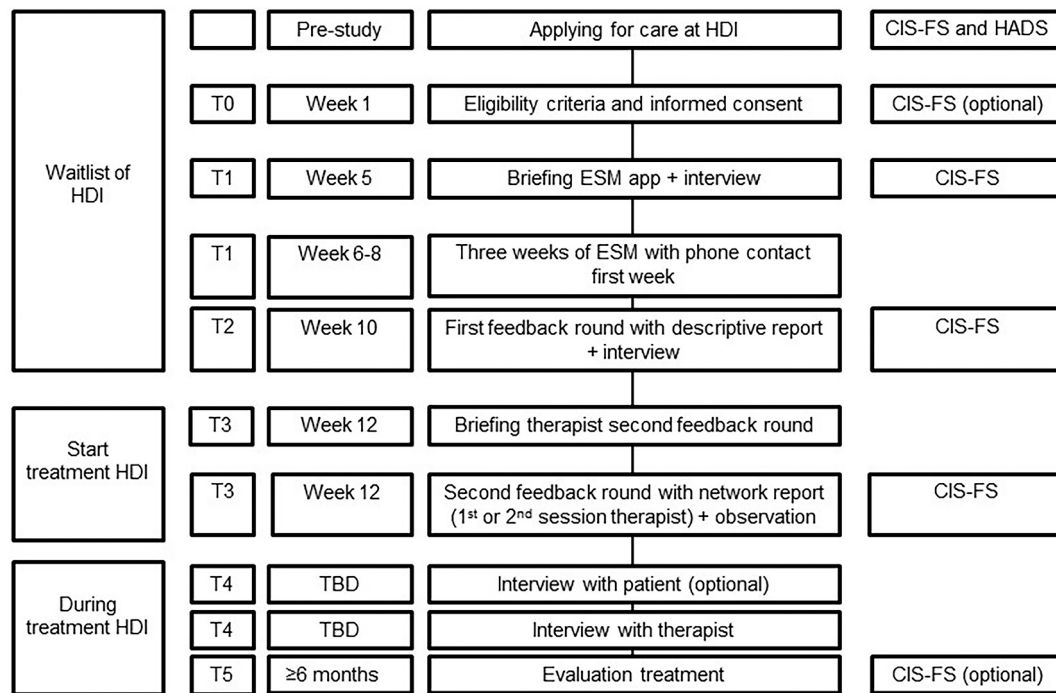|		Pre-study	Applying for care at HDI	CIS-FS and HADS
Waitlist of HDI	T0	Week 1	Eligibility criteria and informed consent	CIS-FS (optional)
	T1	Week 5	Briefing ESM app + interview	CIS-FS
	T1	Week 6-8	Three weeks of ESM with phone contact first week	
	T2	Week 10	First feedback round with descriptive report + interview	CIS-FS
Start treatment HDI	T3	Week 12	Briefing therapist second feedback round	
	T3	Week 12	Second feedback round with network report (1st or 2nd session therapist) + observation	CIS-FS
During treatment HDI	T4	TBD	Interview with patient (optional)	
	T4	TBD	Interview with therapist	
	T5	≥6 months	Evaluation treatment	CIS-FS (optional)

Fig. 1. Flowchart study procedures.

throughout the day (Bootsma et al., 2021b). Patients with CCRF experience several limitations in their daily life. Along the way, learning new habits (e.g., reorganizing and planning of activities and rest) and adapting their beliefs (e.g., accepting their limits) helps them to deal with this long-lasting problem (Bootsma et al., 2021a). The dynamics, differences, and interrelations of experiences and responses to this complex problem require a person-centered approach.

1.2. What works best for whom?

Among effective behavioral interventions are mindfulness-based interventions (MBIs), cognitive behavioral therapy (CBT), and physical activity interventions (PAIs). Although these interventions have shown to be effective in treating CCRF, it is unknown what works best for whom (Mustian et al., 2017). Gaining insight into the needs and characteristics of individual patients can optimize the psycho-oncological care for CCRF patients (Fisher and Boswell, 2016). Such a person-centered approach can help health professionals to make a shared and personalized decision with the patient on the most suitable treatment for CCRF.

1.3. Network approach and case conceptualization

The network approach to psychopathology as developed by Borsboom and Cramer (2013) has inspired the development of network methodology that can be used to empirically support case-conceptualization by visualization of a person-specific network. This approach conceptualizes symptoms as causally connected elements of a complex dynamical system (e.g. sleep problems trigger fatigue and concentration problems, resulting in feelings of worthless and worrying, which can trigger a depressed mood), rather than viewing symptoms as the result of a latent disease (e.g., you feel depressed because you have a major depressive disorder) (Borsboom and Cramer, 2013). Applying the network approach to psycho-oncology helps to shed more light on the interrelated co-occurring trans-diagnostic symptoms cancer patients often experience and overcome the deep-seated body and mind dualism (de Rooij et al., 2021; Schellekens et al., 2020; van der Lee and Schellekens, 2019).

To date, therapists use case conceptualization as a basis for therapy

and shared-decision making in clinical practice (von Klipstein et al., 2020). Therapists' experience and theoretical knowledge is combined with patients' characteristics and daily experiences to formulate a working hypothesis that, similar to the network approach, encompasses the identification of the patients' unique interrelations of emotions, behaviors, cognitions, somatic states, and context, in order to find the best suitable treatment for this individual. While this method can offer valuable insights for patients and therapists, its reliability appears insufficient because it is not feasible to empirically support the complexity of a case conceptualization. There is no golden standard for such a complex problem-solving procedure and it is sensitive to incomplete and biased retrospective information (von Klipstein et al., 2020).

