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Caught up in Care: Crafting Moral Subjects of Chronic Fatigue

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ABSTRACT



Patients with chronic fatigue receive advice to improve symptom management and well-being. This advice is based on ideas of self-management and is conveyed during clinical assessment as “activity regulation.” Based on ethnographic fieldwork in a hospital clinic in Norway, we show how these patients attempt to demonstrate their competences and everyday concerns, and how the ideology of self-management frames the hope for recovery and crafts a subject with the ability to improve. Patients, however, linger between everyday social predicaments and ideals of healthy living, and are caught up in cultural models of care that deflect everyday concerns and agency.

KEYWORDS

Norway; chronic fatigue; activity regulation; agency; moral codes; self-management

The notion of healthy citizens and the idea of one’s health as the enterprise of oneself and an individual endeavor is central to new public health and many medical approaches to treatment and intervention. Several studies have pointed to a new link between public and private life spheres in the management of health. Monica Greco argued early on that every subject possesses the ultimate responsibility for illness, and disease becomes a function of moral qualities of the individual, imposed as a “duty to stay well” (Greco 1993: 370). She further contends that with the change from disease to risk comes a need to see everything as healthy, and that to “prevent” becomes to “cure”. However, that duty to “prevent” comes to rest with the individual, as a personal preventive ability (Greco 1993).

These moral implications are crucial to individual citizens and health professionals. For patients, health becomes a vehicle for self-performance and subjectivities that possess the faculties of mastery, will, and choice. Such faculties may be nursed and operationalized, and health professionals employ the established notions of self-management and self-care specifically to address individual responsibility in the name of patient-centeredness and empowerment (Salmon and Hall 2003). This has moral implications for being a patient in this study, in which we critically investigate the enactment of self-management when diagnosing chronic fatigue in Norway. For chronic fatigue, we find that symptom management and self-care through individual regulation of daily activity (otherwise known in clinical guidelines as “pacing” but phrased as “activity regulation” in a Norwegian context) is a core focus of self-care advice from the involved professionals, mediated and configured by the rationale and technology of self-management. Our aim in this study is to examine critically how self-management advice contributes to the constitution of a particular personhood, precipitating an agency that places individuals in a moral dilemma between the social rules of their everyday lives and the rules of self-care.

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Media teaser: Patients with chronic fatigue are recommended “activity regulation” to recover. They may be caught between everyday predicaments and ideals of healthy living and remain suffering.

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The diagnostic process as a vehicle for self-management

Diagnoses are important vehicles, used to legitimate medical authority, facilitate particular clinical decisions, and to constitute in turn the reality they discern (Rosenberg 2002). Diagnoses classify, label, define, and predict; they create social order, organize illness, and provide explanatory frameworks (Jutel 2011). Diagnoses, however, are also constructed, and the way they seek uniformity carves up the world into bits and pieces, some to be used and some to be left out (Smith-Morris 2015). Diagnostic controversy is inherent to that process, and when it comes to contested disorders such as Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME), the classificatory system is challenged and subsequent treatment becomes questionable.

Very few studies exist on the actual process of being diagnosed with CFS/ME. In one study from the UK, researchers interviewed general practitioners on their role in making the CFS/ME diagnosis, showing how they found it difficult to attribute the label “CFS/ME” to patients and mainly saw their role as excluding other known physical causes (Chew-Graham et al. 2010). A recent focus group study involving general practitioners in Norway explored the logic underlying diagnostic accounts (Rasmussen 2017) and found that balancing anticipated consequences with medical accuracy was central. Hydén and Sachs (1998) did an observational study, including qualitative interviews with doctors and patients, on the diagnostic work of assessing chronic fatigue in Sweden, examining the process toward diagnostic outcome.

A fairly substantial body of qualitative studies deals with patients’ experiences of living with CFS/ME and their illness perceptions and identity processes. This is summarized in a review by Anderson et al. (2012), while an earlier synthesis concentrates on how patients’ identities are challenged and jeopardized (Larun and Malterud 2007). From these reviews, we learn more about the social and personal courses of having chronic fatigue, especially marginalization processes (Ware 1992, 1999), identity trajectories over time and narrative typologies (Whitehead 2006; Whitehead et al. 2016), identity transformation (Asbring 2001), creating personal accountability, making sense of a diagnosis, and making sense of “place” during illness (Horton-Salway 2001; Lian and Rapport 2016; Sachs 2016). A study by Clarke and James (2003) critically analyzed how a contested diagnosis contributed to a radical transformation of the self, an alternative identity developed after diagnosis in the absence of legitimizing discourses in their social surroundings. All these and other qualitative studies deal with phases of being “under illness” and “after diagnosis,” but few studies deal with patients “under diagnosis” and its implications for the formation of subjectivity.

