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Published online: 23 Jul 2020.

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'Fixing my life': young people's everyday efforts towards recovery from persistent bodily complaints

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ABSTRACT

Little is known about the perspectives of young people suffering from medically unexplained symptoms. This study aims to explore the experiences and strategies of young Norwegians related to incipient and persistent health complaints affecting everyday life functioning. The study draws on field notes, video material and interview transcripts from a multi-sited ethnographic study of healthcare services and select schools in a small Norwegian town between 2015 and 2016. A central theme is the emphasis upon social and existential constraints seemingly framed by a social imaginary of youth rather than a medical imaginary, and their active engagements to 'fix' their lives through what we identify as two main modalities of self-care. Navigating temporal and relational aspects of sociocultural configurations of youth in their social environments, they imagine and enact alternative qualifying positions better adapted to constraints, personal preferences and needs. Our findings may add to understandings of the needs and strategies of young sufferers of medically unexplained symptoms, relevant for health and social care encounters.

Introduction

> I can hardly recognise myself. I've had lots of support… But I had to do a lot of work myself as well! (Anne, 15)

In our first conversation with Anne, she smiled shyly and answered many questions with a hesitant 'I don't know'. Anne was a key interlocutor in the study presented in this paper, participating in interviews and collaborative filmmaking. Our mutual process of getting beyond her many 'I don´t knows' over the following year turned out to reflect broader processes of recovery in her life. Anne had grown up in what she described as a 'war zone'

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between her now divorced parents and experienced bullying since she started school. Supported by her mother, school nurse and mental health therapist, she tied many of her recurrent colds, infections, headaches, gastrointestinal problems and episodes of fatigue to past and present adverse experiences. She had illness episodes after involvement in parental conflicts, and when confronted with challenging peer situations or oral presentations at school. During interviews and small talk with Anne, she especially emphasised her own everyday efforts to become more certain about herself as a person, to prevent further illness episodes and overcome her present condition. Anne found 'relief' by explicitly expressing her needs to teachers and the school nurse, and speaking up on behalf of other pupils struggling with non-acceptance of their health related limitations and self-presentation. Such efforts seemed to support a new vision of herself as a person that made her help other vulnerable young people:

> It's not ok to have the attitude that everyone must be the same. It's important for people to be allowed to be who they are. I try to talk to people who seem lonely at school. I know how much it helps. (Anne, film session)

In this paper, we aim to explore the everyday strategies of young people with debilitating, incipient, persistent and medically unexplained bodily complaints. More specifically, we explore the constraints they experience and how they counter them, what they hope to achieve and what they consider 'good' in relation to others in this process. We begin with Anne's experiences because she reflects how our participants attributed their symptoms to social and existential constraints, rather than isolated bodily symptoms. Anne's experiences also illustrate her engagement in acts of endurance and self-care that seem grounded in the 'normative practices of everyday life' (Das 2012, 138). Persistent, medically unexplained symptoms (MUS) denote a social situation and often debilitating predicament (Kirmayer et al. 2004), being typically defined as symptoms causing everyday worries and/or constraints, while clinicians have been unable to fully explain or treat them for more than six months (Henningsen et al. 2011; Peveler, Kilkenny, and Kinmonth 1997). Approximately one in six primary care consultations involve MUS (Rosendal et al. 2017), and between 3-10% involve persistent or recurrent MUS (Aamland, Malterud, and Werner 2014, Swanson, Hamilton, and Feldman 2010). A central theme in the literature on MUS concerns the pervasiveness of ideal biomedical models on patient expectations, that complicate health communication and fail to account for the complexity of life with illness (e.g. May et al. 2004).

While most research focuses on adults, prevalence in children and young people is estimated to be similar (Eminson 2007; Farmer et al. 2004). Qualitative studies have begun to explore the perspectives and meaning-making efforts of young patients (e.g. Moulin et al. 2015), suggesting peer relations influence needs and coping strategies, but more research is needed to better understand such processes and the meaning of everyday contexts. Here, we refer to persistent bodily complaints as a more open term regarding contexts and explanatory frameworks (Marks and Hunter 2015), to encapsulate possible experiences of the phenomenon in everyday life. Drawing on anthropological approaches to youth, subjectivity and ordinary ethics, we bring out everyday forms of reflexivity and agency, for youth with persistent bodily complaints crafting the insistence of imagined futures and being oneself despite illness, marginalization and disregard.

Materials and methods

This study is based on an eighteen month-long ethnographic multi-sited fieldwork (Marcus 1995) in a small Norwegian town in 2015 and 2016 with professionals in the primary sector and young people experiencing persistent bodily complaints referred to us by these professionals or sampled purposefully during fieldwork. We approached school nurses, school advisors, social workers and mental health therapists, through phone calls and oral presentations at existing service venues, and provided flyers and information sheets. In alignment with Peveler's criteria (1997), and to distinguish persistent MUS from more self-limiting and everyday complaints, we asked these professionals to contact the authors if they knew young persons with debilitating bodily complaints that were challenging to understand and treat for more than 6 months. Furthermore, to meet young people in everyday settings, potentially prior to long assessment processes, we chose three local, high schools as fieldwork sites. Two schools offering vocational courses were recommended to us by school leaders, based upon multiple pupil challenges, including "diffuse" bodily complaints. The third was included based on the supposed existence of our target group among pupils aiming for higher education. High school education is universally covered in Norway. The selected schools were state-funded and hosted mainly Norwegian-born students of varying socio-economic backgrounds and career aspirations. Adhering to Norwegian Personal Data Regulations and guideline paragraphs from the National Committee for Research Ethics in the Social Sciences and the Humanities (NESH 2006, ¶12) concerning sensitive topics, children and young people, we obtained written consent from all young participants as well as from parents of participants up to 18 years. We provided face-to face, age adapted information, including information on their freedom to withdraw at any point.