1.4. Use of experience sampling method and personalized network feedback

A more reliable method to systematically collect data and analyze the interrelations of symptoms, emotion and behavior using the network approach is ecological momentary assessment (EMA). EMA is a structured data collection method in which a participant receives questions multiple times a day for multiple consecutive days about their present feelings, activities, and context in their daily living environment (Delespaul, 1995). This results in a rich longitudinal dataset, making it possible to examine the interactions between symptoms and other factors in a detailed, ecologically valid manner at the level of the individual patient (Delespaul, 1995). By applying network analysis, we can visualize the person-specific multidimensional and complex problem of CCRF. EMA is used in clinical research and practice to optimize treatment of different mental disorders (e.g., depression, psychosis) and has recently been introduced in psycho-oncology (Kampshoff et al., 2019; Thong et al., 2020a; van Os et al., 2017). The use of EMA for patients who experience fatigue during and after cancer treatment has appeared usable and feasible (Kampshoff et al., 2019). So far, two studies investigated the use of smartphone-based EMA followed by personalized feedback for severely chronically fatigued cancer patients. In one case study, the most important predictors of fatigue were identified using time series analysis, which resulted in a different treatment plan (Harnas
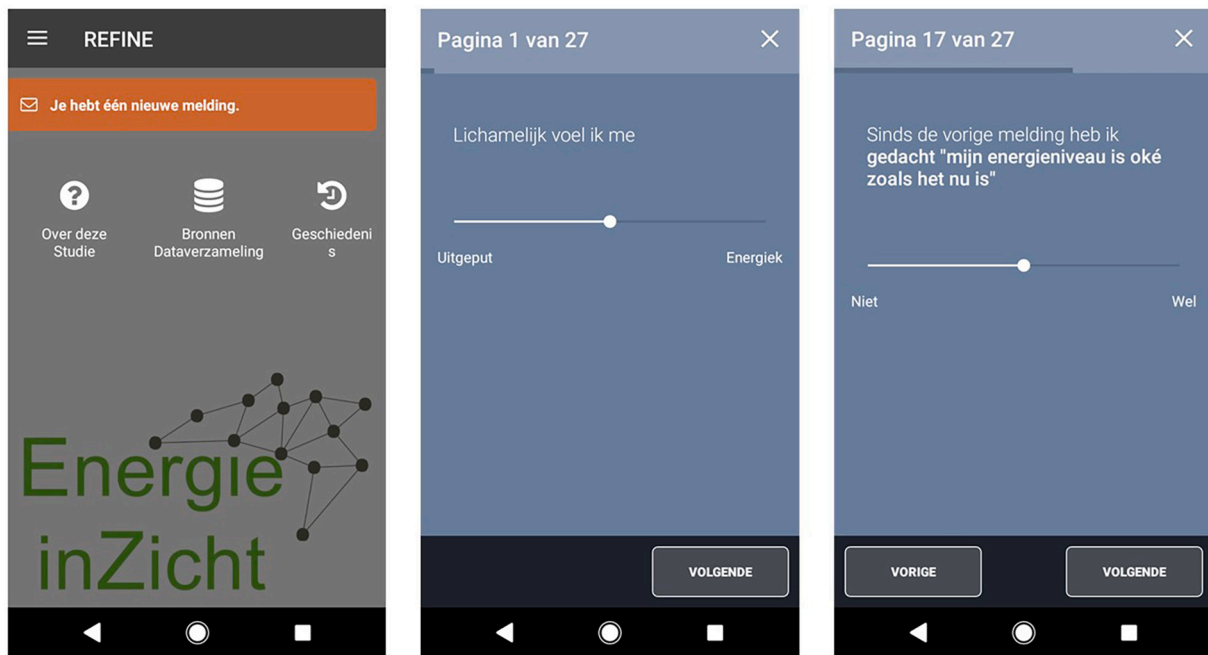
Fig. 2. EMA app *Energy InSight*.

et al., 2021). This personalized treatment plan recommended treating these factors (e.g., fear of cancer recurrence) first during CBT. In another feasibility study, a personalized feedback report based on descriptive statistics and intensive longitudinal data analysis was provided to chronically ill adolescents who suffer from fatigue, and, if possible, discussed with the psychologist or physician to personalize treatment (Nap-van der Vlist et al., 2021). These studies provided limited or no insight in how patients and therapists experience working with such personalized feedback. In the present study, we will evaluate patients' and therapists' experiences and provide personalized feedback reports based on network theory and analysis to investigate personalization of psycho-oncological care for patients with CCRF.

1.5. Aim of study

This current qualitative study focuses on both patients' and therapists' experiences using smartphone-based EMA and personalized feedback in psycho-oncological care of CCRF. The primary aim was to examine to what extent and how a patient gains insight into CCRF by filling in the smartphone-based EMA and receiving personalized (network) feedback. The secondary aim was to explore how this insight can be used to help patients and therapists improve case conceptualization in psycho-oncological care for CCRF.

2. Material and methods

2.1. Study design

This n = 5 proof-of-concept study was part of the routine clinical care of the Helen Dowling Institute (HDI), a mental health care institute for cancer patients in the Netherlands. It was approved by the Medical Ethics Review Committee Brabant (P1935).