Self-management

Self-management approaches to health and illness are based on promoting and supporting a patient to regulate behavior in a direction perceived as healthy. Understanding what motivates health behaviors is an important task for health professionals. Basic psychological needs such as autonomy, competence and relatedness to others may facilitate individual motivation toward change (Ryan and Deci 2017). Closely linked to the concept of motivation is hope (i.e. the belief that recovery is attainable) (Snyder 2000) and self-efficacy (i.e. the perceived capacity to cope with a situation) (Bandura 1977), which also permeates the self-management approach. Adding to this psychological perspective, self-management has been discussed in a critical vein in anthropological and sociological research. In line with Greco (1993), Salmon and Hall (2003), for example, discuss how a discourse of coping and control has transformed the patient from a sufferer into an agent, shifting responsibility from the professional to the patient. This connotes with speaking of the mastery of the self as a prerequisite for health, which then makes the lack of mastery a “disease,” a failure to take care of oneself (Greco 1993: 361). Possible disease becomes a moral, personalized problem, and “moral aptitude” becomes a sign of mastery and responsible agency, fulfilling the duty to stay well. Self-management rests on these assumptions of health and, with Brodwin (2017), we contend that it is closely linked to dominant political discourses on individual autonomy and rights, internalized in neoliberal notions of the person. Additionally, we

see self-management in the light of Foucault's work on the "technologies of the self," which refers to technologies by which individuals may effect specific operations on their way of being, bodies, souls, and thoughts to obtain a certain desired state of being (Foucault 1997). Such technologies produce and create human beings as particular subjects, depending on the historical and political contexts that justify a specific governance; for example, regimes of health and healthy bodies.

This subject formation may however appear in different ways relative to the individual life world, disease and situation. In the case of, for example, diabetes or COPD (chronic obstructive pulmonary disease) patients, self-management has a clear focus on technological use of specific devices for medication complemented with an evidence-based list of what types of life style changes patients should enact. Still, diabetes patients are shown to tinker with this responsibility and experiment with technology to tailor it to individual needs (Hinder and Greenhalgh 2012; Kingod 2020). COPD patients engage in self-treatment, but how depends on their concerns regarding medications and a concern about responsibility (Laue et al. 2017), and they display subjective experiences of negotiating their everyday challenges, not always aligned to conventional patient agency (Oxley et al. 2019). For other patient groups, we learn about specific models of governance within self-management and their different impact. Sandra Hyde (2017) presents how a philosophy of self-regulation and its therapeutic methods is used for patients in a rehabilitation clinic in China for drug addiction, and her study shows that, in the end, residents credit the psychological technologies and the therapeutic regimes that encourage subjects to effect a transformation, regardless of whether they succeed or fail. Angela Garcia writes about drug rehabilitation as well, but from a detoxification clinic in New Mexico, USA (Garcia 2010). Her emphasis on care and treatment centers on the institutional claims of the clinic, and through an analysis of the logics, routines, and practices of medical regimes, she shows how a medical regime constitutes a phenomenon (heroin addicts and addiction) and its subjects (Garcia 2010). These examples point to differences in the content of self-management and in the degree advice is being adapted, i.e. how governance and responsibility is applied in everyday life. The patients with chronic fatigue in this study are characterized specifically by having either no diagnosis or a diagnosis that does not prescribe treatment as such, but recommendations of symptom management. They struggle with legitimacy of their sick role, clinically and socially, and are on their own in many respects, trying to cope with both social life and health systems from which they hope for help. However, with self-management as the central offer, the discourse of self-managing illness risks locating responsibility with patients by constructing them as active agents in the name of empowerment (Salmon and Hall 2003).

Agency

Agency is about acting and doing, referring to individuals being "intentional, individual, rational, and normative" (Honkasalo 2009: 62). These notions of agency we argue are inherent to self-management, in which agency denotes the creative capacities of individuals, including their ability to resist "larger" structures or constraints (for example illness) through mastery of the self (Greco 1993; Ortner 2005). We show how these qualities guide the self-care advice and support offered to patients in this study, and we will discuss how they connect to the presentation and recommendation of "activity regulation." As a technology of the self, patients buy into this advice on self-management, whether in full, reluctantly, or through modulating it. Indeed, patients constantly refer to their social concerns, relationships, situational challenges, commitments, and options from a context in which agency is less about individual qualities, intentions, and capacities, and more a dimension of contingent situations and social practice (cf. Laidlaw 2010). The notion of agency may therefore not be entirely clear-cut. We agree with Honkasalo (2009) who argues that when performing everyday actions that are repetitive, quotidian, and practical, e.g. as acts of enduring with neither visible intentions nor possibilities of social change, we may still talk about agency. On the one hand, we depart from what is crucial to agency in self-management: the inner capacity of an acting individual to perform and will social transformation. On the other hand, we explore other ways of understanding agency, enacted in

the encounter between discourses of self-management and ordinary life, where the “fighting agent” is less prominent than the enduring or the suffering.

