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Abstract

Patient-involved treatment, such as self-monitoring, is a central ambition in health care in Scandinavia. Norway, Sweden, England and the Netherlands have enacted legislation on the patient’s right to involvement [1]. In Denmark, patient involvement is formulated as one of the ten national health goals [2]. Patient-governed treatment is politically articulated as a way to individual empowerment [3]. Nevertheless, doctors and nurses find that many patients express reluctance and a lack of motivation [4]. In line with the political discourse and with an ambition to uncover work-related stressors the authors developed the self-monitoring method Ecological Momentary Storytelling. The purpose of the article is to present test participants’ articulated experiences with using the method. Through a grounded theory based analysis of follow-up dialogues with the participants, the findings emphasize how motivation is not solely anchored inside the individual as a personal desire to master a situation or be empowered. Matters such as complex life situations, inability to handle technology and problems understanding questions posed are to a large extend externally anchored and articulated as hindrances for motivation.

Keywords:

Occupational Stress, Ecological Momentary Assessments, Telemedicine, Sense of Coherence, Grounded Theory, Hearing Loss, Motivation, Methodological Study

Introduction

The use of self-monitoring is playing an increasing role as a solution to prevention and treatment in the Scandinavian healthcare system. Based on a broader understanding of health and illness, which has evolved through World Health Organization (WHO) strategies for health in recent decades, self-monitoring has a strong ideological link to the concept of empowerment [5]. Through the focus on empowerment, the use of self-monitoring is driven by the logic that patients should be experts on their own diseases and that this expertise leads to empowerment [6,7]. Self-monitoring is politically formulated as a way patients can take care of themselves and be released from time-consuming medical visits. The overall goal is for the patient to achieve a greater degree of autonomy and thus, be less dependent on hospital and health professionals [6].

In addition to benefitting the patient, self-monitoring is argued to comply with economic demands in society as successful patient involvement is aimed at qualifying the treatment, reducing professionals’ workload and thus, reducing healthcare expenses [8]. Evidence for the effect of various self-monitoring methods is extensive in the literature, for example, in connection with the treatment of chronic disorders [9] and mental illnesses [10,11]. In much of this literature, researchers conclude that these new treatments have the potential to make the patient a “master of [his or her] own disease” [11–13].

Despite the asserted evidence-based effects, the empowering visions and economic achievements, many self-monitoring initiatives end up as pilot projects and do not become a robust part of daily practices [14]. One reason is that patients are reluctant and lack motivation [4]. In this sense, it seems that there is a discrepancy between the political discourse and practice [15].

A search of the literature on motivational factors and reluctance to practice eHealth, mHealth and self-monitoring shows that the field appears to be dominated by almost everything except a focus on long-term motivation—and especially spontaneous reluctance [16]. The majority of studies focus on eHealth in relation to clinical outcomes and less on patient engagement [17]. In literature dealing with patient engagement in connection with self-governed treatment, the terms used to describe patient engagement are diverse. Patient engagement, or patient activation, has become a generally accepted umbrella term, which positions patients in a central role in their own care [17]. Patient engagement considers patients as consumers involved in a specific sociocultural context as the term is derived from marketing literature [18], and patient engagement, driven by inner motivation, is increasingly considered a crucial factor in the quality of health care [19,20].

The purpose of this article is to evaluate Ecological Momentary Storytelling – a method for self-monitoring experiences of stress. Our ambition is to contribute to the field of engagement and motivation in self-monitoring processes by analyzing which factors the participants in the study articu-
lated as determinant to their positive and negative experiences with using the method. We therefore ask:

Through which norms and interpretative frameworks do the participants understand the monitoring and its output? How is this interpretation related to either staying motivated or developing reluctance?

Background

The self-monitoring method, Ecological Momentary Storytelling, was developed as a result of a collaboration between the authors, who shared an interest in occupational stress. One project had a special focus on communication and stress among hearing impaired people in the Danish work force, while the second project aimed at identifying which discourses on work-related stress were produced in the professional field of teachers.