2.2. Study procedures

Fig. 1 shows a flow chart of study procedures. Between September 2019 and February 2020, patients on the waitlist for HDI were consecutively selected for participation by their screening therapists (T0). Participants provided written informed consent. We checked the

diversity of participants based on different demographic (i.e., gender, age, educational level, partner) and clinical characteristics (i.e., cancer type and (time since) treatment) and ensured sufficient time before the start of treatment to follow the study procedures. Eligibility criteria included: 1) adult patients $\geq$ three months since the end of curative cancer treatment; 2) severely fatigued (score $\geq$ 35 Checklist Individual Strength - Fatigue Severity subscale (CIS-FS)) (Vercoulen et al., 1994); 3) no current or former severe psychiatric comorbidity; 4) referred to HDI with treatment indication: CCRF; 5) sufficient Dutch language proficiency, and 6) own a mobile phone with an Android or iOS operating system. Participants received instructions by e-mail to install the EMA app on their mobile phone. During the first session (T1) with participants the installation of the EMA app was checked by TB and one participant used a loan phone because of technical problems. While being on the waitlist for psycho-oncological care, participants filled out the EMA items for three weeks (T1). Within a week, they received a personalized descriptive feedback report from the researcher (T2). Before discussing the network feedback with their client, therapists received instructions on interpreting the network figures. At the first or second treatment session, the therapist discussed the personalized network feedback report with the participant (T3). TB observed and evaluated patients' experiences with the EMA app (T1), the descriptive feedback report (T2), and the network feedback report (T3/T4). In addition, patients filled out questionnaires prior to the EMA period (T1), and before receiving the descriptive feedback (T2) report and the network feedback report (T3). TB collected qualitative user experience data from the therapists with the personalized feedback reports during the first phase of treatment (T3/T4).

2.3. Measures

2.3.1. Development EMA items app Energy InSight

The selection process of EMA items was guided by previous qualitative research on the patients' perspective on CCRF, group-level network studies on CCRF, and clinical expertise in treating patients with CCRF (Bootsma et al., 2021a, 2021b, 2020; Bruggeman-Everts, 2019; Schellekens et al., 2020; Wolvers et al., 2021). We selected items that we expected to vary momentarily and measured the experiences and responses to CCRF: fatigue-related symptoms, positive and negative

mood, activity, coping with fatigue, and context (Table A.1). The selected items were described elsewhere (Schellekens et al., 2021). The items were mainly positively framed, e.g., "energy" instead of "fatigue". Fatigue-related symptoms and mood items started with "I feel" or "I am" and were phrased momentarily. Activity and responses to CCRF were framed in terms of "in the past three hours" because that is the average time between two questionnaires. We organized two group meetings with patient experts, clinicians, and (EMA) researchers to discuss, refine, and validate the 24 selected questions of the EMA app named *Energy InSight* (Dutch: *Energie InZicht*). The name *Energy InSight* comprises a double meaning: *Insight* and *in Sight*.

We used the custom-built smartphone app Ethica to build in *Energy InSight* (Ethica, n.d.) (Fig. 2). TB pilot tested the questionnaire with patients and therapists and performed a cognitive walkthrough of *Energy InSight* and instructions (Light et al., 2018). Based on these findings, all documentation and *Energy InSight* were improved, validated, and finalized.

After evaluation with the first three participants, we decided to further refine *Energy InSight* and instructions. Participants reported that the extreme response options (exhausted-energetic) of the bipolar scale of the item "Physically I feel" were insufficiently recognized as an item about fatigue severity. We proceeded with the use of the word "fatigue" and a unipolar scale (not at all – a lot) for this item by the last two participants. We added one negative mood item "I feel anxious", because this was reported as missing. We added verbal instructions on what it means to be physically active (e.g., walking or biking) and mentally active (e.g., reading or administrative tasks) because participants had questions concerning the meaning of these items.

Following the briefing session, the three-week EMA study period (T1) started and the measurements were timed according to patients' sleep-wake schedule (i.e., average wake time during the week and in the weekend). Patients received five EMA prompts per day for at least three weeks at quasi-random time points (i.e., three-hour time windows). Two additional short questionnaires were sent at fixed time points in the morning (questions about sleep hours and quality) and evening (questions about energy level throughout the day, taking naps, and open comment field for personal remarks). Participants had a 30 minute time frame to respond to the beep for the assessment (which took approximately 3 min to complete). In the last week, it was decided whether enough EMA ($\geq$90 assessments) were filled out or whether an extension of a couple of days was needed to analyze reliable person-specific networks (Epskamp et al., 2017; Kampshoff et al., 2019).

2.3.2. Presenting personalized feedback reports

RvW constructed a personalized descriptive and network feedback reports, including verbal and visual feedback. The tone of the text of both reports was descriptive and informative, without giving advice. We continuously improved lay-out, explanation and visualization of figures.

The descriptive report included 1) Fatigue level during the day and throughout the 3-week period in relation to Physical Activity, 2) Concentration level during the day and throughout the 3-week period in relation to Mental activity, 3) Level of Positive and Negative Feelings during the day and throughout the 3-week period, 4) Context and Company in relation to Fatigue. We used different figures: bar charts, graphs, pie charts, and plots.

The network report included the visual display of network models. In a network model, the *nodes* represent the variables (e.g., symptoms, mood) and the *edges*, which are the lines between two variables, represent a positive or negative association (e.g., a partial correlation between two variables). A thicker and more saturated *edge* means a stronger positive or negative connection between two *nodes* (Borsboom and Cramer, 2013). The feedback report included 1) a contemporaneous network based on partial contemporaneous correlations among items and 2) a temporal network based on partial directed correlations including autoregressive and cross-lagged effects. For a description of data analysis, see the preregistered data analysis plan at the Open

Science Framework (https://osf.io/7z69j/) and our case study (Schellekens et al., 2021).

