

‘Not a film about my slackness’: Making sense of medically unexplained illness in youth using collaborative visual methods

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Abstract

Persistent medically unexplained symptoms (MUS) have debilitating consequences for adolescents, dramatically altering their social world and future aspirations. Few studies have focused on social and moral aspects of illness experience relevant to adolescents. In this study, the aim is to explore these aspects in depth by focusing on a single case, and to address how young people attempt to create social accountability in a search for meaning when facing illness and adversity. The study is based on a view of meaning as dialogically constituted during the research process, which calls for the use of collaborative film methodology and life-mode interviewing. With a dialogic-performative approach to a narrative emplotment of MUS, we present Peter as intentional and purposive, and as a person who in a reflective process of meaning making claimed his own voice and developed his own strategies of coping with his illness. The analysis brings forward a narrative of suffering, hope, and intentionality that is configured by the immediate limited possibilities of agency due to Peter's medical condition. It is, however, configured to an even greater degree by aspirations, i.e. to become an accountable person through social experiences and to meet sociocultural and moral expectations of being an adolescent. The study provides insight into relational and existential aspects of meaning making in dealing with contested illness in youth, and points to the potential of visual and other experience-near methods for supporting adolescents in their coping attempts and in overcoming communication barriers in everyday life and clinical encounters.

Keywords: adolescence, contested illness, dialogic-performative, illness experience, meaning making, MUS, narrative, visual methods, youth

Introduction

For a substantial proportion of people presenting chronic symptoms of headache, dizziness, pain or fatigue, medical assessment is unable to establish a clear diagnosis. The category 'medically unexplained symptoms' (MUS) emerges when persistent illness experiences and biomedical systems of classification do not overlap. Studies report that MUS account for around 20 per cent of GP consultations (Rosendal *et al.* 2005). Most research has concentrated on adults, even though studies have shown a similar prevalence of MUS in children and adolescents (Farmer *et al.* 2004). Among children and adolescents, the

prevalence of MUS has been estimated at up to 25 per cent (Eminson 2007). Recurring debilitating symptoms may have a profound effect on young people's lives and the transitional and developmental tasks they are facing, leaving them unable to attend school, take part in physical activities, or function socially (McWilliams *et al.* 2016, Moulin *et al.* 2015a). While most research on MUS has focused on aetiology, qualitative studies have contributed to our understanding of the consequences, experiences, and efforts of meaning making from adolescents' own perspective (Karterud *et al.* 2016, Kornelsen *et al.* 2016, Moulin *et al.* 2015a, 2015b). The challenges for young people experiencing MUS are different from those faced by adults. Not only do they have to make sense of the serious and enduring violations of self-respect and embodied self-control that accompany the symptoms, they also have to find ways to reorganise developmental aims and domains for social participation. Dropout, isolation from friends, increased dependency on parents, and disruption of future ambitions stand in the way of following an inscribed pathway that supports a personal developmental trajectory from youth to adulthood. The illness-induced need for care and dependency is detrimental to the task of growing up. More research on contested illness conditions in youth is needed, especially studies that focus on how adolescents attempt to make sense of and cope with specific developmental challenges amplified by the symptoms, and embodied and social aspects of the illness experience (cf. Karterud *et al.* 2016, Risør 2010).

Subjective experience and embodiment

The central role of subjective illness experience is well documented in social studies on health (Kleinman 1988). Biehl *et al.* (2007:12-13) argue, however, that research is still needed to develop our understanding of peoples' inner life processes and affective states, their lived experiences of risk, values and envisioned futures, while also accounting for "vulnerable, failing and aspiring human beings" (*ibid.*). In this way, Biehl *et al.* wish to leave theories of subjectivity that have been too dehumanising, and to bring forward central concerns that display the fractured nature of subjectivity. In other words, this represents a focus on the constitution of persons through social experience, the transformations of how we value life and relationships, what it means to feel and regard oneself as human, and how this is related to what may be understood as affect, agency or morality, which is always both subjective and social (*ibid.*).