Personhood

Both agency and subjectivity (Biehl et al. 2007) inform the idea of person and personhood (see, e.g. Appell-Warren 2014; Carrithers et al. 1985). Suffice it here to state that discussing personhood we refer to the social dimensions and social definitions of what constitutes oneself and how one practices and lives with social relations. Being a person is not a given but is negotiated in specific times and places and in reaction to varying situations and social relationships. Nevertheless, it is tied to specific social roles and moral responsibilities (Mauss 1985 [1938]) as well as to rights and duties, and faculties of reason and communication (Desjarlais 1999). In this study, we see a close link between the formation of subjects enduring chronic conditions and satisfying situational, local norms of moral responsibilities and judgments. Notably, Zigon (2010) described in a study of a drug rehabilitation program in St. Petersburg how the rehabilitants learned and achieved a new moral personhood in a mutual therapeutic process, one that supported them to live in the social world and “fit” with the self-responsibility and self-vigilance expected from good neoliberal subjects (Zigon 2010). Buchbinder (2011, 2015) demonstrated how personhood may be enacted through diagnostic techniques that serve to categorize selves-in-the-making and have moral implications for care and recovery (Buchbinder 2015). These implications induced a transformation of moral personhood deriving from the moral and relational entailments of social categories or clinical typologies. Looking at diagnostic processes or self-care advice to understand this entailment particularly calls for a critical attitude to how agency, personhood, and subjectivity become intertwined (cf. Buchbinder 2011).

Our argument here is concerned with the links between agency, personhood, and subjectivity, and we suggest that self-management advice not only encourages a certain kind of agency but also dismisses a less acknowledged agency mode. This we contend brings on radical consequences for patients, constituting both moral subjects and defining patients’ personhood. The available interpretive repertoires afford only certain subject positions and we argue that chronic fatigue patients become caught up in the affordances of care while challenging the ordinary logic inherent in self-management, which risks increasing their marginalization rather than empowering them. Our aim in this article is to explore how a diagnostic process enacts these affordances of self-management through the interaction of health professionals and patients, how “activity regulation” becomes a vehicle for the constitution of certain moral personhoods and moral priorities, and how both troubled and untroubled subjects are created in clinical encounters.

MATERIALS AND METHODS

The study

Over a 3-month period of fieldwork in 2017, the first author observed patients during consultations with health professionals belonging to a special multidisciplinary team at the university hospital in Tromsø, Norway. The team had as its specific task to assess each referred patient and reach a diagnostic decision, whether the patient could be diagnosed with CFS/ME, or if the patient’s complaints were best explained by another diagnosis. Following a decision on either CFS/ME or another fatigue diagnosis, the team would offer self-management in terms of coping courses, e-learning platforms, and detailed advice on how to improve a balance in daily activity. The study was designed to explore questions about the course of a diagnostic process in a team of professionals, especially the negotiation between health professional and patient, and the presentation of symptoms by the patient and their mutual interpretations and understandings. What triggered our attention early on in the fieldwork was the way talking about “daily activity” pervaded all consultations, even before a diagnosis was reached. It was both part of the diagnostic criteria, central to all encounters, and part of

the advice on self-care, framing the understanding of the patients' complaints. Management of activities and a specific way of talking about activity became the pivotal point for how to improve the present situation for most patients, regardless of which fatigue diagnosis. This approach, based on "activity regulation", made us realize the power of talking about "activity" as central to both assessment and self-care advice. Both health professionals *and* patients referred to highly valued cultural norms pertaining to activity, however in different ways. Here we explore how these discursive positions permeate the intersubjective diagnostic process. Hence, we do not concentrate on the diagnostic *decision* process but on the logics and particulars of self-management that run through the clinical sessions and eventually frame the understanding of chronic fatigue and patients with chronic fatigue.

For the study, we used an ethnographic fieldwork approach with observations of the multidisciplinary team and of consultations over a period of 3 months, undertaken by the first author (Wolcott 2008). On the assessment days, the first author presented herself at the clinic and asked patients for their consent before the consultations began. Staff had already given their consent prior to this. The first author observed 48 consultations based on the consecutive inclusion of 12 patients with four consultations each. Field notes were made on all parties during consultations and when waiting with patients in the waiting room, before, between and after consultations. Notes also stemmed from informal conversations with both patients and health professionals, and the study included one semi-structured interview with each health professional. Only 2 out of 14 patients asked declined to be accompanied during assessment. Nine women and three men were observed, ranging in age from 19 to 52 years. The three youngest patients were trying to finish high school, while six had no education and three a short vocational education. All nine were currently unemployed and were supported by the social security system through close follow-up with activity plans and work assessments. All observed consultations were audio-recorded and transcribed afterward.