2.3.3. Additional questionnaires

As part of routine clinical care, patients filled out the Hospital Anxiety Depression Scale (HADS) (Zigmond and Snaith, 1983) to assess psychological distress (cut-off $\geq$15) and CIS-FS (Vercoulen et al., 1994) to assess fatigue severity (cut-off $\geq$35). In addition, the CIS-FS (Vercoulen et al., 1994) was used to monitor whether fatigue severity did not increase during EMA period.

2.3.4. Qualitative user experience methods

TB used think-aloud procedures, semi-structured interviews, and observations to assess the user experiences. He has a medical background and previous experience with qualitative and user experience research in psycho-oncology. He took field notes and observed during all study procedures. Sessions were recorded and transcribed verbatim.

Patients were invited to think aloud when using *Energy InSight* (T1) and looking into their descriptive feedback report (T2). Therapists were invited to think aloud when evaluating the instructions during the briefing of the personalized network report (T3). They were encouraged to make both positive and negative comments during their review and pretending that the researcher is not present. If the participant or therapist was quiet for a while, the first author intervened by prompting an open-ended question, for example "What are your thoughts right now?" to maintain the flow of the conversation.

Patients' and therapists' experiences with *Energy InSight* and personalized feedback reports were evaluated with semi-structured interviews (see Appendix C Supplementary materials topic guides), which were held at the patients' home or HDI. After the COVID-19 lockdown regulations in March 2020, all patients had completed T1. The study procedures (T2/T3) with patients and therapists took place online (Teams), and they received all materials by e-mail or post. Patients were instructed that it was not recommended to read their personalized feedback reports before the session and to keep their personalized feedback reports at hand during the online sessions (T2/T3). We used video connections during these online sessions to observe patients and therapists. The semi-structured interviews (T4) were held through telephone or the video platform Teams.

2.4. Qualitative data analysis

Data collection and analysis were an iterative process. The six phases of inductive thematic analysis were followed, based on a realist method to report experiences, meanings and reality of participants (Braun and Clarke, 2006). In the first within-case analysis phase, TB and RvW started with reading and rereading the transcripts of the first participant in chronological order. In the second phase, transcripts of all study time points (T1-T4) were openly coded with MaxQDA (Plus 2020 student version 20.1.0) and a coding framework was developed and continuously adapted (Crowe et al., 2011). The codes were discussed until consensus was reached. The first author continued with open inductive coding of all the sessions (T1-T4) of the four other participants in consecutive order. In the third cross-case analysis phase, the codes were organized into potential themes in the codebook. In the fourth phase these themes were checked with the interview data. In the fifth phase, two group sessions with the multidisciplinary team were organized to identify final themes. In the sixth phase, the manuscript was written with selection of extracts in relation to the research questions and we decided to present one box with presentation of a participant to illustrate the case conceptualization process.

Table 1
Characteristics of five participants.

Characteristics	Sylvia	James	Maria	Cassie	William
Age	31–40	71–80	51–60	51–60	61–70
In a relationship	Yes	Yes	Yes	No	Yes
Educational level	High	High	Low	High	Intermediate
Employment	Fully disabled	Retired	Part-time job	Partly disabled	Sick leave
Tumor type (+metastasis)	Gynaecological +M	Urogenital	Breast	Breast	Urogenital
Time since diagnosis (months)	28	11	49	36	21
Treatment	Surgery, chemotherapy	Surgery, chemotherapy	Surgery, chemo-, radio-, hormonal therapy	Surgery, radio-, hyperbaric-oxygen therapy	Surgery
Time since end of treatment (months)	14	3	29	26	21
Comorbidity	Bowel, musco-skeletal, renal disease	No	No	Thyroid, musco-skeletal disease	Depression, Herpes Zoster
Medication use with fatigue as potential side-effect	Yes	Yes	Yes	Yes	Yes
Prior professional support cancer and/or fatigue	Yes	Yes	No	Yes	No
Start severe fatigue	Since treatment (1–2 year)	Since treatment (6–12 months)	Since treatment (2–5 year)	Since treatment (1–2 year)	Before diagnosis (2–5 years)
HADS (pre-study)	13	9	21	16	25
CIS-FS (pre-study)	49	50	40	46	53
CIS-FS (T0)				41	50
CIS-FS (T1)	42	39	28	37	53
CIS-FS (T2)	39	23	33	37	51
CIS-FS (T3)	45	22	23	33	51
CIS-FS (T5)	37	24	32	24	50
EMA duration (days)	21	24	22	22	21
Compliance (n/N (%))	99/110 (90)	96/119 (81)	91/112 (81)	92/110 (84)	95/105 (90)
Latency time (M (SD))	6.16 (7.44)	7.43 (7.45)	9.89 (8.48)	8.71 (7.44)	4.88 (7.12)
Main problem treatment after EMA study	CCRF	Coping with cancer	Fear of recurrence	CCRF	CCRF

Table 2
Themes of patients' and therapists' experiences.