We base the analysis in this sub-study on field notes, video material and interview transcripts relating to twelve girls and five boys between 14 and 23 (Table 1). Professionals referred nine young participants. These participants were wholly or partially out of school and work due to their complex health challenges. Eight pupils contacted the first author directly in the schools, one of them guided by his school health nurse. All participants were

Table 1. Young participants experiencing persistent symptoms.

	Age at first contact	Recruitment path	Self-reported symptoms *Terms used by referring professionals in italics*
Girl	14	Pedagogical-psychological services	*learning challenges, non-verbal, refusal to attend school* Headaches, stomach problems, tiredness
Boy	18	Psychologist	*gastrointestinal problems* Headaches
Girl	16	Psychologist	Tiredness Concentration problems
Girl	16	Psychologist	Fatigue, Food intolerance
Girl	22	Social worker	Headaches
Girl	19	Social worker	Pain in several parts of the body
Girl	20	Social worker	Headaches Back pain
Boy	15	Hospital ward	*diffuse case, non-verbal* Tiredness
Boy	20	Social worker	Shoulder and back pain
Boy	17	School nurse/ fieldwork	Stomach pain
Girl	19	Fieldwork in the schools: sampled by researcher	Back pain Paralysis episodes
Boy	17		Back pain Concentration problems
Girl	17		Pain in several parts of her body
Girl	17		Jaw and joint pain
Girl	17		Stomach problems
Girl	17		Joint pain Easily sick
Girl	17		Daily headaches

current or previous clients of school nurses, mental health services and/or social workers, and some had previously been diagnosed with anxiety, PTSD or depression. We applied visual methods (Youth Gaze methodology) to explore otherwise hard to reach aspects of their experience (Pink 2007, MacDougall 2006, Waage 2016), and to engage in ongoing analytical and reflective dialogue with the participants (Waage 2013). We also conducted nineteen in-depth interviews with thirteen of the participants. These were life form interviews (Haavind 2007), involving detailed questions about a recent day in order to let experiences, events, relationships and involvements emerge in relation to their everyday context. We then analysed the interviews and field notes using thematic analysis, applying a constructionist informed inquiry into latent and semantic levels of meaning (Braun and Clarke 2006). The analysis was also informed by anthropological theoretical discussions on youth, subjectivity and everyday forms of agency (Biehl, Good, and Kleinman 2007; Dalsgård et al. 2014; Das 2012; Lambek 2010; Vigh 2006, 2009a, 2009b).

Collaborative film, participant observation and interviewing provided complementary forms of data. Using film for example opened up for participation and dialogue with less verbally expressive youth on their experiences, and interviewing in combination with participant observation allowed for exploration of a broader meaning context of seemingly minor non-verbal acts of containment in the schools. The main themes presented in this paper were found consistently in each case and across film, observation and interview-based encounters, supporting the dependability of the findings and their relevance for young person's experiences of MUS in everyday contexts (cf. Guba and Lincoln 1994).

Inspirations from an anthropology of youth

In an influential review, Bucholtz (2002, 535) argues that advances in the anthropology of youth need to explore young peoplés practices from their own viewpoint. This serves to recognise how they 'relate, adapt to and negotiate often untenable situations' through everyday forms of cultural critique and production. In line with this, Christiansen, Utas, and Vigh (2006, 11) argue for analysis which acknowledges both social and experiential aspects of youth. Here, we take inspiration from such approaches within an anthropology of youth to illuminate how young people with experiences of persistent MUS make sense of and cope with their experiences of social expectations and life challenges.

Recent qualitative additions to the literature on MUS in youth have emphasized the meaning of a peer relational and cultural context (e.g. Moulin et al. 2015). Youth is a flexible and contestable social category (Bucholtz 2002; Cole and Durham 2007). Anthropologists argue that young people are expected to relate to their futures in culturally defined ways (Cole and Durham 2007), and are considered at risk due to their struggles to achieve what is considered 'good' transitions (Dalsgaard et al. 2008). Yet they also negotiate their possibilities through their challenges (Dalsgård et al. 2014) and may seek imagined futures (Cole and Durham 2007). Imagined future possible selves are 'grounded in … past experiences and present circumstances', but may also 'motivate intentional changes in behaviour and action' in the present (Hardgrove, Rootham, and McDowell 2015, 165). Such efforts to adjust one's temporal experience, or 'time work' (Flaherty 2011), may account for both socialisation and self-determination, cultural continuity and change. Vigh (2009a) argues that we are all constantly engaged in navigating our social environments, coping with social pressures and considering these pressures in relation to present possibilities and envisioned

trajectories. Approaching youth as a moving position (Christiansen, Utas, and Vigh 2006; Vigh 2006), we take into account how young people experiencing MUS are positioned as well as how they try to move within social positioning in their environment. Constraints, pressures and how young people relate to them in everyday life, may be understood as a social imaginary that incorporates the way people 'imagine' (Taylor 2002, 23–26) their social existence, and how they 'fit together with others' (ibid.), a sense of expectations and legitimacy and more or less implicit and/or habitual repertoires of possible ways to act. Through social imaginaries, young people interpret past and present aspects of their social existence, and envision their potential in ways that guide action (Vigh 2006, 2009b). This includes their health related explanatory models and how they navigate social configurations of youth with persistent bodily complaints.