The second author was the psychologist in the team for the first five patients observed. She contributed essentially to this study with clinical knowledge of the field and critical psychological views on self-management. We consider her dual role to be a strength of the study, combining academic knowledge from two disciplines, and her input is reflected in both the theoretical and analytical sections of the article. This centers especially on emphasizing the goals and working conditions of the health professionals concerning this particular patient group and how they strive to improve well-being for the patients employing the most viable method available.

Consultation work

The health team observed consists of a physician, a psychologist, and an occupational therapist. They assess two to three patients a week; the patients spend 60–90 minutes with each health professional over 2 days, ending with a session where the final decision on diagnosis is first discussed by all team members, and then extended into a final consultation including the patient where the result is presented. Several Norwegian hospitals have established multidisciplinary teams for the assessment of chronic fatigue and possible CFS/ME. Patients are typically referred from their general practitioner following a long history of illness without a diagnosis, and they often wait months after referral to get an appointment at the hospital. The assessment of chronic fatigue follows the national guidelines for diagnosis and treatment (Helsedirektoratet 2015). This guideline builds on the most commonly applied set of criteria provided by Carruthers et al. (2011), commonly termed the Canadian criteria. According to these, the main criteria are physical and mental fatigue resulting in a 50% reduction in daily functioning, post-exertional malaise and/or slow recovery, sleep dysfunction, and pain. Additional criteria include cognitive, neuroendocrine, autonomic, and immune manifestations. The task of the multidisciplinary team is to assess the complaints of the referred patients according to these diagnostic criteria. CFS/ME will be the diagnostic outcome if supported by the assessment and if other disorders are excluded. During the observed consultations, the health professionals introduced what to talk about, defined the agenda and sampled information for their assessment. In contrast to other

studies (e.g., Hydén and Sachs 1998), the patients were not just hoping for a CFS/ME diagnosis and did not necessarily seem eager to pursue a disease label. Rather, their main concern was to receive help to recover and get back to “normal” life again. In our analysis, we look into what patients were eager to display during consultations, particularly their main concerns and ways to manage their lives, as well as how clinical dynamics centered on activity, as specific clinical advice in contrast to activity in ordinary life.

Displaying competency and what matters

During consultations with Clara, the physician, clinical issues dominated, while Erin, the occupational therapist, had mainly daily rhythm and functionality on her agenda, and Linda, the psychologist, enquired more into daily life, interests, family, history, and social relations. All, however, talked about and referred to the patient’s levels of activity, trying to draw, model or merely understand the extent of fatigue through activity as a measure. All made an effort to attune their approach to the patient’s life and experiences, and to give advice that was thought to fit priorities of each patient, giving hope and encouragement according to ideas of empowerment and autonomy. This worked to a point, but still, the patients made an effort to divert the clinical logic of questioning and instead display personal moral values and choices, and experiences and priorities in their own understanding. All attempted to tell a coherent everyday life narrative, whenever they got the chance to jump in, of how they had been able to keep a life together despite pain and fatigue. It was pertinent for the patients to present who they were as persons, what their competences were, and what they invested in, morally and socially. They made an effort to act normal and with dignity by doing what was socially and morally legitimate: a mix of making their lives personally meaningful and attempting to fulfill a sick role (Parsons 1951). Agency, in other words, was displayed in both empowered and suffering ways, while hoping for help.

Mary (20) had quit high school due to fatigue that had increased during the last year, and she also suffered from a rheumatic disease. She lived together with her partner. She sat in her parka coat when attending her consultations, not moving around very much and with a sense of wariness when talking. She was mainly brief and not very detailed in how she answered questions, especially with Clara, the physician, who guided the conversation quickly through all the issues relating to the Canada criteria. In the beginning she asked Mary about her interests but did not elaborate on this. With Erin and Linda, Mary revealed a bit more about how she spent her weekends during winter, going on snowmobile trips with her partner and his family. Erin wanted to know more about the level of strain this activity contained, and Mary explained:

We have, next to the cabins of his (her partner’s) grandparents and uncle, a cabin, so there is a lot, together with their kids . . . We go on snowmobile trips, I have my own snowmobile but lent it out this year a lot because I was worn out, but now I sit behind my partner but I have to hold on tight and I get tired and sore, I have also been sitting in the sledge which is better. I am not that active during the trips, while the others fish, talk, or prepare the fireplace etc . . . After the trips I relax in bed or on the sofa, watch series or the like.