Patients' experiences	Using *Energy InSight*	Personalized descriptive feedback report	Personalized network feedback report
Negative reactions	Negative reactions and questions of others (Sylvia, James, Cassie)		
Awareness	Self-awareness of body, (dis-)abilities and feelings (Sylvia, Maria, Cassie and William)		
Visibility and acknowledgment of CCRF	Visibility and acknowledgment of CCRF (Cassie and William)	Visibility and acknowledgment of their main problems (all participants)	
Emotional confrontation		Positive emotional confrontation with their current experiences (Sylvia, Maria, Cassie and William)	Emotional confrontation with their current experiences (Sylvia, Maria, Cassie)
Identification and recognition of CCRF		Identification of their main problems (all participants)	Identification and recognition of their main problems in relation to other issues (all participants)
Initiation to change	First steps to behavioral change (Sylvia and Cassie)	Next steps to behavioral change (Sylvia and Maria)	Set goals or change direction for treatment (all participants)
Therapists' experiences		Limited use of descriptive reports (therapist of Maria and William)	Insightful, useful and "accelerator" in treatment (therapist of Maria, Cassie and William)
			Refinement of main problems (therapist of James, Maria, Cassie and William)
			Difficulty to discuss network associations (all therapists)
			Gap between translation of abstract network towards practical use in treatment (therapist of Sylvia and James)

3. Results

3.1. Participants and their therapists

A total of eleven patients were purposively selected from the HDI waiting list. Two patients were ineligible because they had no mobile phone or received active cancer treatment. Four patients declined participation because they expected it would take too much time (n = 2) or experienced improvement of their symptoms during the waitlist (n = 2). Five eligible patients signed informed consent and were assigned to four different therapists. The characteristics of the five participants are summarized in Table 1. To protect the participants anonymity we use pseudonyms. The therapists (three women, one man) were aged between 52 and 63 years old and had varying work experience as a

therapist (2–25 years) and in the field of psycho-oncology (0–8 years).

3.2. Compliance

All five participants completed the study period (Table 1). The average overall compliance rate was 85 %. It took participants on average 5 to 10 min to answer the EMA questions after receiving the prompt.

3.3. Cross-case insights of patients and therapists

Table 2 shows how patients experienced using *Energy InSight* and receiving personalized feedback reports. The use of *Energy InSight* resulted sometimes in negative reactions of others and increased awareness of their present experiences. The *Energy InSight* app and the descriptive feedback report provided visibility and acknowledgment of suffering from CCRF. The discussion of both feedback reports was emotionally confronting for patients and resulted in the identification of their main problems. The network feedback was of additional value to the descriptive feedback because it led to recognition of the (inter)relations of their main problems with other issues. Using *Energy InSight* and its feedback provided individual insights into CCRF, opened a dialogue about their main problems, and initiated steps to behavioral change to learn to better respond to CCRF.

Additionally, Table 2 shows how therapists experienced the use of personalized feedback supporting their treatment. On the one hand, therapists mentioned difficulties with discussing network feedback that were related to lack of statistical background (abstract network), lack of experience as therapist, lack of background knowledge of participant (first treatment session). But on the other hand, they reported the potential of feedback to aid case conceptualization and accelerate treatment by translation of network figures towards practical use in treatment.

The feedback reports showed differences in daily and weekly symptom levels and associations in the networks. These differences were reflected in treatment choice. Cassie, Sylvia, and William started with different psycho-oncological treatments for CCRF and their experiences will be presented in the results section. James' and Maria's treatment changed after discussion of feedback because they learned from the network visualization that CCRF was not their main problem. Cassie's case is presented Appendix B. For extensive description of Sylvia's case, see Schellekens et al. (2021).

3.3.1. Patients' experiences using Energy InSight

Filling out *Energy InSight* was overall positively evaluated, although some participants reported that it was disturbing during conversations with others because they did not want to miss a questionnaire.

Participants experienced an increased awareness of their bodies, feelings, and (dis)abilities. Furthermore, responding to *Energy InSight* increased visibility of their problems with energy levels and led to acknowledgment.

William: "*Yes, you'll actually start noticing what you hadn't noticed before. That's pretty… like for me, at the moment, I'm not seeing myself making any progress. At a certain point I felt like it was producing a lot of the same answers, so you'll feel like you're not actually progressing. And that, yeah, that hits harder, let's put it that way. (…) However, that was also actually a positive experience, because it makes you realize that that's what's going on*".

This awareness, visibility and acknowledgment could help set the first steps to change their behavior in favor of responding to CCRF.

Sylvia: "*This app really forced me to pay attention to my energy levels, which I believe to be a good thing. You really need to take an honest look at yourself and reflect on what you are really feeling and what is going on.*

I believe that that alone had an effect, resulting in me hitting the brakes and listening to my own body more often".

3.3.2. Patients' experiences personalized descriptive feedback report

Participants got more insight in their fatigue experience through the descriptive feedback. It helped visualize the fatigue, which usually remains invisible. Patients described they would share the report with relatives or close friends to increase understanding of their experiences. The personalized descriptive report helped to identify or confirm their main problems.

Cassie: "*The level of fatigue is very high I see. And if you see this curve, I expected more association between physical activity and fatigue. Mental activity and concentration that is also something I noticed. Because of concentration I have trouble reading certain stuff. I recognize this in the report. It is very clear, what my experiences were in three weeks*".

This report was experienced as a positive emotional confrontation with their current experiences and prepared them to set next steps for behavioral change. Patients were looking forward to starting their therapy and handling CCRF.

William: "*Well yeah naturally it's never really pleasant to hear that you've come less far than you previously thought. So that does make you aware of your current situation. I didn't expect that, if I'm honest. But it is good to be aware of your situation because then you know that you need to put in more effort. And the helplines are open, so I hope that this report can be used to make it easier and faster to diagnose and start the right treatment*".