The concept of embodiment refers to the body as a source of subjective and intersubjective experience through which the individual constitutes its existence. Rather than taking the body for granted as ‘an object’ for study separated from consciousness, approaches to embodiment explore “the ground of perceptual processes that end in objectification” (Csordas 1990, 1994, Merleau-Ponty 1962). These processes are understood as ongoing. Csordas (1990) develops and broadens the concept of embodiment by combining the phenomenology of Merleau-Ponty with Bourdieu’s (1977) theory of practice and the concept of the habitus. The habitus accounts for predispositions for certain ways of acting, but these predispositions are constantly modified. With this combination, analyses of embodiment may explore how indeterminate modes of engagement in the world such as practices and perceptions are made from the vantage point of socially informed bodies. The concept of embodiment may thus bridge the levels of lived experience and practice as well as situating these within historical and sociocultural contexts (Desjarlais and Throop 2011).

In line with this sociocultural phenomenology developed by Csordas and others (1990, 1994), and more recent conceptualisations of subjectivity (Biehl *et al.* 2007), we understand subjective experience as a complex, embodied process shaped within specific contexts. However, we see subjectivity not only as “the outcome of social control or the unconscious”, but also as “the ground for subjects to think ... and ... feel through” (Biehl *et al.* 2007: 14-15) their challenges, and to make and remake meaning in dialogue with moral stances in their sociocultural contexts. To make sense of embodied engagements and account for subjectivity (Biehl *et al.* 2007), it is therefore necessary to bring forward both individual and collective processes of ongoing, indeterminate interpretation.

Social processes of healing and recovery through narrative meaning making

In research on recovery, healing processes have been demonstrated to take place beyond clinical contexts, as active and ongoing processes of meaning making in everyday life. Patients are shown trying not only to get rid of their symptoms, but also to live meaningful lives, belong, and uphold an identity separate from illness (Davidson and Chan 2014). Some studies have shown that patients experiencing MUS perform a range of activities directed towards healing and recovery, actively engaged in finding meaning and trying to manage their daily lives (Risør 2010, Whyte 2005). Consequently, it has been suggested that the illness experiences and health-seeking behaviour of patients with MUS should be described as a continuous social healing process (Risør 2010). In this line of thinking, ‘health’ is

understood not only as a medical or biological definition referring to the absence of illness, but also as contingent on social and moral contexts. By extension, ‘healing’ is not only the removal of disease, but covers a hybrid of physical, mental, social, and existential contexts, transforming the relations between self, body and the social world (*ibid.*).

One way to explore the process of healing is through the theoretical lens of narrative. Central to a narrative approach is the development of a phenomenological understanding of the unique order of meaning constitutive of human consciousness (Crossley 2000). One of the main features of this ‘order of meaning’ is the experience of time and temporality. Narrative emplotment (Mattingly 1994) involves making a configuration in time, creating a whole out of a succession of events, thereby rendering each individual event understandable as part of a larger and coherent whole (Riessman 2008). To gradually emplot unresolved symptoms, suffering, and inarticulate feelings into a meaningful narrative creates a sense of control and purpose that pushes us towards action (Bruner 1991, Bury 1982, Frank 1995, Kleinman 1988). This might prove especially challenging, but be even more essential, when one is faced with life-altering circumstances like the experience of a long-term medically unexplained illness.

Recent decades have seen a burgeoning of the literature on illness narratives in the social sciences (Bell 2000, Bury 2001, Hydén 1997, Riessman 2003), and some of this research has focused specifically on illness experiences in patients with MUS (Kirmayer 2000, Nettleton 2005, Nettleton *et al.* 2005). Most of this research, however, has been based on clinical encounters, with an emphasis on experiences determined by healthcare settings (Nettleton 2005, Risør 2009, Salmon *et al.* 2004). Little is known about people’s recovery processes in an everyday context, focusing on the social aspects of healing.

In our study, we look at meaning making of suffering through the construction of narratives as an intersubjective process in everyday encounters. Based on research on the challenges of persistent MUS in adolescence, and a performative and collaborative approach that emphasises narrative as social action, our aim is to explore the social and moral aspects of illness experiences by looking at the process of creating social accountability and meaning through dialogical-performative narrative emplotment (Bakhtin 1981, Mattingly 1994).

Methodology

Study Design

As a research group with a background from psychology and anthropology and previous experience of working with adolescents in clinical and research contexts, we were interested in relational and social processes in the understanding and handling of illness in youth. Aiming to explore the process of accountability and meaning making, and the social and moral aspects of illness experience, the first authors organised film courses and conducted interviews with adolescents recruited from the local primary care services and university hospital.