In addition to having work-related stress as a common subject field, the authors had both a methodical ambition and a methodical frustration that coincided. Both projects originally set out in a qualitative method: We wanted to talk our way into the core of stressors - interact with the relevant actors and through reflective dialogues gain insight in experienced stress issues. Both authors aimed that the studies should give voice to those who have tried practice and possibly stressfulness on their own bodies. After having had several conversations with both teachers and employees with hearing loss, we shared the same thoughts and frustrations. We had gained insight into practice, but at the same time, we had an experience that many of the conversations were sensibility produced retrospectively. The stories outlined events that were often months or years old – told many times before. A story built on memory and ‘backbone sense’ can be fruitful and contain qualities - our memory enables us to actualize a forgotten knowledge and if it was not for this ability to forget and remember we would be left to the madness [21]. However, much research indicates that there are differences between the narratives produced from memory and narratives that reflect spontaneous here-and-now reactions to being in practice [22–25]. How could we deal with these differences? How did we capture both types of narratives? Another problem in relation to understand and capture stressors was a basic assumption that there may also be a silent knowledge of stress - for example bodily reactions that are not observable. The bodily signals can only be felt by the individual - it is a ‘private language’ [26] or a ‘silent knowledge’ [27], which is not always articulated. Therefore, it was crucial for us to develop a method that could provide insight into both spoken and silent knowledge [28]. These challenges became the starting point for the development of the self-monitoring method Ecological Momentary Storytelling.

In developing the method the authors shared an understanding of stress as a phenomenon with several, fundamentally inseparable, dimensions and the development of the stress tracking method was based on a holistic, interdisciplinary and bio-psycho-social stress concept [29]. In an attempt to reflect this understanding of stress, we developed a data-triangulation method, Ecological Momentary Storytelling, in which the theoretical inspiration was taken from the linking of EMA (ecological momentary assessment) [24] such as ESM (experience sampling method) and HRV (heart rate variability measurements), medical sociology and humanistic psychology. The authors also adapted a salutogenic approach to stress and coping [30], which in recent years in health practices in Denmark has been widely applied especially within the nursing area [31].

The Ecological Momentary Storytelling method consisted of three main pillars:

1. Reflective Dialogues: To make the data-logs accessible to the participants themselves we had to create a space for them where they could move from tacit to explicit knowledge. A start-up and follow-up dialogue were implemented as a part of the method. In our understanding of the dialogue concept, we relied on humanistic psychology. We were particularly inspired by Kristiansen and Bloch-Poulsen [32] who define dialogues as unpredictable, risky and exploratory conversations, where there is no predetermined truth and where creations are produced in the interpersonal contact. The goal was to open up new insights and opportunities together. Central to this dialogue understanding is that it is a special way of being present - inspired by Carl Rogers’ three relational concepts: "Empathy, congruence and unconditional positive regard" [33].

2. Ambulatory monitoring: Drawing on existing research on ambulatory monitoring in relation to stress tracking [i.e. 33,34] we chose to log HRV measurements to inform us on physical reactions and possible bodily experiences of stress. The HRV data was used in a qualitative way where peaks and deviances in the data were related to the contexts and the ESM-data and reflected upon by the participants themselves in the reflective dialogues.

3. ESM (experience sampling method): The test persons logged their here-and-now experiences with ESM on a smartphone. This way psychological and also social aspects of a situation were logged and reflected upon in the dialogues.

The authors integrated the salutogenic perspective into the content design by translating the three dimensions of the SOC (sense of coherence): 1) manageability, 2) comprehensibility and 3) meaningfulness [36] into questions on here-and-now experiences of inner balance, overview, and meaningfulness. This was done in order to evaluate the overall ability to handle stressors in the moment of logging. To develop the content of the ESM we used design methods based in participatory design thinking such as a type of cultural probing inspired by a Dutch study on hospital reality from a lying perspective [37] and material storytelling [38]. Through these activities, persons in the target group helped define central issues to address in the ESM. The final design included
logs on mood, energy- and noise-level, experiences with communication and number of people in the room (see Picture 1-3). To anchor each log to something that would support a fairly precise mental reproduction of the different situations during the week and thus lower the risk of memory bias when reflecting on the context of the separate logs in the dialogue session, the option for taking a photo and / or recording 10 seconds of sound was present. The method was developed and user-tested during 2012 – 2013 [12].