3.3.3. Patients' experiences personalized network feedback report

Participants evaluated the network report as having additional value compared to the descriptive feedback because of the visualization of the relations among symptoms.

Sylvia: "*Yes, I am convinced that the network report has additional value. The descriptive report was, in my opinion, a visualization of the data without relations and the interpretation to give personal meaning. For example, in the morning, you experience a higher level of fatigue than in the evening. This report shows good results but is mainly descriptive. And in the network report, you can see connections or no connections. And I think it's more on the side of interpretation and the real meaning of these things. I think that is really an addition.*"

During the open discussion of the personalized network report with the therapist in the first or second treatment session the meaning of (the relations of) their main problems presented in the contemporaneous and temporal networks were explored and mostly recognized. The discussion of the personal meaning of the personalized network report was again experienced as an emotional confrontation with their current experiences. Discussing the network report helps patients realize they can play an active role in managing their fatigue. It was helpful to set a treatment goal.

Cassie: "*Well, the fact that I can influence it [energy level]. Yes, I can work with it [energy level] and or play with it [energy level]. I have to look at it [energy level]*".

3.3.4. Therapists' experiences with personalized feedback reports

Therapists experienced discussing the network feedback report with their patients as insightful, useful and "an accelerator" in the treatment process.

Cassie's therapist: "*What it brought me is that I gained insights into things I can work on with my client. Because I know what the issues are. So I don't have to look around. I can directly start with therapy*".

Despite the briefing session, therapists experienced some difficulty

with discussing the network associations with the patient. While therapists thought the feedback reports were helpful in refining the main problems, some therapists experienced a "gap" between the abstract network report and applying this during treatment.

Sylvia's therapist: "*At this moment there is no clear relationship in the network with the main problem fatigue. I keep in mind that guilt is a problem and ruminating. But to structure the treatment according to the CBT model of fatigue after cancer as I am used to do, it does not completely match*".

4. Discussion

4.1. Principal findings

A three-week EMA period, while being on the waitlist for psycho-oncological care for CCRF appeared feasible. The EMA monitoring and feedback reports provided patients new insights into their main problems. In turn, these insights can aid patients and therapists in case conceptualization and setting goals for psycho-oncological treatment. Because the feedback reports showed that the complex CCRF network was indeed person-specific, this approach seems well suitable for case conceptualization of patients that suffer from CCRF and/or other psychological problems.

4.1.1. Patients' experiences

Patients' findings of gaining awareness, new insights in to CCRF and initiating behavior change are in line with previous qualitative studies. These studies investigated experiences with EMA and personalized network feedback for the treatment of depression, showing improved coping with the disorder, facilitated communication between patients and clinicians, and informed treatment direction (Bos et al., 2019; Folkersma et al., 2021; van Os et al., 2017). In addition, our patients reported less desirable effects of EMA, such as filling in the questionnaire on "automatic pilot" and receiving negative comments from others. Fortunately, our patients did not experience increased fatigue symptoms due to EMA, which has been reported in previous studies among patients with mental disorders (Bos et al., 2020). However, we should be aware of the burden EMA puts on patients and that the data can be emotionally confronting and challenging to interpret by patients. Involving their therapist and discussing the networks together; can help patients deal with the feedback and increase their insight.

4.1.2. Therapists' experiences

The evaluation among therapists showed several advantages of the personalized feedback reports based on EMA, i.e., they can help refine the main problems and work as an accelerator in treatment. These advantages are similar to the findings from other qualitative studies (Bos et al., 2019). Therapists in our research, however, mentioned some difficulties interpreting network associations with patients and integrating them into treatment. To overcome these difficulties, it could be helpful to train therapists with feedback about the interpretation of network associations in clinical practice (Bos et al., 2019).

4.2. Strengths and limitations

We used data triangulation with multiple sources of data (i.e., observations and (think-aloud) interviews) and incorporated patients' and therapists' perspectives to increase the internal validity of this study (Crowe et al., 2011). All included participants completed the study. A possible explanation for the successful compliance might be the context in which patients responded to the EMA app (Vachon et al., 2019). Participants mentioned that filling out the questionnaires while being on the waitlist is beneficial for motivation. The EMA data collection empowered patients to change their behavior and become actively

involved in their treatment (Simons et al., 2015). Based on the positive experiences of five patients and their therapists in this proof-of-concept study, EMA and discussing personalized feedback seems usable in psycho-oncological practice, however, we should be aware of several limitations. First, although we used purposive selection of participants on the waitlist who suffered from CCRF, in the end, two cases were treated for other psychological problems. Evidently, the findings of this qualitative research, based on a small sample, cannot be generalized. To investigate the effectivity of the use of personalized (network) feedback in the CCRF population a larger quantitative study is warranted. Second, while the EMA items were carefully selected and both patients and therapists considered the items as important in relation to CCRF, we might have missed some potentially relevant items. Offering patients the opportunity to add an item they consider relevant for their CCRF might be a valuable next step in using personalized feedback of network models in clinical practice (van Os et al., 2017).

4.3. Recommendations for implementation in psycho-oncological practice and future research

In order to implement *Energy InSight* and personalized feedback in psycho-oncological practice we need to further automatize the process of data collection and generating feedback reports. Using automated apps, therapists can easily run a script and generate a personalized feedback report for their patients. To further improve user-friendliness for patients, the automated personalized feedback might be incorporated into the EMA app.