In order to capture performative aspects, we chose a narrative approach (Bakhtin 1981, Mattingly 1994, Riessman 2008). A performative approach emphasises narrative as action and as an intentional project, and analysis shifts from the 'told' to the 'telling' (Mischler 1995). Individuals negotiate how they want to be known in the stories they create collaboratively with their audiences. Adding to such performances, research has highlighted the potential of visual methodologies in the study of health and illness, particularly the ways in which participants interpret, give meaning to, and make sense of their experiences (Chalfen and Rich 2007, Guillemin and Drew 2010). Visual methods are powerful tools for eliciting individual experiences and thus offer new perspectives from which to view a phenomenon (Pink 2007). These may include embodied aspects of experience as well as culturally inflicted relationships (MacDougall 2006, Pink 2006, 2007, Stoller 1997). Visual collaborative methodologies are often applied in youth research as tools to promote more empowering research relationships and to facilitate and complement ways of understanding across social, cultural and generational communication barriers (Chalfen and Rich 2007, Johnson and Alderson 2008, Waage 2013, 2016).

Recruitment and sampling

The participants for this study were recruited by contacting health professionals in different child and adolescent services, requesting them to engage young people who experienced debilitating symptoms that had remained a long-term challenge for health professionals to medically understand, explain and treat. The health professionals were encouraged to contact the first authors if they had patients or service users who might be interested in participating and sharing their experiences. Arrangements for meeting possible participants were made with the health professional, and at an introductory meeting between the health professional, the young person and the researcher, further information on the study was given and a final decision on participation was taken. Eleven adolescents were recruited, seven of whom

participated in some variant of the film course. The results presented in this article are based on one of the participants in the film course, Peter, who had been struggling with symptoms of fatigue, dizziness and pain for the six months prior to our first encounter, and had dropped out of school and leisure activities as a consequence of these symptoms.

The case

There were several reasons for purposefully selecting Peter's case for in-depth analysis. During the initial steps of the analysis, his case gave extensive and specific answers to the questions we were interested in exploring, namely, how young people might make sense of the experience of bodily symptoms and suffering that defy explanation from medically approved notions of disease, and the disruption of social life and future aspirations that follows. Peter's experiences and the way he enthusiastically took part in the dialogical exchanges with us and his engagement in the process of filmmaking evinced both the psychosocial consequences of MUS and the search for trajectories of change. His story gave a thick description of the search for meaning in dealing with medically unexplained illness in youth. Peter's way of dealing with his symptoms and altered life circumstances made us aware that illness can be dealt with in different ways, not only by handling or getting rid of the symptoms, but by reorienting into another way of understanding oneself, one's future and the social world.

Data collection

The data for this article consists of ethnographic observations from 14 film workshop sessions over one year, Peter's film "*Derailment*", as well as six interviews held concurrently with the filmmaking process. The film sessions were partly conducted individually and partly in a group with other young participants. The interviews were based on an adapted version of the life-mode interview (Haavind 2007, 2014), where the participant is asked to describe activities throughout the day. The focus is on everyday life, rather than directly addressing experiences of symptoms and bodily constraints, which we believe to be an advantage when talking to adolescents and children, from both a methodological and an ethical perspective (*ibid.*).

We based our visual methods upon the collaborative youth gaze methodology (Waage 2013, 2016), where young participants are invited into a small workshop setting to make individual films about a topic close to their experiences. Dialogue during the filmmaking process aims to create momentary common ground through communicating otherwise unavailable or hard-

to-reach aspects of their experiences (Pink 2006, 2007), and opening up reflective processes where individual interpretations and dilemmas may be explored (Carlson *et al.* 2006, Johnson and Alderson 2008).