The snowmobile trips came up every now and then, because they were Mary’s main activity and a priority. She justified in the above how she adapted to her condition still to be able to participate and take care of herself. Mary emphasized how she wished to prioritize these weekend events. Her partner worked away from home during weekdays, and for their time together she saved energy for the snowmobile trips. During the week she slept a lot and saw perhaps her mother or brother, or a few friends. She did very little in the house – not much cleaning or cooking. However, she emphasized that she could manage most things if she went for it, only that she got tired, and compared to earlier she could still participate in weekend activities, only at her own pace. Apparently, Mary had found a rhythm that suited her and her present life; she adapted and managed what was significant for her: her partner and their time together. When talking to Linda, the psychologist, she added another dimension to this: the feeling of guilt. Mary felt guilty because she was “not able to do what I should be able to, because my partner and my mom have to do so much, housework.” Apart from housework,

she lamented that she “should be able” to go to school, have a job, help out. This made her sad, and she was worried that she made the wrong priorities during the week; however, “the thing is, I am ill.” Despite this experience of desperation and suffering, she conveyed both what mattered to her at the moment and how she tried to accomplish this, struggling along and trying out what worked. Still, she was caught in a constant negotiation of possible priorities that would bring her pain and shame, whatever she chose. The health professionals, as we see later, tried to insist that Mary reordered her priorities, not exactly to forget about the snowmobile rides but to help her balance her activities differently. The balance of living up to competing affordances of a sick role and a normality in life course is, however, challenging, especially in the light of chronicity where the sick role concept may no longer be applicable in its basic understanding (Varul 2010).

Anna was in her early 30s and a single mother with two kids. During consultations, she presented her life story with past and present troubles, colored by feelings of regret, loss, and grief, related to being unable to keep a job she enjoyed and to her fatigue condition. She slept most of the time when the children were at school, and she forced herself to stay awake when they returned, to take care of them, cook, and clean, until they were ready for bed. Erin asked her what her main problem was:

Anna: It is that I do not manage to deliver like 100 percent; I do not manage to be a mother for my kids; that is what exhausts me the most.

Erin: Maybe you can tell a bit about the role of being a mother and how the fatigue affects you?

Anna: Hmm . . . It is hard to know that I cannot be a mum like I should be, that wears me down. I don't know how to answer this; I do not manage to take them out, for a trip, I must sit down when dinner is prepared. Parents go swimming with their kids, they participate in their activities.

Anna first stated her main concern clearly and then was prompted to reflect on “how fatigue affects” this. She answered this by comparing her situation with what others are able to accomplish and what she used to be able to do. She got back to her mother role several times by herself, and it stood out clearly as her deepest concern. Still, it also was her passion, her everything – “things make me happy, it is the kids who do that, keep me going” – and she constantly returned to how she managed despite her fatigue: “It is when the kids are at home that I do the most, I manage to push myself, because I have to be awake when they are.” Anna clearly prioritized her children, both as a duty (“because I have to”) and as a source of joy. She also expressed that her loss of previous capacity felt as a defeat. She talked about this with regret and with a sense of shame, that she was no longer able to work, to go hiking with the kids, travel or visit family compared to what other parents accomplished. Instead, she had concluded “I just have to decide” what to prioritize and in that decision her children came first.

With the psychologist, Linda, it became clear that Anna had experienced several traumas in her life – violence in childhood and in her own marriage – but she had also shown a capacity to fight these incidents. She spoke about this and emphasized often how she made an effort to do good, especially in relation to her children: “I do as best as I can” – meaning, for example, that she struggled to get a good arrangement for the children to see their father, who had been absent and not obliging so far. This presentation of competence and effort to make the proper choices and to spend what energy she had on what mattered to her was a constant theme in her response to the health professionals, displayed as a paradox of utter distress and remarkable resources. Her choices, however, were not only dependent on individual inclination but were also determined by what mattered socially, what was morally right to prioritize and what was socio-culturally valued.

All the other patients in their own way had similar presentations of their concerns, their competences, and what they hoped to get help with. Trond (52), who had experience with various kinds of businesses of his own and had worked hard all his life, was eager to tell how he was struggling with fatigue and cognitive problems, preventing him from doing what he used to do. Still, Trond managed to show his competences despite his problems: running a weekly café support group for cancer patients (being a former cancer patient himself), exercising twice a week, and coordinating a collection for cancer aid once a year. This made him feel good, as he gained a lot from helping

others. Social acceptance and acknowledgment was a priority to Trond as for others. His many activities, however, made the health professionals question whether he could be seen clinically as suffering from fatigue. Balancing one's sick role was complex, and trying to engage in activities to earn respect could cause set-backs, socially or clinically. At the same time, there was an expectation that one should make an effort to get back to normal life. In the middle of this, Trond was tormented by and ashamed of all the things he could not accomplish, viewing himself as a failure. The response from the health professionals for him was to work with acceptance of his limitations and try to find activities that were not guided by a social demand but a personal desire, looking to what gave him most joy.