Subjectivity and ethics in everyday life

To further explore forms of navigation and agency related to young people's experiences of bodily and social constraints with MUS, we draw on recent anthropological conceptualisations of subjectivity and ethics in everyday life (e.g. Biehl, Good, and Kleinman 2007; Das 2012; Lambek 2010). The concept of subjectivity generally directs our attention to 'actors' thoughts, sentiments and embodied sensibilities, and, especially, their sense of self and self-world relations' (Holland and Leander 2004, 127). Recent approaches within anthropology have emphasised the existential complexity of the individual subject (Ortner 2005), viewing subjectivities as more open-ended, unfinishable entities than predefined identities or subject positions. By attending to subjectivity in ethnographic terms, Biehl, Good, and Kleinman (2007) seek to develop our understanding of how persons are constituted through social experience, while still accounting for how subjects endure experiences reflexively and emotionally.

Subjectivity in these perspectives is 'made through dialogue' (Fisher 2007, 442), within practices of everyday life. Subjects are made through 'forms of inhabiting the world in which one tries to make the world one's own, or to find one's voice both within and outside (available)… genres' (Das 2007, 216). Das points to the amount of work done under constraining conditions to endure and renew life. This work, she claims, is often done by a 'descent into the ordinary' (2012), in other words an ethical cultivation of sensibilities (Lambek 2010) within everyday life itself. Speaking and acting in certain ways has ethical consequences, such as protecting one's own or another's dignity or denying it (Das 2012). Apparently insignificant everyday routines, judgements and practices may presuppose a kind of moral action, a heightened awareness and attentiveness. What is 'right' in the face of persistent MUS in youth emerges through ongoing practical judgement and performative acts (Lambek 2010). Thus, attending to subjectivity and ordinary ethics, we explore the trajectories of young persons with persistent bodily complaints, and we ask how modes of subjectivities are configured during their everyday efforts to manage their symptoms and inhabit their social environment.

'Fixing my life'

We begin by briefly presenting how our young participants emphasised social and existential constraints as the worst and most important elements to overcome. Like Anne, all stressed complex relations between illness and life-world. Their illness affected their everyday life

and future life prospects of who they could become as persons; conversely, certain life experiences seemed to affect their health and how illness was experienced. A central theme, the experience of disordered, disrupted or imbalanced young lives in need of 'fixing', emerges in all accounts. This 'fixing' required reflexive efforts of self-care, coping with their symptoms and promoting their overall health, in dialogue with their social environments.

Participants experienced bodily, social, emotional and existential constraints as variously intertwined. Their bodily symptoms varied from debilitating pain, tiredness and recurring infections to gastrointestinal problems. However, they emphasized the social, emotional and existential consequences of their situations as equally or more challenging than the bodily distress. Especially, they stressed how their symptoms constrained their ability to pursue certain educational, qualifying trajectories towards adulthood and to socialise informally on equal terms with their peers:

> The diarrhea, gas, bloating and pain makes me tired and resigned, and my school-day and social life difficult. My doctor cant´t find what´s wrong. Íve only told my mother and one of my friends about it. I spend a lot of time alone in my room. (Line, 17, life form interview)

Some had left education and felt too ill to work. Others experienced disregard of their condition and recurrent absence from class, and/or struggled to perform and participate as expected. Anne and her mother expressed feelings of shame in their roles as pupil and parent. They recalled how Anne's teachers claimed her social problems at school only existed 'inside her', reported her absence to the social services, and advised her mother to ignore symptoms understood as 'mere psychosomatics' and pressurise her to attend school. Even those who excelled academically expressed difficulties to maintain their previous level of performance and who they 'used to be' in relation to others due to their symptoms:

> Every day at school is a battle. I can hardly pay attention to the teacher writing on the blackboard. Tests are the worst. It seems like stress makes it worse, and I can almost not sit still because of the pain. In a way it has made me an underachiever (Lasse, 17, life form interview).

Conversely, all understood their persistent health problems as amplified or caused by life challenges, using terms like 'stress' to describe very diverse and complex experiences of suffering apart from those related to school performance. Five of them had been persistently bullied for standing out among their peers, adding to an overall experience of pressure to meet the criterion of living accepted young lives:

> You have to be like everyone else to avoid being bullied. I haven´t managed that. (Jeanette)

All the participants expressed uncertainties about who they could become, and how to best understand themselves with their health constraints, in relation to life challenges. Their scope of recovery therefore seemed much broader than achieving a healthy, 'absent' (Leder 1990), physical body, implying a broader understanding of health than physical aspects of healing alone (Risør 2010). For Mary, 19, to 'get back on her feet again', for example, she not only sought relief for her excruciating pain in several parts of her body, but was also involved in efforts to, more broadly, 'fix her life'. Mary distinguished between school- related stress and her own personal stress. She had agreed with her teachers to postpone her schooling, since the stressors in her turbulent family life were too great to manage all at once. Even though she still sought out new health professionals, hoping for a medical explanation and alleviation of her bodily pain, she understood this as only part of the solution:

> If this is the kind of pain I think it is, I won't be any better until I get my life back in order. But it's good to have something that stalls it a bit.

Some had been told by health professionals to 'wait and see' if they would grow out of their diffuse conditions, or if the symptoms would pass. However, all described a need to 'get on with' their lives, to alleviate painful experiences of problematic, threatened or disrupted transitions and restore or install a sense of 'order' in their lives in line with their own and others' expectations.

Ultimately, their understanding of their constraints and the practices needed to overcome them relate to everyday tasks and expectations rather than bodily suffering alone. Their hopes and goals seem to be framed by a social imaginary of youth as much if not more than by a medical imaginary. All participants expressed a need to act upon their overall suffering and constraints, seeming in part to embrace 'repertoires' of legitimate action (Taylor 2002, 23–26). They thus seem to relate to cultural models that value active anticipatory engagement to repair life in a productive world and suffer successfully (Frank 1997; Hay 2010, 271). Adding to this, we also find traces of everyday reflexivity (Biehl, Good, and Kleinman 2007), cultural critique and production in their practices (Bucholtz 2002).