Analysis

The analysis was conducted with an explorative approach, inspired by a dialogic-performative approach to narrative analysis (Frank 2010, Holquist 2002, Riessman 2008, Shotter and Billig 1998). This development of narrative analysis is informed by the ideas of human relations as dialogue developed by theorist Mikhail Bakhtin (1981). The dialogic-performative approach focuses on both thematic content and performative aspects in the construction of narrative, e.g. the narrator's strategic choices in the illness narrative, positioning of characters, audience, and self (Riessman 2003). Intersubjective and co-constructive aspects were present in both the collaborative nature of our data production and the analytic process throughout the project, and are elaborated in detailed processual descriptions in the presentation of the findings. Both researcher and participant contributed to the data and the interpretation and analysis of these data. The researcher role becomes equivocal in this process, being both a part of the field of study and an observer of the same field. As researchers and participants explored themes in collaboration both in interviews and in the film group, subject-object relations could be said to have been "reworked and remodeled in ways that subtly alter the balance between actors and those acted upon" (Jackson 2002: 4), allowing participants to feel active and engaged in an ongoing reflective and communicative process (Waage 2013). The analytic voice of researchers engaged in a dialogical relationship with a participant shares authority as one of many, open to contestation by the research subject (Frank 2005). In our analytic process and text, we emphasise "the participant's own engagement [in his] struggles of becoming" (Frank 2005: 968), rather than applying potentially finalising, static themes and typologies to our case. These characteristics of a dialogical research relationship strongly influence the representations in this study, in the direction of a more dynamic, open-ended and less externally finalised understanding of who the participant is and may become.

At the first stage of our analysis, the first authors looked at textual and visual content in line with general approaches for thematic analysis, considering overarching themes in the personal narrative. We discussed immediate and preliminary interpretations with the rest of the research group, as well as in our conversations with Peter, developing and consolidating

the analysis through shared exploration and reflection. The theme “derailment” was a concept that first arose in the negotiation and dialogue with Peter, and was further developed into two main themes in discussions with the research group. During this reflection process, we became interested in performative actions as well as structural elements, asking why a particular narrative was produced in a particular context, for whom, and for what purpose. We explored in greater detail how the accounts were produced interactively and dialogically and hence performed narratively (Bakhtin 1981). Narratives are polyphonic, containing several different voices, such as hidden internal politics, historical discourses and ambiguity (Riessman 2008). Thus, we started to look for less obvious voices, hidden or taken-for-granted discourses, gaps and indeterminate sections that related to shared discursive practices in social, cultural and theoretical contexts (Davies and Harré 1990). By engaging in this type of re-contextualisation with the research material, a larger narrative about long-term illness in youth and coping emerged; this included both subjective and performative aspects in a story of becoming accountable.

Ethics

The Norwegian Centre for Research Data (NSD) provided approval of this study in August 2014 (ID 39362). We adhered to ethical scientific conduct and ensured user involvement and informed consent throughout the study. Our participant was informed that we would publish a case study based on the conversations and collaborative process with him. Before our last encounter, we contacted a youth organisation working with film, to enable him to maintain his involvement in the field if he so desired.

Findings

1. Derailment I

We start our co-constructed narrative by presenting Peters’ story of past events that he, through his ongoing narrative work, came to understand as leading up to where he found himself at that time. Through the dialogical employment of the narrative and the process of exploration, Peter came up with the metaphor of railways as useful for portraying his experience of disruption. This first theme concentrates on his story of this experience, where he used the idea of “derailment” as a description of the dramatic altering of his social world and future aspirations that the onset of illness left him with.

1.1 A purposeful actor encountering obstacles on his path

Peter was from a middle-class family. In his early teens, Peter's interests were mainly school and soccer. Peter's dream was to be a professional soccer player, and his future plans were to go to a high school that specialised in sports to fulfil this dream. Peter shared his strong interest in sports with his father and brother, and he knew most of his friends through a soccer team. In the story of these years, Peter described himself as mostly happy, although he sometimes experienced headaches and fatigue, needing to be away from school and soccer practice because of it.

Six months before his first encounter with us, Peter enrolled in the sports high school as planned. At that point, he was starting to feel worn out more often than before, experiencing increased symptoms of headache and dizziness. Peter felt these early symptoms to be a stress reaction due to strong pressure to achieve and to find his place in a new environment. Peter also described feeling self-conscious, shy and uncomfortable, and he was beginning to feel unsure of the future.

"I felt a bit uncomfortable. Even with people I knew and went to class with. I just felt it was uncomfortable talking to them. It felt like they were ignoring me. I felt completely uneasy... I don't know. Maybe I'm more vulnerable... I can't exactly say I'm the most sociable of people, and I'm also a bit shy. And that doesn't exactly help when you're ill a lot of the time as well."

When talking to us and looking back on his life, Peter wondered whether his uneasiness had always been there, and he was beginning to feel that he had a character flaw that had made it more difficult for him to attain his goals. Peter's narrative is characterised by his experience of internal and external conflicts and obstacles that he felt he needed to overcome to be able to continue on the path of becoming an accountable young man (Frank 1995, Haavind 2007).