![Picture 1-3: The images show screens of the application, where activities and experiences can be logged throughout the day. Picture 1 (from the left) shows the screen where you can register the activity you are engaged in, as well as add text. Picture 2 (in the middle) shows the screen where you can log the experience of the energy level, the number of people in the room and the mood. Picture 3 (right) shows the screen where you can log SOC by recording an assessment of whether you feel balanced, have an overview and feel what you are doing is meaningful.](image)

**Participants**

Contact to the 48 persons with hearing loss who volunteered in joining the project was established through the National Hearing Association in Denmark. The association informed their members about the opportunity to take part in the study, and interested members then contacted the project by e-mail. Eight participants were picked from the group. Participant criteria was that there should be some degree of hearing loss present and that the person should be engaged in work if not for full hours then at least some days during the week. This standard was important because a focal point of the study was to examine the effect caused by a hearing loss in work situations as a part of daily life. The eight hearing-impaired participants were between ages 43 and 64. Two participants withdrew from the study after only a couple of days due to technical challenges, and therefore the participant age for the remaining six ended up being 50-64 years. The results from this study therefore indicate contexts of importance particularly among this group but may be significant to the entire group of people with hearing disabilities in the working age. Three men and three women with hearing loss were represented in the study. The six participants were engaged in the study one week each during 2013 and 2014 and the data material exceeds 2000 hours of HRV-measurements, experience-loggings and follow-up dialogues.

**Method**

The data, which is analyzed in this article, is based on the dialogues following a week of data collection with the Ecological Momentary Storytelling method [39]. In the follow-up dialogues, the participants reflected on daily activities based on the HRV and ESM data. To reach an understanding of the multiple contexts that affected momentary experiences throughout a day, we decided to code the transcribed dialogues using grounded theory [40]. This inductive approach to data was originally developed to counterbalance the deductive and positivist sociological method of validation and verification of existing theories, which in several cases proved insufficient when attempting to describe what was really going on in a certain sociological context [40].

The analysis of the transcribed dialogues happened through three levels of coding: open coding, selective coding, and theoretical coding [40]. In the process of open coding, detailed reflections from the dialogues as well as different topics that were touched upon through the dialogues were divided into a large number of subcategories. In the second coding process, the categories were merged into more superior categories, and at the same time, notes were taken on how the different categories appeared to be connected. All categories were subsequently examined in a third layer of coding through citations from the dialogues in order to understand the nature of the contexts better. This was also done to reach a conceptual understanding of the correlations that merged into theories and models describing the challenges and possibilities of combining hearing loss and work life [41].

The categories that represent reflections on the method, technology, and usability are to be found in Table 1. These categories have emerged through two levels of coding. Here, the categories concerning ‘Role and identity’, ‘Control’ and ‘Biopsychosocial contexts’ are greyed out as our focus in this paper is on the categories concerning the method in order to evaluate different aspects of this: 1. The process of data collection, 2. Data as an indicator for here-and-now experiences, and 3. Assistive perspectives of the method. In the following, the categories undergo a third layer of coding when looking into the participants’ reflections related to the three categories.
Results

The results will be presented as a summary of the main categories concerning the method identified in the coding of the data, accompanied by representative quotations from the participants.

The process of data collection

Some participants were excited about the technical aspects of the method. The gadget effect was particularly dominant among a group of the participants who were eager to get their hands on the devices, put on the HRV electrodes and find out how the ESM system worked. They did not show signs of nervousness and tried to fix technology breakdowns themselves during the week, either alone or with help from their spouses. One participant expressed a level of flow using the technology: “After the first day, I just started logging when the phone buzzed...I just logged how I felt at that particular moment.” He seemed to stay at this level during the rest of the test week despite several technical problems, which for a short while sent him back to a level of mixed experiences and then allowed him to reach flow again after the problem was solved.

However, and in line with existing findings, we also experienced that technology breakdown can make people feel powerless [42]. Some participants were nervous about being alone with the system during the test week. They expressed insecurity and even anxiety about what to do if the system behaved differently from what they expected or if a technology breakdown occurred. These observations are in line with studies on care technologies, where technologies that have been designed to provide care sometimes end up having the opposite effect making patients feel alienated and even causing anxiety and anger [42,43].