The *Energy InSight* app could be connected with actigraphy measurements, to gain a more objective sense of physical activity. Such data would be interesting to use in PAIs and help patients balance their activity and rest.

Based on therapists' experiences, training is recommended to improve the knowledge and take into account precautions of interpretation of network associations (Bringmann et al., 2022).

All therapists and patients agreed that the best moment to discuss the feedback and optimally aid case conceptualization is a second face-to-face treatment session. In this second session, there should be sufficient time to reflect on the meaning of the personalized feedback. Moreover, patients experience no stress for meeting their therapist for the first time and uncertainty about the possibilities for treatment, and the therapist knows the patients' background for interpretation of the networks. Future studies could focus on the feasibility and efficacy of EMA and automated personalized feedback compared to usual psycho-oncological care in a larger sample of patients with CCRF. By using activity trackers and other wearables, the personalized could be extended beyond psychosocial care and also include PAIs. These studies could benefit from a reduction of the EMA items and use only momentarily items to prevent recall bias and include more items in temporal networks.

5. Conclusions

Based on patients' and therapists' experiences presented in this proof-of-concept study, using *Energy InSight* combined with personalized (network) feedback seems a feasible and usable method in psycho-oncological care for patients with CCRF. The use of Energy InSight during the waitlist and personalized feedback with a discussion of the personal meaning of interrelated problems at the start of treatment can provide insights to refine the main focus and direction of the treatment.

Credit authorship contribution statement

MvdL conceived the study and MvdL, TB, MS, RvW, designed the study. TB conducted the interviews. TB and RvW worked on the coding of the transcripts and the qualitative analysis with supervision by MS, JS and MvdL. RvW constructed the personalized feedback reports with

supervision of TB and MS. TB did the final write-up. All authors contributed to, read, and approved the final manuscript.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Financial disclosure statement

The authors have no financial relationships relevant to this article to disclose.

Ethics approval and consent to participate

This study is part of the REFINE project. This proof of concept study has been approved by the Medical Ethics Review Committee Brabant, Tilburg, the Netherlands (P1935). All participants signed written informed consent before the start of the study and were free to end study participation at any time without consequence.

Appendix A

Table A.1
Items of EMA app *Energy InSight*.

	Items	Scale options
Fatigue-related symptoms	Momentary	
1. Fatigue	Physically I feel	0 = Exhausted; 100 = Energetic
1. Fatigue (changed after 3 participants)	Physically I feel tired	0 = Not at all; 100 = A lot
2. Concentration	I am able to concentrate	0 = Not at all; 100 = Very well
3. Motivation	I feel like doing fun things	0 = Not at all; 100 = A lot
4. Pain	I am in pain	0 = Not at all; 100 = A lot
Positive mood	Momentary	
5. Happy	I feel happy	0 = Not at all; 100 = A lot
6. Enthusiastic	I feel enthusiastic	0 = Not at all; 100 = A lot
7. Relaxed	I feel relaxed	0 = Not at all; 100 = A lot
8. Curious	I feel curious	0 = Not at all; 100 = A lot
9. Content	I feel content	0 = Not at all; 100 = A lot
Negative mood	Momentary	
10. Frustrated	I feel frustrated	0 = Not at all; 100 = A lot
11. Agitated	I feel agitated	0 = Not at all; 100 = A lot
12. Down	I feel down	0 = Not at all; 100 = A lot
13. Insecure	I feel insecure	0 = Not at all; 100 = A lot
14. Guilty	I feel guilty	0 = Not at all; 100 = A lot
15. Anxiety (added after 3 participants)	I feel anxious	0 = Not at all; 100 = A lot
Activity	In the past 3 h…	
16. Physically active	I was physically active	0 = Not at all; 100 = A lot
17. Mentally active	I was mentally active	0 = Not at all; 100 = A lot
Coping with fatigue	In the past 3 h…	
18. Pondering	I thought about my energy level	0 = Not at all; 100 = A lot
19. Allowing rest	I took into account my energy level by allowing myself rest (other than sleeping)	0 = Not at all; 100 = A lot
20. Accepting	I thought "my energy level is okay right now"	0 = Not at all; 100 = Strongly
21. Hopeless	I had the idea "my energy level will never improve"	0 = Not at all; 100 = Strongly
22. Control	I had the idea "I could influence my energy level"	0 = Not at all; 100 = Strongly
Context	Momentary	
23. Location	I am	1) At home 2) Elsewhere
24. Alone	I am alone	1) Yes 2) No
25. Company	I am with	1) Partner 2) Children 3) Family 4) Friends 5) Colleagues 6) Health professionals 7) Unknown persons 8) Other

Appendix B

Case illustration of Cassie

Cassie's had no specific motivation to participate other than she was always open to research.

After completion of the EMA period, Cassie reported she realized that fatigue plays a major role in her daily life, while other problem, such as sleep, negative feelings, and fear of recurrence improved. Cassie mentioned a change in habitual behavior. She restarted to plan activities and rest that she learned during group therapy in the hospital.

The descriptive feedback report provided insight into her experiences of the last three weeks. Cassie concluded that her fatigue was more extreme than she had expected (Fig. B.1). She reported that reading the personalized descriptive feedback report was emotionally confronting in a good way, and she gained insights into her problems from the report but did not know what to improve.