1.2 Breaking point

As his bodily symptoms intensified, they took up more and more space in Peter's awareness. Peter told us that the *"illness put his life on hold"* when he suddenly experienced a physical breakdown in a training camp and had to leave abruptly. At first, he was not too worried about what had happened to him, thinking that it would pass after a while. Peter even found it slightly comfortable to be able to get a break from all the pressure he had experienced lately.

However, as Peter soon discovered, the difference in this episode was that he was not getting better as he did before:

"It had been a bit... high school was a bit rough. It had taken a lot of my energy, and the trip had taken a lot of my energy. I felt worn out. The first two weeks were OK, I felt comfortable. It wasn't that bad. But it started to... when it lasted for longer, I started to feel worse."

As time went by, the experience of not getting better was manifested as a critical event in his life (Jackson 2002). Peter sometimes had a few days or hours when the symptoms were less intense, but they never dissipated completely, and soon they returned with even more strength than before. In this part of the narrative, the obstacles Peter was facing became greater and his illness drama intensified (Mattingly 1994).

1.3 Isolating experiences and a dawning quest

Peter was no longer able to follow lessons in school, and had to give up soccer practice. He conveyed a strong feeling of isolation and loneliness when describing his days at home. Peter mostly spent his days alone, sitting in bed in his room watching films, reading or scrolling through social media online. His brother and parents seldom came down to his room, and they rarely did anything together as a family. Peter described himself as distanced from friends and family life, seldom interacting or sharing anything of emotional importance to him.

In conversations with us and in film sessions, he was trying to make us understand how isolating and existentially difficult this experience of not belonging had been for him, and how important it was for him to make people around him understand the way things were:

"I just want people to see - to sort of sense that feeling of isolation, loneliness and insecurity."

This project of making people around him understand, thereby breaking down the barrier between himself and others and stepping out from the sidelines, seemed to become an important aspect of what he was trying to achieve in his contact with us. This project was what drove Peter's narrative forward, rendering his experiences meaningful and thereby pushing him to act, take risks and move towards change (Mattingly 1994).

1.4 Clinical encounters and their role in the project of meaning making

As time passed and his symptoms did not disappear, medical examinations commenced. In the medical encounter, his fluctuating embodied experiences were explained in terms of a preliminary disease model, as the health professionals tried to provide answers. His first encounter was with his general practitioner, who referred him to a physiotherapist, followed by referral to hospital to see several different specialists, and eventually to see a psychologist. All of the health professionals had different theories in attempting to explain his ailments, and they discussed at length what diagnosis to give him, sending him to all kinds of tests and examinations. He himself was not greatly concerned about the ongoing process, however, feeling that it had little relevance to him what the physicians and specialists decided to call his problems. He had a feeling that none of them could help him by giving him answers to his questions on how long his problems would last and what significance they would have in shaping his future.

"I'm not thinking too much about it... what I'm thinking about is when it will pass. That's what I'm concerned about. The diagnosis isn't that important to me. (...) Or.. Well, if there was anything drastic to be done to improve the situation, but.. there isn't anything.. so."

Finding himself in a situation without any effective support from medical explanations and treatment, he had to wait for an indefinite time for the symptoms to improve.

The medical diagnostic language had little relevance to Peter, as he was trying to find a voice of his own in figuring out what his illness meant in his life, and for his future. What he considered important was to build a future for himself that he and others could acknowledge, making sense of the biographical disruption that illness had left him with (Bury 1982).

2. Derailment II: Another developmental story

Through reflective encounters in introductory film sessions and interviews, we became aware of Peter's ongoing efforts at narrative reconstruction (Williams 1984). The extent to which Peter was negotiating with moral dilemmas in his everyday life, and with available social and cultural resources, opened our eyes to his capacities as an active narrative subject (Frank 2016), despite his uncertainty. Our project provided him with a suitable first avenue to filmmaking, but more importantly, Peter seemed to be able to utilise our communicative methods to support his own emerging developmental project. Using collaborative methodology allowed us to take part in Peter's ongoing work at making sense through

dialogue and negotiation. Examples from this process may serve to illustrate how meaning is not simply found, but created through active employment by positioned subjects (Frank 2016, Mattingly 1994, 2013, 2014).