During the test week, the developers continuously updated the system. However, some updates decreased usability to such an extent that one participant became frustrated although she had started the week with great enthusiasm: “The latest update was quite bad” and “It is unsystematic when it crashes.” In addition, the participant expressed her concern that the technical issues might have affected her mood and some of her answers during the experience logging.

A participant stated, “It took a little getting used to all the equipment, as people with hearing loss already carry around a whole lot of gear1. It was kind of a stress factor for me at least on the first day.” This quick resolution indicated that some of the problems had to do with getting comfortable with using the system. However, in some cases, the technical challenges became too overwhelming and caused the participants to become frustrated or even unable to register experiences in the ESM. In several cases, they described the log-activity as a burden rather than a gift: “I couldn’t turn it off during the night, and it was lying on the table buzzing until it fell on the floor... It was really annoying.”

One of the two subjects who had to end the test prematurely because she felt that she was carrying too many technical devices around seemingly found it more difficult than another participant who carried around the same number of technical devices. The participant who ended the week prematurely had recently received cochlear implants and was getting used to the new hearing devices, and she was still in some pain after the operation. She was also in a stressful work situation as she was a trainee at a company as a part of her education, and the relationship with her immediate superior was not going well. This story indicates that there has to be some degree of stability in the lives of the participants for them to follow through with the test. In this case, the mindset depended highly on the resources available to the participant.

Data as an indicator for here-and-now experiences

Intensive data logging was necessary in the setup, as we wanted to be able to compare the detailed connection between the HRV and the momentary experiences. In addition, memory is potentially biased by time [44,45] and by logging experiences in the present moment, we believe that the participants remembered more precisely what had actually happened and what they felt at a particular moment. Logging the data did actually seem to help the participants remember - a participant stated, “The picture [the visual representation of

1 Persons with hearing loss, who are fitted with hearing aids, cochlear implants or other hearing devices, often also have an FM (frequency modulation) system, which is a wireless sound transmission method to i.e. improve the sound from the television and from people talking.
the online data] fits very well with how I experienced the various situations.”

All participants were curious to see how the HRV data reflected different activities. One participant was particularly curious to see whether feelings of frustration would show in his HRV data when he was engaged in a task that he felt was a waste of time. Another participant was curious to find out whether a specific situation, which drained her, would be traceable in the HRV data. There were also comments like “It’s a lot of fun looking at your sleep pattern in your HRV”. These comments indicate that the participants were enthusiastic when they looked at the HRV data, but the comments also tell us that the participants suspected certain situations to have an effect on not only their mental state but also their physical state. They were curious to have this suspicion confirmed or rejected through gaining an insight into their bodily reactions.

What seemed to be connected to the participants’ motivation was whether they could relate to categories and questions in the ESM. There appeared to be a correlation between a clear understanding of the purpose and the relevance of the questions and an acceptance of the data showing “the real me”, which often led to constructive reflections on life circumstances and possible ways of creating change. In cases where the participants expressed an understanding of the categories and questions, they often interpreted the ESM-data as consistent with the physical and mental state they remembered to have experienced. One participant stated:

In general, I can say that I have been confirmed in the feeling I had of my mood for the most part is good. And then I also think that the context I’m in, and the people I'm together with on a normal working day and in my spare time generally have a positive influence on my mental and physical balance.

Another participant stated:

It’s really nice to see how fast my body relaxes after such a conflict [...] I’m a bit surprised that I seem to be so relaxed while teaching because I often have to ask students to be calm and quiet. So, it’s good to see that I’m still calm.

In both quotations, there seems to be a pattern: The participants interpret the measurements as something that can document a particular reaction or condition and thereby capture a here-and-now experience. The monitoring is not only used to “spot the self” but also to confirm “yes, that’s right—this is actually how I feel”. This experience of documentation seemed to be very motivating and led to further monitoring. The participants felt that the monitoring device was actually able to reflect their state of mental health and the situations and context they were a part of which created a meaningful setting.

In some cases, the participants had difficulties understanding the categories and questions. One stated, “I’m not sure how to answer the question of ‘overview.’ How should it be understood? Is it my own sense of overview, or is it my expectation of others’ experience of my overview?” Another participant said, “I think the categories get abstract, and it’s hard to know how to answer the questions correctly.” In both cases, the difficulties and reflections about how to answer the questions correctly had an impact on the participants’ interpretation of the data from the monitoring. If doubt arose about whether the questions were answered correctly, the measurements were not considered a correct reflection of the condition of the participant. The participants experienced the measurements as demotivating, which led to a loss of belief in the devices and the ability to use the data.