Imagining future selves

One central theme in all our participants' actions to overcome their constraints and 'fix' their lives was an orientation towards potential future scenarios, including who they could become as persons and their occupational 'possible selves' (cf. Hardgrove, Rootham, and McDowell 2015). Although some struggled more than others to 'keep up hope', all emphasised the need to cultivate hope to generate a meaningful life. Thus, one modality of self-care identified is their ongoing imagining and enacting what a good life might entail.

Anne's verbal and visual expressions, or lack thereof, may illustrate how subjectivity is projected and constructed in social practice, as in language use (Biehl, Good, and Kleinman 2007, 408). Anne's initial tendency to say 'I don't know' in her communication with teachers, health professionals, peers and the first author as researcher seemed to reflect feelings of scepticism and uncertainty tied to illness and social experiences of failures and non-acceptance:

> Nothing I said used to matter. I still say ´I don´t know´ when I feel uncertain.

> (Final interview)

Anne had been recruited partly due to her perceived strength in visual rather than verbal communication. However, in our collaborative filmmaking, we struggled for a while to find a topic for her film. Anne's initial filming assignment showed a silent gaze at other peoplés feet. Reflecting on her footage together it became clear how vulnerable Anne felt regarding what others might see and how they might judge a film focusing on herself. However, some of her dawning sensibilities and critical judgments surfaced in editing, as she looked for 'interestingly different' images and decided against adding music she used to listen to 'only because other people liked it'. In subsequent visits to Anne's home, she shared everyday episodes she had experienced since we last met with increasing trust and critical reflexivity. Through participant observation and ethnographic conversations in their home, it became clear that Anne's developing interpretations of how she had reached where she was, how

she fitted in with others and who she could be as a person were supported by her mother and therapist, using stories from her everyday life. Realising that she was not alone in experiencing illness constraints and external judgements, she began to adopt an alternative sense of competency and agency:

> I now know what to say if someone's ill or in a conflict… It really should be taught in school' (Film session)

Anne started her own blog, joined several anti-discriminatory youth organisations and considered one day studying law or media communication. She seemed to imagine and enact a new, hopeful vision of her future self as an engaged young advocate and broker on behalf of other suffering youth, thereby repositioning herself into a more positive youth role in the present. When she was allowed to use our collaboration to enact this vision and 'make a difference' by speaking out on behalf of young immigrants, she enthusiastically chose a theme, shot and edited her film and screened it in several public venues, including her school.

All participants' visions of 'getting on with' one's life presupposed some form of mastery, or a fragile sense of being on a path, leading up to future educational and/or professional possibilities generally considered a good adult life. This was expressed by Mary who was out of school and work due to her complex challenges including debilitating pain:

> I dream of becoming an adult. Of one day managing a job… But I don´t know what's possible.

Mary spent her good days learning new cosmetic skills on YouTube, visualizing a future profession that would allow her to work sitting down. All described a process of reconsidering former dreams, taking present needs and challenges more into account. Their new dreams seemed to balance inner and outer conditions differently from how they used to envision themselves:

> I've always been interested in constructions, but when it came to deciding upon my future career, I had to consider my back first. Now Ím aiming to become a health secretary. I have always been a caring person. (Julie, 19 year, quote from life form interview)

The first author met Kine, struggling with chronic pain, anxiety and depression, during participant observation in one of the local high schools. Kine's process may further illustrate how our participants seemed to be engaging in forms of 'timework' (Flaherty 2011), by imagining future 'possible selves' (Hardgrove, Rootham, and McDowell 2015) that seemed to motivate enactment of forward-oriented new roles for themselves in the present. During visits in the school, Kine and several of her co-pupils emphasized their caring class environment. Kine played an active role in communicating classmates' needs and constraints due to the pupils' many health complaints and strong resistance to expectations and judgement on their performance. In an individual interview, she revealed background experiences that motivated her present role:

> I was called a problem child and there were meetings at the headmaster's office and all that. And my class hated me because I made such a fuss…I was bullied by all the older boys as well. (Kine, 17, life form interview)

Kine felt let down by her family and by care workers for several years. She struggled emotionally and her legs and stomach started to hurt persistently. At one point, Kine was

actually met by a couple of officials who saw her potential, restoring some of her faith in adults and most importantly, in herself:

> When he suggested that they take me there, they said 'no, she's too good at school for that'. It was a really good feeling, that things maybe weren't all bad.

Kine recalled proceeding to aim for top marks, to get more positive attention and to build upon a new vision of herself as a clever pupil. Ambitiously, she first enrolled in a university-preparatory high school, but when her first test results were mediocre she started crying in the classroom. Being dependent upon this kind of feedback made her feel increasingly vulnerable and 'stressed':

> It turned into a chase. I had to be the best. It's been a process, learning that if I get a low mark it's not the end of the world. (Kine, 17, life form interview)

Gradually she started to adjust her vision of self, taking her challenges and resulting constraints more into consideration. For the first time in a new school, she had a good relationship with her main teacher. Although she had a 'support system' of her GP and a social worker, she felt that she could manage quite well without them for the moment. Kine emphasised her own work to keep 'destructive' thoughts from affecting her future plans. Wearing high school graduation-related apparel helped her keep up hope and get to school every day. She dedicated most of her time on the Facebook chat to helping her classmates with questions about their schoolwork. In light of her own bullying experiences, she made efforts to include all her classmates socially. Seeing how some of her own adverse experiences could come of use, she discussed her classmates' needs and reactions to school demands with her teacher as a kind of broker:

> It's easy for me to sympathize with how they feel because I had so many negative experiences with previous teachers. (Kine, 17, life form interview).