Together with her therapist Cassie explored the meaning of the contemporaneous network and found out she responded differently to CCRF at work in the morning and at home in the afternoon (Fig. B.2). Control over her energy level appeared an important node, which was positively connected with allowing rest and feelings of hopelessness (i.e. fatigue will never improve). Cassie realized that in the afternoon at home her energy level is lower and it is more difficult to take her rest when she takes care of her adult son. In those moments she feels the fatigue will never get better. Cassie started eMBCT to search for more helpful ways to deal with CCRF. Based on the feedback report, her therapist would focus on setting boundaries and taking rest during therapy.
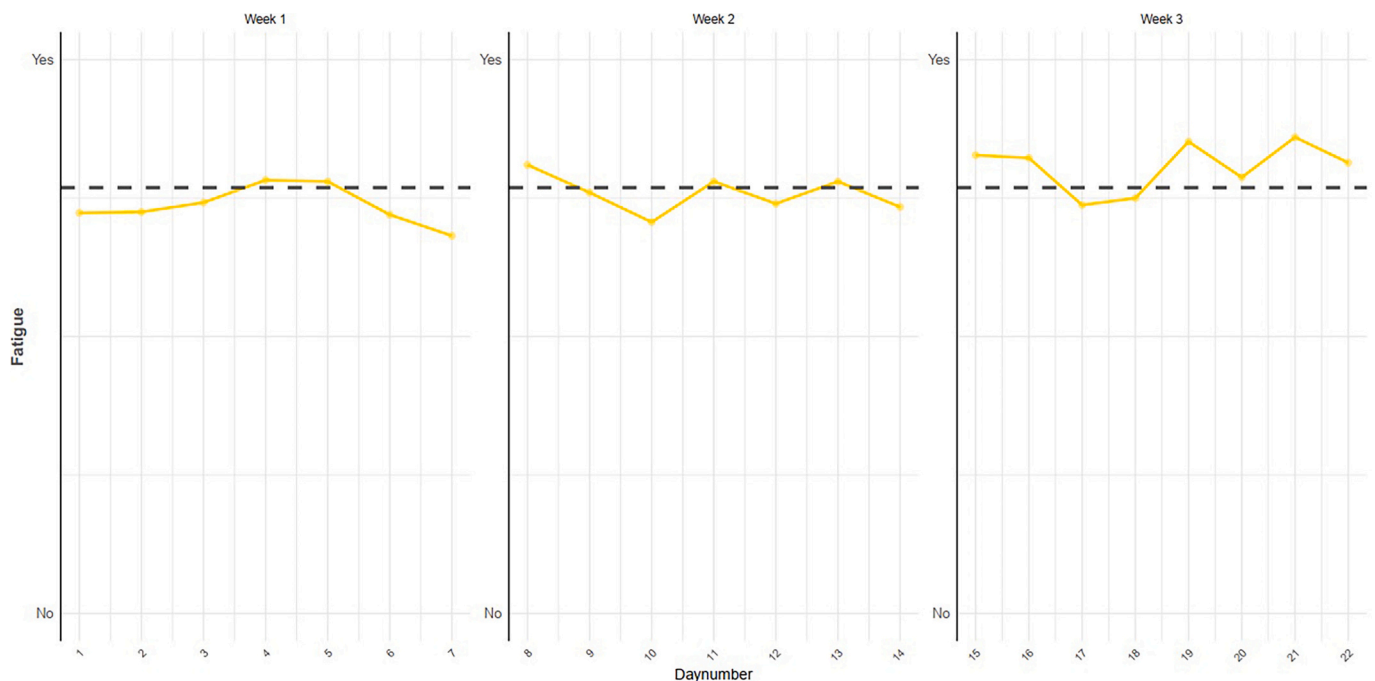

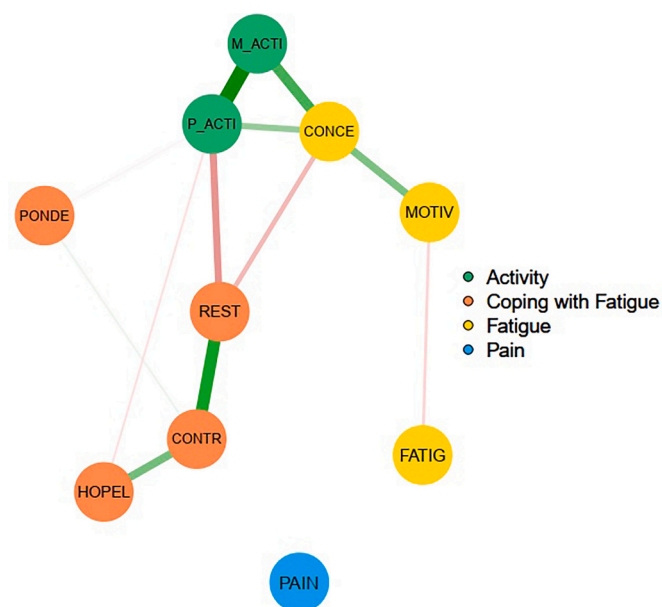**Fig. B.1.** Average fatigue level from day to day of Cassie.

Fig. B.2. Contemporaneous network of Cassie.

Note. A connection between two nodes in this network is based on partial contemporaneous correlation. The stronger a connection between two nodes, the thicker and more saturated the edge. Positive and negative connections are denoted by green and red edges, respectively. FATIG = fatigue; CONCE = concentration; MOTIV = motivation; PAIN = pain; P_ACTI = physically active; M_ACTI = mentally active; PONDE = pondering; REST = allowing rest; HOPEL = feeling hopeless; CONTR = feeling in control.

Appendix C. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.invent.2022.100568.

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