**Assistive perspectives of the method**

Based on Antonovsky's salutogenic approach [30], each test course was initiated with an individual conversation, in which the test person set a personal goal or identified a particularly important topic, which could be a focus during the week of monitoring. All participants expressed a high degree of motivation for using the method to increase awareness of the processes and reactions in their body and mind, and it seemed very easy for the participants to identify something they were curious about regarding their own patterns of behavior and well-being.

A general reaction when the participants dealt with their own physical and mental measurements seemed to be that the participant positioned himself or herself outside his or her own experience and responded to it with a new experience, such as surprise. The monitoring became a way of seeing oneself through a second-order observer position [46]. A participant stated:

I’m surprised that I had so much energy when I worked every night in the week leading up to the deadline Friday. On the other hand, I was completely exhausted Saturday. I have not really thought so much about how exhausted I am both physically and mentally after such a deadline is reached.

In this quote, the participant stated he was surprised by his own bodily and mental reactions to the workload he had experienced during the monitoring period. He acknowledged that the period had been stressful, but he became more aware of the degree of strain after he was confronted with the bodily and mental fluctuations the monitoring showed. He articulated that the self-monitoring data had been a new way to understand and reflect on how his work tasks and work hours affected him physically and mentally.

For this participant, the new insight became a positive motivational factor. He experienced empowerment, which led him to further desire to monitor. As he put it:

Everyone should have access to this! I map many of the activities I do—use my calendar a lot. Here it is interesting for me to see how my body reacts, for example, when I work in the evening, go for a walk in the city or after an important deadline. Not everyone uses a calendar the way I do, and for those who don’t, I think that this type of questionnaire is a great way to remember what you have been up to.
Other participants expressed the same feeling of empowerment and gain of new insight that made them stay motivated to monitor. Another example was a participant who feared a specific meeting with her manager, which, for her, was associated with major conflicts. Her mental reactions before the meeting were characterized by feeling depressed, having low energy and being generally unhappy about attending the meeting. Subsequently, the physical measurements showed that her body was surprisingly very calm during the meeting. She expressed her interpretation of the measurements as follows:

I was excited to see how my body responded when I had to confront my manager with a problem I needed to talk to him about. I was surprised that I was so calm, and there was nothing at all to see at my heartbeat. It’s a problem that has been haunting me for a long time, and the monitoring actually gives me energy to continue the struggle to get my manager to understand how I feel.

For this participant, seeing that her body apparently mastered the situation was an eye opener. This experience motivated her to continue the monitoring in order to reflect on how especially negative expectations could lower her energy level. She used the insight to work with her expectations in similar conflict situations, and she saw it as a reason to talk with her manager about specific situations in which she experienced a similar mental pressure.

However, not all participants had the same positive and motivating experiences when they looked at their physical and mental measurements. For some, the increased awareness seemed to be connected to concerns, which led to reluctance. A recurrent pattern among these participants was that they not only interpreted their current condition but also widely used the measurements to assess the risk of more negative potential health issues both physically and mentally. A participant articulated this topic as follows:

I have a feeling that some things that the body absorbs and reacts to affect me. Because I can sometimes be so extremely tired—not physically but mentally…and I do not always understand why. I think that’s because the body has reacted in situations that I wasn’t really aware of and then I think: now that we’ve been wearing that heart rate monitor… is my heart also working overtime?

In this statement, the participant reflected on the question, “Is there something wrong with me that I have not been aware of?” The pattern of interpretation relates to a current condition but also to a potential negative condition. The increased awareness did not lead to sound thoughtfulness but to a kind of pathologizing where the risk of the potential undesirable condition invariably lurked around the corner. This way of understanding and interpreting the data seemed, for some of the participants, to lead to an understandable reluctance.