Another patient, Karen, also a young mother, focused her concerns on the family, especially on giving her children the best possibilities. Karen underlined how she downgraded things that took her energy but prioritized things that were fun to do with her children – accompanying them to football training and doing voluntary work at the football club. Being able to undertake this latter activity and to contribute socially were important to her own self-image compared to other busy mothers. We see a difference here related to gender and age, concerning the way activities were valued, socially and morally. The women were mainly interested in performing as mothers while the men wished to earn respect through job-like activities. Even so, several women lamented not being able to work properly anymore. In terms of age, the youngest participants (all women) reflected many traditional female values but also had educational goals they wished to pursue. Participants in their thirties or forties were mostly keen on keeping up social acceptance through their activities. The performance of moral personhood was hence linked not only to the dominant discourse of the consultations, but also to social values related to gender and age.

In essence, how one envisioned oneself, and how one struggled to be a competent and morally legitimate person in everyday life, emerged as pressing issues in the encounter with the health professionals. Patients seemed to need to display both their suffering and their competence as moral subjects, but risked a legitimate position if they prioritized the “wrong” activities. The self-management discourse that promoted activity regulation as self-care reflected to some extent the life views of the patients but also deflected them when reducing the care advice to technical instructions on individual activity, denying certain modes of subjectivity.

Regulating activity and the articulation of agency and personhood

In the guideline for assessment, diagnostics, and treatment of CFS/ME, several suggestions for coping and rehabilitation are presented (Helsedirektoratet 2015). The ME team in this study adhered to “activity regulation” as their basic advice, the Norwegian translation of “pacing”. Activity regulation is based on an individually adjusted activity plan that includes any activity (not just exercise), and intends to teach patients to increase gradually all their activities without feeling exhausted. The pace of activities is also set according to individual limits, on the principle of learning to balance used energy. The physician used a map where she made the patients indicate what hours/periods they were active and when not, and what they managed to do earlier compared to now to estimate the level of function. The occupational therapist went through detailed accounts of activities with the patients, and filled in a “wheel of the day” for them. This was meant to make patients conscious about their possible imbalances, and it often served as a starting point for specific, person-oriented advice on activity regulation. Such could be advice on how to rest, on cutting down slowly on sleep during the day, on changing a few habits, on weighing up activities against each other. The approach was overall patient-centered, but often the health professionals obviously adhered to care logics that valued different activities than those valued by the patients and established a moral scale of activities. For example, often the occupational therapist engaged in suggesting and directing patients into activities justified as joyful, based on the principle that patients should prioritize activities that give better quality of life. Doing “happy” things, however, established a new moral scale apart from the affordance to balance ordinary activities. Trying with good intentions to empower the individual and her personal desires, risked making the patients feel even more shameful when not making that priority. It set a norm for

the patient, on top of what the sick role prescribed (Varul 2010). Ultimately, talking about regulating daily activity constituted a clinical narrative informed by a self-management ideology and spoke to a specific kind of agency that affected the moral constitution of personhood. It also implied a transfer of responsibility from the health professional to the patient, who became enacted as a particular, self-governing person who could do what was needed to recover (cf. Buchbinder 2015). Further, it possibly obfuscated patients' needs rather than illuminating them (Salmon and Hall 2004).

In the case of Anna we learned how she suffered from fatigue and that she had a daily rhythm with more sleep than active periods. The final advice for her was a recommendation to stabilize her condition through regulation strategies and the avoidance of symptom provocation:

Erin: [T]he things we know that work to stabilize, there's no medicine you can take, what you can do is to kind of stabilize your environment and work to regulate how active you are when you are active . . . [W]hat we know works is daily structure, regulation of activity, support, and acceptance. So, like, to work with these things means you can stabilize, that you don't get those ups and downs so much, and that when you've been stable for a period you can start gently to increase the activity, and then you should increase it slowly and just a bit without experiencing lots of symptom aggravation and things.