Kine eventually reinterpreted her experiences of having been 'problematic' into a form of competency or knowledge, drawing upon them in her imagining. Ultimately, these practices and performances helped Kine to imagine herself as 'getting on with life', i.e. repositioned her as a resourceful person on her way to adulthood. Several others who were out of school or still were not convinced they had found the right path, also described experiences of having achieved greater insight than their peers, of having matured, enabling them to take better care of their own and others' needs. Some enacted such strengths by listening and sharing experiences to alleviate others' suffering. Tommy 18, for example, had experienced regular childhood neglect and violence. He spent his days alone with persistent gastrointestinal pain, headaches and depression, but found a new and more empowered role through caring and honest online chatting:

> If I see that I'm helping someone, I'll keep going. My friends can talk to me about anything. I know about lots of things.

Taking activist, broker and caring roles provided new hope to overcome past constraints and perhaps rework them into resources for the future. An ongoing formation of what was experienced as legitimate yet viable 'possible selves' seemed to motivate all to health promoting everyday life changes and management strategies. In the words of Mattingly (2010), they attempt to envision and enact ´imagined future selves´, mainly by drawing upon

positive and negative social experiences as sources of hope and negotiating sociocultural expectations of good lives. This theme of cultivating hope for future adulthood is especially significant as it focuses on alleviating social and existential suffering more than bodily symptoms alone.

Efforts to 'be oneself' with others

Another modality of self-care identified is the attention to relationships and how the participants can 'move in social landscapes' (Vigh 2006, 2009a), to 'be oneself' while participating well with others. All described needing to navigate sociocultural expectations to participate in peer contexts without neglecting their own limitations, preferences and needs:

> Everyone wants to do well in school, look good, and show that they have the perfect life on social media. I try not to care so much about it. It´s not good for me to carry all that pressure. (Line)

Through everyday reflexivity and sensing ethically acceptable practice, however, many found ways to inhabit their social environment that felt more sustainable and personal. One way of managing a balance between onés own constraints and the value of participation, was through ignoring and/or containing (Alonzo 1979) health challenges. Containing symptoms could prevent them from interfering with expectations or defining their person in unwanted ways:

> Normally, I don't care too much, because there's a lot I have to say. And then I feel kind of tiresome (Sofie, 19, quote from life form interview).

The practice of 'not caring' too much about one's symptoms and constraints onstage often meant considerable offstage preparation. Before going to school, Sophie and Julie carefully stretched their aching bodies, did not carry heavy books and always took painkillers with them. Sophie also applied supporting bandages, and kept her hands extra clean to prevent more infections and thus absences. Mainly, however, efforts to 'not care' were described as a form of reflexive orientation to adjust one's experience of suffering temporarily to adapt to school routines. Several did this by engaging in 'positive thinking', a skill they remembered practicing with a school nurse or child psychologist.

> I started getting stressed out and did some thought practices with the school health nurse. And then I kind of transferred that to the feeling that Ím in pain and feeling down, but not wanting it to affect my day and my friendships in a bad way. And so I'm just going to be happy. Trying to keep it positive and keep all the negative stuff to myself. (Sophie)

Their present efforts at positive thinking seemed mainly directed towards 'not caring' about their symptoms or containing their constraints to facilitate participation in peer contexts.

> You can have a backache but still feel really good about yourself. Then it doesn´t bother you as much. But if you have a backache and feel bad it affects you even more. I try not focusing upon it. Pushing myself until I am done doing what Ím supposed to do and then I can relax afterwards. (Julie)

In particular, those in school described efforts at containing health complaints that might interfere with their self-representation as capable young people. However, all participants mentioned constraints that had proved challenging to negotiate or contain. Although Sophie made attempts to 'bother' less about her aching joints and sore muscles, she soon became known in her new school as 'the fragile girl', despite her strengths in other areas. Several participants had long-term experience of being judged as weak, different, weird or simply wrong. They seemed to be searching for approaches to find their place and attune themselves to others while not neglecting their own needs. In other words, they also emphasised the importance of developing independently and 'being themselves' while focusing less on others' expectations. Thus, another way they seemed to balance expectations and needs was to ignore or negotiate with external pressures by orienting their attention, or 'care', more towards their own preferences. Jeanette, 20, recalled always having stood out as different, unable to contain her ADHD, tomboy preferences and a later persistent pain problem for example. She shared how her main challenge was not her actual health complaints, but struggling to understand herself and how to mix with others with the resulting constraints. Having been considered too healthy for psychological consultations, Jeanette now emphasised working to enhance participation with her peers:

> I feel it's important to be myself. Because if I'm not comfortable with myself, other people won´t like being with me.

An important route to be able to participate socially while 'being oneself' was to seek social arenas and groups that might support critical production of new, more experience-based norms or imaginaries on which to base their actions. Jeanette described the friends she had found over time as 'different' in their own ways, making it easier to understand and accept each other and themselves with their different constraints:

> I'd say most of my friends are different. But that sort of becomes the normal thing, as we're all different in our own way. So, it's easier to understand.

Being 'different' due to various health and other constraints was thus redefined as a resource for many, an ethical stance, as when Jeanette stated that she was 'trying to not be like everybody else'.