Conclusions

In this article, we have explored participants’ experiences using the self-monitoring method Ecological Momentary Storytelling. The incentive to investigate the participants’ experiences was, as mentioned initially in the article, an apparent gap between political ideology and the use of self-monitoring in practice. On the one hand, the use of self-monitoring is articulated as a way to empower the individual. On the other hand, it seems to be connected with difficulties to carry this empowerment out in practice. Health professionals experience how some patients resist and many projects using self-monitoring never become a long-term part of practice but stop at the pilot project stage. The majority of studies that deal with evaluation of self-monitoring efforts focus on either effects or economy. Our ambition with this study was to provide a qualitative contribution focusing on the participants’ expressed experiences. We therefore asked the question:

Through which norms and interpretative frameworks do the participants understand the monitoring and its output? How is this interpretation related to either staying motivated or developing reluctance and/or dropping out?

Based on grounded theory, the participants verbalized experiences were divided into three main categories: 1) The process of data collection. 2) Data as an indicator for here-and-now experience. 3) Assistive perspectives of the method

There was apparently no correlation between the technical skills, which the participants possessed, and the ability to complete the test week – but technical challenges with the program crashing and the smartphone acting unexpectedly, clearly caused reluctance and even stronger feelings, like anger and irritation. This underlines the importance of interpreting the technology as reliable and as a relevant dialogue partner in order to stay motivated. The platform design should support and be flexible to a broad type of individual preferences and technical introduction and assistance should be available.

The findings also indicate that the interpretation of using the technology as a relevant dialogue partner is strongly connected to the experience of understanding categories and questions appearing on the mobile device. In cases where the participants expressed a clear understanding of the questions and categories, they also expressed confidence in the data showing a ‘real me’ and a true representation of their here-and-now experiences. This was clearly a motivational factor, which emphasize the importance of thorough introduction to basic concepts and underlying logics on the questions on the mobile device before the monitoring starts. Confusion about how to understand or answer specific questions often led to demotivation and lack of interest.

Regarding the participants’ articulated experiences of interpreting the method as assistive, most of the participants regarded the method as a fruitful and helpful way of gaining and maintaining insight into own patterns of behavior and level of energy in connection with everyday life activities. They expressed how the new insight led to further motivation.
for monitoring, because the data led to a new opportunity for changing existing negative patterns. In some cases, however, the insight did not lead to a positive awareness. Part of the participants interpreted the data with increased concern, wondering if the data showed any first sign of a negative development in their health and well-being. For some of the participants this increased concern led to declining motivation. For some of these participants motivation for monitoring was maintained, but in a way which appeared to be more pathologizing than empowering.

**Discussion**

Retrospectively, it has become clear to us how we, in the development of the method, were linked to an existing discourse on health and treatment. Establishing a methodological framework with inspiration from Antonovsky and Rogers, the focus was kept mainly at the individual and the individual's own opportunity to free up his potential and master the challenges he faced. In these methodological approaches, the basic assumption is that the individual is capable of coping, by increasing awareness of the management of energy in everyday life, and by gaining a meta perspective on both silent and spoken narratives. This means that the contexts and challenges anchored outside the individual is more or less absent. For example, we do not consider whether the test subjects actually face "unreasonable task overloading" or double-binding situations, which could be part of the focus in more context-oriented approaches to stressors [47].

It is important to emphasize that our study was not carried out as a part of the health care system and the participants were not diagnosed patients. Nevertheless, we believe that the above findings may help raise questions about the new forms of practice that emerge in the wake of the political discourse. As described initially, empowering the individual is a central political concept in the existing health promotion and treatment discourse. However, as the findings point out, being motivated or reluctant towards self-monitoring is not always anchored inside the individual. It is not only a matter of ‘individual mastering’, setting a goal or having a personal desire to be empowered. Based on the participants’ experiences being motivated or reluctant often reflects matters, which are anchored outside the individual; A complex life situation, experienced ability to handle and make technology fit into everyday life and the experienced resources to understand questions and categories posed on mobile devices. Another part of the findings shed light on how the increased awareness on body and mind seemed to be a double-edged sword leading both to experienced empowerment but also, for some of the participants, to increased concerns, which was pathologizing rather than empowering.

In continuation of these findings, it is relevant to address issues such as: How do we ensure that self-treatment takes into account complex life situations and varying individual resources? Moreover, how do we ensure that the individuals offered this form of treatment are those who can profit from it through experienced empowerment?

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