This piece of advice is legitimized by “knowledge” and speaks to the basic ideas of activity regulation. In follow-ups to this, Erin also stressed specifically that Anna should try to spend less energy on caring for the children since it left her exhausted, and that she should look for things that made herself happy. Anna, however, was adamant that her children were her source of joy, although eventually – during her final consultation – also admitted that she needed to prioritize herself. The quote above also speaks to the “you” – the patient and her capacity to work with this, her input to make this work – and it envisions how she will be rewarded if she works with this in the right way. Anna received several detailed explanations of how to follow the advice, often containing many examples adjusted to the patient's life but addressing activity as a personal capacity. After several more comments along those lines, Anna finally said, very wearily: “I'll try. As I always do, I'll try.” We already learned that Anna had a lot on her shoulders and still demonstrated that she was intent on managing her priorities (her children) as best as possible while also being keen on receiving help. The agency she demonstrated, however, was related to more than intentional and rational skills. It was also a situated agency; it was about struggling along, about cooking, cleaning, and nursing in ways that she could manage, about balancing social interaction, about forging everyday concerns and enduring (Honkasalo 2009). Both Honkasalo and Bottner (2019) argue for a rethinking of the notion of agency to include varieties of agency and moving toward modalities where strengths, skills, and merely everyday coming to grips count as agency, being more about social interaction and enduring in a local moral world (Kleinman 1992) than about rational acting. In the final clinical encounter, however, Anna accepted the professional advice that implied thinking about herself as an individual person who has the capacity to, and is morally responsible for, getting well (Greco 1993). In Anna's case, this may eventually increase suffering because the model and advice she tries to adhere to is not just straightforward but also risky, in the sense that there is no guarantee she may fulfill the obligations of her sick role (Parsons 1951). If she fails, she may end up doubting herself and her competences, feeling ashamed and devalued socially (Varul 2010). As Hay argues, “culture has failed to provide resources valuing existence without agency” (Hay 2010: 271).

Mary's consultations ended in a similar way, but she was less accepting or compliant than Anna. Mary's main priority was to spend weekends with her partner. The health professionals discussed this with her, but from a position where they all agreed to her weekly rhythm being a problem. They therefore advised her to restructure her activities, to start with a change in her weekdays and to cut down on weekend activities. During her consultations she received several lengthy instructions about this, and when the team delivered its diagnostic conclusion to her, the team members narrowed down their advice like this:

Erin: Well, we talked a bit about this, about regulating “down” the activity in the weekends and maybe get a bit more variation in activity during weekdays; that lying in bed could be less, and help the body to differ between

night and day, with quite simple moves like getting up at fixed times, yes, get dressed and make your breakfast and in a way transfer to the sofa at least, so that you begin slowly. Because it is as you say, if you begin to be very active during the days before the weekend then you will be even more exhausted, and then it perhaps influences your weekend, and this is not what you want. These routines in everyday life and the structure that helps the body to differ between night and day – that can be a good start.

This advice tried to make Mary reflect upon and rethink her main concerns, the weekends, and gave her the responsibility (“this is not what you want”) to regulate her energy. Even though Erin related her advice to fit Mary’s priority, it was closely related only to Mary’s abilities as a person, not recognizing that her concerns were part of specific social predicaments and an agency that consisted of accountability, participatory skills, and moral choices. In this final consultation, Mary did not bring up her social commitments again, only inserting a few times that she had tried most of what they told her to try. Overall, she accepted the idea of thinking about the advice and the coping courses she was offered, but she was unenthusiastic. We see Mary as an example of how the advice on regulated daily activity tries to contain a patient’s everyday life but lacks the potential to address it on the premises of the patient and the social and moral stakes of her local world. Individual agency and personhood was targeted but only half accepted, perhaps because Mary was unable to do more at the moment than choose “the suffering response” (Hay 2010: 261) and try to preserve her own moral choices.

These two examples are parallel to the dilemmas that Karen, Trond, and others were caught in – their efforts to comply to self-care as suggested by the health professionals, despite being worn down, and their doubts about the advice because their social commitments counted for more or because what they were able to do was to tag along, enduring. The recommendations from the team seemed, despite attempts to do so, only partly to include the patient’s experienced suffering and social predicaments and represented a choice of care and agency inherent to the current institutional and cultural logic of health and recovery. This choice speaks to individual agency, and patients like this will essentially continue to be on their own, saying “I will try, as I always try.” When this is said, there may be a variety of forms of agency emerging from specific cultural contexts, and agency is not ontologically prior to local context – not a given phenomenon but bound to interaction (Bottner 2019; Honkasalo 2009). Some patients may embrace the core of self-management because it gives credibility to being ill while also fulfilling a norm of being a capable person, even as chronically ill. In addition, it may give patients legitimacy to change their actions and social behavior and to move in new directions, such as choosing actively which norms they wish to live up to, to balance and choose which social networks to engage in, and to embrace the concept of regulated daily activity, taking control and being agentive. Among our patients, Beth stood out as an example of this.

Beth was around 50 years old, had grown-up kids and grandchildren, and she reflected constantly on how she understood her complaints, how she dealt with them, and what her goals in life were. She had a long history of stress, disease and abuse with tough social and bodily strains in her youth and adult years, as well as a life “full of energy,” as she said. She no longer had such energy, but she elaborated vividly on how she regulated her daily chores, how she worked with acceptance, how she tried to listen to her body, how she had managed to get away from abuse, and how she worked with her needs, relations, and life goals. Her personal priorities focused a lot on how she could balance her energy: sharing her time and activity with grandchildren, being active out-doors and being with her partner. This parallels other patients’ priorities but compared to others she gave a strong impression of being in control, of knowing what worked and not, of having adopted all the right strategies. The health professionals all praised her for standing up for herself, and they supported her strategies while acknowledging her challenges. The ideology of self-management seemed to work for Beth, she seemed to be empowered and adopting a moral position that gave her credit in the health system and in her social life.