Anne's increasingly empowered expressions and actions at school may illustrate how efforts towards 'being oneself' while being well with others seemed to involve a 'cultivation of sensibilities' (Das 2012; Lambek 2010) about the right thing to do. Anne shared many episodes from her life, seeming to experiment at school by actively working to 'not care' about what popular pupils would think, and being sociable in new ways. For Anne, school was where she 'spoke out' against practices she judged as adversely affecting her own and others' health, such as bullying and gendered and ethnic discrimination. She felt that these independent comments and ethical judgements helped her to participate more successfully and on her own terms:

> I've done a lot lately that's made me surer of myself as a person… and better at school…. I wear clothes that I like but nobody else does. And I speak up in class against the boys. Nobody else does that. (Film session)

Anne had long struggled to contain her health challenges and constraints and to conform to the peer norm, and emphasized in our repeated encounters how these forces still affected

her everyday life. She shared for example, how the most popular boys in school spitefully called her 'the lesbian' and 'the immigrant whore' for standing up to racist and sexist language and actions and for spending time with diverse pupils. Teachers sometimes also disapproved of her criticism of other pupils who might have their own challenges. One day her teacher had told her that they were in control and that she need not report any negative events unless specifically directed at her. Anne described how she initially felt her motivation and trust fading due to these obstacles, wondering if she was wrong to care so much, and she notably felt some of her symptoms reappearing. However, her subjectivity also seemed to provide 'the ground for her to think… and feel through her experiences' (Biehl, Good, and Kleinman 2007, 14), enabling her to endure and overcome unbearable circumstances in new ways. After a few days of thinking and making decisions at home, Anne returned to school. She angrily pointed out to her teachers that speaking out on behalf of others was the right thing to do and that she expected others to do the same for her. Later, she smilingly shared how her teacher acknowledged her rare contribution to their school, suggesting that it might help others to stand up and protect their own integrity and needs. In this sense, Annés everyday fights against failures in her social environment that she tied to experiences of illness, might be seen as sites of youth cultural critique and production (Bucholtz 2002). Through reflexive navigation in her social environment, she fought experiences of neglect in the school arena and of delimiting youth positions. Furthermore, she seemed to renew her world by carefully creating alternative ways of relating and new positions that she and others with illness, social and existential constraints might inhabit.

All the young people participating in our study valued being sociable with peers while also 'being oneself', negotiating between others' opinions and their own needs and ethical judgements. Their understanding of how they might fit in their social environments related to their perceived expectations to conform and perform among peers, which they did by containing their symptoms and constraints as far as possible. However, many like Anne and Jeanette, had to find new ways to participate with a better balance between self and social forms of 'pressure' on them. Grounding their imagining in everyday judgements and actions, i.e. through ordinary ethical engagements, they seemed to create new norms and positions from which to act (Lambek 2010), adjusted to their perceived strengths, weaknesses and needs. Their 'descents' (Das 2012) into everyday cultivation of sensibilities to be well with others seemed equally directed towards change, i.e. establishing a new normal rather than maintaining status quo.

Discussion

This paper has explored the everyday experiences and strategies of young people suffering from persistent, medically unexplained, bodily complaints. We have shown what constraints they experience in everyday life and identified two main modalities of self-care. Their constraints complicate their future life prospects and who they can be as persons, but their efforts at managing constraints are more oriented towards a social imaginary of youth than a medical imaginary.

Although levels of suffering varied between participants at school and those out of school and work, every participant's processes of becoming were in some aspects vulnerable and uncertain. A central theme in their everyday self-care practices was their valuing of and active efforts at 'fixing' their lives, i.e. getting their lives 'in order' by navigating temporal

and relational tensions in their social environments. Firstly, we focused on their evolving navigation in temporal tensions in youth, in transitions understood as 'problematic', and showed how they imagined their potential through on-going future-oriented processes of interpretation. These efforts resemble forms of time-work (Flaherty 2011), described in ethnographies on youth facing constraints in other sociocultural contexts (e.g. Dalsgård et al. 2014). They also seem motivated and influenced by the formation of future possible adult selves. This illustrates the potential benefit emphasized by Hardgrove, Rootham and McDowell (2015) of young peoplés future imagining to motivate intentional action in the present. Our findings underscore however the need for our young participants to navigate 'pressures' on them as youth and as ill; in other words social expectations and ideals of the possible selves they ought to aspire to and by what means, by adjusting what a good and healthy path and level of participation may be for them. In these processes, our young participants engage selectively with digital platforms such as YouTube and Facebook chats to support alternative learning opportunities and enact possible selves. The affordances of digital platforms and their role in constituting identity, both constraining and enabling, could have been emphasized even more, in line with Hanckel et al. (2019).

Secondly, we showed their navigation in relational/spatial dimensions of their social environment, addressing relationships allowing one to 'be oneself' and be comfortable within the youthscapes they imagine at school, online and elsewhere. This modality of self-care confirms accounts of how young people move within and escape restrictive positions, conditions and configurations of youth (Christiansen, Utas, and Vigh 2006). In the words of Das (2007, 216), we see them working to 'inhabit their world… and find their own voice within and outside of available genres', taking their illness and related constraints into consideration. The subject positions they take are defined by deliberately choosing how to contain and manage one's condition and social self as youth, despite persistent bodily complaints.

Their imaginings of future selves and balancing orientations of their 'cares' may be symptomatic of a broader sociocultural and historical context and thus constitute morally sanctioned technologies of the self aimed towards the making of productive, positive subjects that suffer successfully (Frank 1997; Hay 2010), maintain their duties to be well (Greco 1993) and realise their potential as good neoliberal citizens.

However, we also find traces of everyday reflexivity (Biehl, Good, and Kleinman 2007), cultural critique and production in their practices (Bucholtz 2002) that reflect subjectivity in the making. From this perspective, their self-care efforts to cultivate hope and attune themselves to others might also constitute sites where the meaning content of available subject positions is reinterpreted and horizons of potentiality are reimagined. While the participants' dreams partly reflected normative frames for good adult lives and good pathways towards them, they left school paths they found incompatible with their constraints. When such imaginings took their constraints into consideration, positive thinking as a moral expectation was partly renegotiated. As Mattingly (2010) suggests, their cultivation of hope seems more, or as much, a practice as a cultural attitude. Furthermore, while they contain their symptoms and related constraints to be sociable in recognisable ways, they also emphasise creation of new spaces and new ´normals´ to 'be oneself', to become accountable young subjects despite their challenges.

Conclusion

Through methods and theoretical tools that promote dialogue and exploration of everyday engagements, we have shown young people with persistent bodily complaints and their active efforts to reflexively navigate, adjust and repair transitional and relational aspects of their lives. Their strategies seem framed by sociocultural and contemporary expectations of good lives and good transitions, and resemble those shown in an anthropology of youth elsewhere in the world, of young people struggling to endure and overcome constraining conditions threatening their projects of becoming. Notably, even though the young people with MUS may be 'defined by a medical gaze' their efforts of 'fixing' are oriented towards life in general, more specifically life as youth, as other research is beginning to show (e.g. Moulin et al. 2015). This then becomes partly a matter of self-care, requiring a 'descent into the ordinary' (Das 2012) in everyday life, as persons more than patients. To improve encounters and communication with youth suffering from persistent health complaints, professionals may gain from knowledge about their self-care efforts and projects and what is important in their lives. Such insights may be essential in enhancing clinical communication.

Ethical approval

Acknowledgments

Disclosure statement

References

Aamland, A., K. Malterud, and E. L. Werner. 2014. "Patients with Persistent Medically Unexplained Physical Symptoms: A Descriptive Study from Norwegian General Practice." *BMC Family Practice* 15: 107. doi:10.1186/1471-2296-15-107.

Alonzo, A. 1979. "Everyday Illness Behavior: A Situational Approach to Health Status Deviations." *Social Science & Medicine* 13a (4): 397–404.

Biehl, J., B. Good, and A. Kleinman, eds. 2007. *Subjectivity: Ethnographic Investigations*. Berkeley: University of California Press.

Braun, V., and V. Clarke, 2006. "Using thematic analysis in psychology." *Qualitative Research in Psychology*. 3 (2): 77–101. doi:10.1191/1478088706qp063oa.

Bucholtz, M. 2002. "Youth and Cultural Practice." *Annual Review of Anthropology* 31 (1): 525–552. doi:10.1146/annurev.anthro.31.040402.085443.

Christiansen, C., M. Utas, and H. Vigh, eds. 2006. *Navigating Youth, Generating Adulthood: Social Becoming in an African Context*. Uppsala: Nordiska Afrikainstitutet.

Cole, J., and D. Durham, eds. 2007. *Generations and Globalization: Youth, Age, and Family in the New World Economy*. Bloomington: Indiana University Press.

Dalsgaard, A. L., M. P. Franch, and R. Scott. 2008. "Dominant Ideas, Uncertain Lives: The Meaning of Youth in Recife." In *Youth and the City in the Global South*, edited by K. Hansen, A. L. Dalsgaard, and K. V. Gough, 49–73. Bloomington: Indiana University Press.

Dalsgård, A. L., M. D. Frederiksen, S. Højlund, and L. Meinert. 2014. *Ethnographies of Youth and Temporality: Time Objectified*. Philadelphia: Temple University Press.

Das, V. 2007. *Life and Words: Violence and the Descent into the Ordinary*. Berkeley: University of California Press.

Das, V. 2012. "Ordinary Ethics." In *Companion to Moral Anthropology*, edited by D. Fassin, Vol. 20, Blackwell Companions to Anthropology, 133–149. Chichester: Wiley-Blackwell.

Eminson, D. M. 2007. "Medically Unexplained Symptoms in Children and Adolescents." *Clinical Psychology Review* 27 (7): 855–871. doi:10.1016/j.cpr.2007.07.007.

Farmer, Anne, Tom Fowler, Jane Scourfield, and Anita Thapar. 2004. "Prevalence of Chronic Disabling Fatigue in Children and Adolescents." *The British Journal of Psychiatry : The Journal of Mental Science* 184: 477–481. doi:10.1192/bjp.184.6.477.

Fisher, M. J. 2007. "Epilogue." In *Subjectivity: Ethnographic Investigations*, edited by J. Biehl, B. Good, and A. Kleinman, 423–447. Berkeley: University of California Press.

Flaherty, M. 2011. *The Textures of Time: Agency and Temporal Experience*. Philadelphia: Temple University Press.

Frank, A. W. 1997. "Illness as Moral Occasion: Restoring Agency to Ill People." *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 1 (2): 131–148. doi:10.1177/136345939700100201.

Greco, M. 1993. "Psychosomatic Subjects and the 'Duty to Be Well': Personal Agency within Medical Rationality." *Economy and Society* 22 (3): 357–372. doi:10.1080/03085149300000024.

Guba, E. G., and Y. S. Lincoln. 1994. "Competing Paradigms in Qualitative Research." In *Handbook of Qualitative Research*, edited by N. K. Denzin and Y. S. Lincoln, 105–117. Thousand Oaks, CA: Sage Publications.

Haavind, H. 2007. "Accountability in Persons. What is in the Telling to Others about Yourself?" In *Magtballader [Plays in Power]*, edited by D. Staunæs, and J. Kofoed, 159–178. Copenhagen: Danmarks Pædagogiske Universitets Forlag.

Hanckel, B., S. Vivienne, P. Byron, B. Robards, and B. Churchill. 2019. "That's Not Necessarily for Them': LGBTIQ + Young People, Social Media Platform Affordances and Identity Curation." *Media, Culture & Society* 41 (8): 1261–1278. doi:10.1177/0163443719846612.

Hardgrove, A., E. Rootham, and L. McDowell. 2015. "Possible selves in a precarious labour market: Youth, imagined futures and transitions to work in the UK." *Geoforum* 60: 163–171.

Hay, M. 2010. "Suffering in a Productive World: Chronic Illness, Visibility, and the Space beyond Agency." *American Ethnologist* 37 (2): 259–274. doi:10.1111/j.1548-1425.2010.01254.x.