We suggest that Beth is an example of a patient who had internalized the institutional logic of self-management and adopted a specific agency and personhood accordingly, while her priorities produced justification of her life. In a narrative terminology, she represented a restitution narrative, giving a very serene account of her life (Frank 1995). Her language use was close to the terminology used by

the clinicians and it suggested a strategic approach, almost performing as a “therapeutic citizen” (Nguyen et al. 2007:S34). Notably, her account was met with acknowledgment and praise from the health professionals. Her illness history was longer than most of the others and her strategies might have developed over time. Nevertheless, despite different reactions and different life stories, we argue that clinical enactment of self-management has a crucial impact on how fatigue patients are constituted. A specific kind of agency is promoted and evoked, and it is both exploited, accepted and challenged by these patients, but is also constitutive of their subject position. Beth’s mode of being relates more to a “John Wayne response” (Hay 2010: 269) than to a “suffering response”, the more common response among the patients in this study. This final case tries to emphasize that shaping patients during the diagnostic process of fatigue is dependent on clinical dynamics as well as on the potency of the notion of agency. In some cases, self-management is established as a mutual notion, but in other cases, the health professionals do not capture the lives of the patients, and they have to struggle to legitimize a more contingent, quotidian, and socially informed agency.

CONCLUDING DISCUSSION

In the above analysis, we have shown on the one hand how clinical encounters frame what to talk about and, on the other, how to talk about issues relating to chronic fatigue. Mary and Anna together with other patients were eager to display both their regrets and sorrows concerning their life conditions and to utilize their resources and competences to balance health complaints and social demands. However, the response from the health professionals framed the consultations toward prioritizing individual concerns whilst downplaying everyday social concerns and obligations, making a distinction between “good” and “not so good” priorities. This, we argue, is a powerful effect of the implicit notion of agency inherent in self-management discourses, a notion that deflects the significance of social demands, social acceptance and endurance in routine life. Following this, we demonstrated how the concept of “activity regulation” was enacted during consultations and how this furthered the constitution of a distinct personhood. The emphasis on “activity” in diagnostic criteria, mapping of daily life, and in giving care advice pervaded all consultations. However, patients and health professionals talked about activity from different positions and meanings. The professional position prevailed and we contend that it had a different impact on the patients according to their life situations, some were empowered or already perceptive to empowerment while others failed and risked being further disempowered. The powerfulness of this self-care advice constitutes both more vulnerability and trouble in very unequal relations or strengthens the subject who may have integrated the affordances of self-management already. Agency and “activity” become vehicles for the constitution of moral personhood enacted during clinical dynamics and the recommendations of regulating activity. Activity crafts a distinct, responsible, and virtuous personhood, containing expectations of living up to its moral and relational implications. We have further suggested that an immediate incompatibility existed between the moral choices and social values that patients already relied on and considered important, and the afforded personhood. Certainly, there were degrees of integrating the self-care advice and, as in Beth’s case, patients might still embrace the logics of activity regulation. However, what was at stake when trying it out like Anna, being ambivalent like Mary, or embracing it fully like Beth?

Tanya Luhrmann (2006) suggests that suffering subjects may struggle all the more when they experience and live by competing emotional codes while also moving in and out of social spaces where these codes and their matching display rules dominate. She states, “The emotional vise arises not only out of there being two codes – different appraisals, different appropriate displays, different representations – but a recognition that in *being responsive to each, one fails both*” (emphasis added). We suggest that for the patients assessed by the CFS/ME team the real dilemma is that they want to and will try to live up to two codes of living at the same time: their own and the health professionals’ advice. Most of them will strive to do so in their efforts to recover, but they may fail because the two codes are often not compatible and belong to different social and cultural spheres. We see this incompatibility and

dilemma very clearly in Mary's case and in her wish to prioritize her partner, but we also believe this is what Anna expresses through her willing though reluctant responses. Beth may stand out as a patient feeling at home in her choice, but this also implies changes and adaptations, moving into a new moral personhood (Zigon 2010). It is still a choice of code, and it may not fit everyone; for some it may distance them from basic local rules and social reciprocity.

Consequently, trying to be responsive to one code and one cultural model may mean failing parts of another code. But you try, as you always try. These pathways seem to constitute the predicament of self-management: the paradox of suffering and conflicting subjects attempting to exercise incompatible modes of agency. The approach of activity regulation and patient support is definitely the most viable in a clinical sense, but it is also crucial to the paradox and we contend that diagnostic processes and management strategies designate and shape more than a disorder. They also shape how we think about ourselves and how we may understand what it is to be human persons.

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