Henningsen, P., P. Fink, C. Hausteiner-Wiehle, and W. Rief. 2011. "Terminology, Classification and Concepts." In *Medically Unexplained Symptoms, Somatisation and Bodily Distress: Developing Better Clinical Services*, edited by F. Creed, P. Henningsen, and P. Fink, 43–68. Cambridge: Cambridge University Press. doi:10.1017/CBO9780511977862.003.

Holland, D., and K. Leander. 2004. "Ethnographic Studies of Positioning and Subjectivity: An Introduction." *Ethos* 32 (2): 127–139. doi:10.1525/eth.2004.32.2.127.

Kirmayer, L. J., D. Groleau, K. J. Looper, and M. D. Dao. 2004. "Explaining Medically Unexplained Symptoms." *Canadian Journal of Psychiatry. Revue Canadienne de Psychiatrie* 49 (10): 663–672. doi:10.1177/070674370404901003.

Lambek, M., ed. 2010. *Ordinary Ethics: Anthropology, Language, and Action*. New York: Fordham University Press. https://ebookcentral.proquest.com.

Leder, D. 1990. *The Absent Body*. Chicago, IL: University of Chicago Press.

MacDougall, D. 2006. *The Corporeal Image: Film, Ethnography and the Senses*. Princeton, NJ: Princeton University Press.

Marcus, G. E. 1995. "Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography." *Annual Review of Anthropology* 24 (1): 95–117. doi:10.1146/annurev.an.24.100195.000523.

Marks, E. M., and M. S. Hunter. 2015. "Medically Unexplained Symptoms: An Acceptable Term?" *British Journal of Pain* 9 (2): 109–114. doi:10.1177/2049463714535372.

Mattingly, C. 2010. *The Paradox of Hope: Journeys through a Clinical Borderland*. Berkeley: University of California Press.

May, Carl, Gayle Allison, Alison Chapple, Carolyn Chew-Graham, Clare Dixon, Linda Gask, Ruth Graham, Anne Rogers, and Martin Roland. 2004. "Framing the Doctor-Patient Relationship in Chronic Illness: A Comparative Study of General Practitioners' Accounts." *Sociology of Health & Illness* 26 (2): 135–158. doi:10.1111/j.1467-9566.2004.00384.x.

Moulin, V., C. Akre, P.-Y. Rodondi, A.-E. Ambresin, and J.-C. Suris. 2015. "A Qualitative Study of Adolescents with Medically Unexplained Symptoms and Their Parents. Part 1: Experiences and Impact on Daily Life." *Journal of Adolescence* 45: 307–316. doi:10.1016/j.adolescence.2015.10.010.

Ortner, S. 2005. "Subjectivity and Cultural Critique." *Anthropological Theory* 5 (1): 31–52. doi:10.1177/1463499605050867.

NESH 2006. Forskningsetiske retningslinjer for samfunnsvitenskap, humaniora, juss og teologi. NESH (The National Committee for Research Ethics in the Social Sciences and the Humanities).

Peveler, R., L. Kilkenny, and A. L. Kinmonth. 1997. "Medically Unexplained Physical Symptoms in Primary Care: A Comparison of Self-Report Screening Questionnaires and Clinical Opinion." *Journal of Psychosomatic Research* 42 (3): 245–252. doi:10.1016/S0022-3999(96)00292-9.

Pink, S. 2007. *Doing Visual Ethnography*. London: Sage Publications.

Risør, M. B. 2010. "Healing and Recovery as a Social Process among Patients with Medically Unexplained Symptoms (MUS)." In *The Taste for Knowledge. Medical Anthropology Facing Medical Realities*, edited by S. Fainzang, H. E. Hem, and M. B. Risør, 133–149. Aarhus: Aarhus University Press.

Rosendal, M., T. Olde Hartman, A. Aamland, H. Van der Horst, P. Lucassen, A. Budtz-Lilly, and C. Burton. 2017. ""Medically Unexplained" Symptoms and Symptom Disorders in Primary Care: Prognosis-Based Recognition and Classification." *BMC Family Practice* 18 (1): 18. doi:10.1186/s12875-017-0592-6.

Swanson, L. M., J. C. Hamilton, and M. D. Feldman. 2010. "Physician-Based Estimates of Medically Unexplained Symptoms: A Comparison of Four Case Definitions ." *Family Practice* 27 (5): 487–493. doi:10.1093/fampra/cmq051.

Taylor, C. 2002. "Modern Social Imaginaries." *Public Culture* 14 (1): 91–124. doi:10.1215/08992363-14-1-91.

Vigh, H. 2009a. "Motion Squared: A Second Look at the Concept of Social Navigation." *Anthropological Theory* 9 (4): 419–438. doi:10.1177/1463499609356044.

Vigh, H. 2009b. "Wayward Migration: On Imagined Futures and Technological Voids." *Ethnos* 74 (1): 91–109. doi:10.1080/00141840902751220.

Vigh, H. E. 2006. "The Colour of Destruction: On Racialization, Geno-Globality and the Social Imaginary in Bissau." *Anthropological Theory* 6 (4): 481–500. doi:10.1177/1463499606071598.

Waage, T. 2013. "Seeing Together: Towards a Shared Anthropology with Visual Tools." In *Transvisuality: The Cultural Dimension of Visuality*, edited by T. Kristensen, A. Michelsen, and F. Wiegand, 157–173. Liverpool: Liverpool University Press.

Waage, T. 2016. "Confronting Realities through Reflexive Visual Storytelling. Ethnographic Film Courses for Teenage Girls." In *Quand les professionels de la santé et des sciences sociales se rencontrent*, edited by L. Purchez, 105–115. Paris: Éditions des archives contemporaines.