2.1 Everyday experiments in developing a new interest: Peter takes control

Peter's ideas about what he might do in the future were gradually adjusted. Still hoping to be able to "get far" while "doing something he liked", he spent his days trying out "new interests". About two months into his sick leave from school, Peter began to develop "an extreme interest in film". While he had difficulty with physical exertion and extensive reading, watching films was something he felt more able to do. He rediscovered a documentary series on the history of film (Cousins 2011), "this time" having "enough time to get a better understanding". Peter's list of "186 favourite films so far", published on his film community website account, may illustrate the extent of his engagement. Peter told us his goal was "to know" and "to watch as many quality films as possible" on days when he had enough energy, to keep from "coming to a halt", now that he was unable to attend school and other social activities:

"At least I'm doing something, I'm not just gaming."

Defined by Peter as a forward-oriented and meaningful activity, films played a crucial role in his everyday life coping with illness. Watching films was not only a way to pass time, adapted to the constraints of his illness, but it also played an existentially significant role in managing hopes and fears for his future. Peter was trying out "a new interest", practising for a potential new role as someone who was knowledgeable about films as a way of narrative re-envisioning (Mattingly 2013). Participating in our research project was an opportunity to develop further his newfound engagement in film, thereby supporting his ongoing re-envisioning and developmental project.

2.2 Not a film about slackness: negotiations in a mutual process of sense making

During collaborative filmmaking, we as facilitators and researchers took part in mutually positioned negotiations with Peter about how to spend our time together. This enabled Peter's boundaries of self-representation to become more visible, positioning him as an active subject in a moral historical and sociocultural context.

Peter was informed at recruitment that the objective of the film workshop was to facilitate the making of short documentary films. Most of all, he said, he would like to make a poetic film inspired by his favourite directors, preferably surrealistic with no apparent meaning, and with the use of professional light and sound equipment. During the initial interviewing, Peter questioned the prospect of making a film about his experiences. While three others in the film group chose to film scenes from their living spaces as an introductory assignment, Peter asked if he could film “*a place he liked*” instead.

“Others are in their room a lot. I’m almost only there. (...) My room’s boring. I lie in bed watching films. I look slack. I don’t want to make a film about my slackness. I want to make a symbolic film instead.”

Through making a symbolic film, Peter could indirectly learn from his favourite directors and play with the idea of someday becoming a name in film. The intellectual artist role was one of the available positions for him to try out, now that the athletic path he had been following was no longer available. But we also understood from the way he spoke about his “*slackness*” that he felt embarrassed about the uneventful way he was living his life then and the messy state of his room. It seemed to us that “*slackness*” had both a physical and moral meaning for Peter, and we gradually realised how portraying his life “*in the comfort zone*” where he “*looked slack*” might not be supportive of his hopes to reintegrate as an accountable young man with a new interest. Peter told us that his biggest fear in life was to be “*a failure*”. He emphasised that he found it pleasurable to “*be in the comfort zone*”, but probably “*should challenge*” himself by “*coming out of*” it. Peter described people who were successful as people who were “*able to relax*” without being perceived as “*slackers*”, and who could handle pressure without the risk of burnout. In the course of such negotiations, and in the gradual emplotting of a storyline that made sense to Peter, we could trace a moral ‘duty to be well’ (Greco 1993: 340), to regulate and handle risk according to internal and external demands. By extension, we became aware of the importance for him to experience our assignments as meaningful in his own broader process of healing (Mattingly 1994).

2.3 Making sense of embodied experience by using film

Peter told us that watching certain types of films “*makes me become completely calm*”, despite initial “*tenseness*” and fatigue, thus alleviating his symptoms. He explained how the most “*interesting*” films enable new emotive and reflective responses:

“(...) they make you... feel emotions, and you get new ideas and new... ways of thinking ... see things a bit differently than before.”

Peter told us he “*had a certain director in mind*” when filming his first scenes. Specifically, he tried to express the resonant moods of Tarkovsky’s films of “*isolation*” and “*insecurity*”, but also beauty that he was “*longing for*” while being isolated:

“There’s an emotion there, that I’m not so aware of (...) I want to inject an emotion into the viewer.”

Peter tried to communicate aspects of his own experiences that he found challenging to put into words by referring to embodied ways of knowing. As we see it, Peter used both nature and visual media art representations of emotive states as tools to change and redefine painful aspects of his experience. Revealed through the language of visual and symbolic art, his challenges may be intuitively re-interpreted as inherently human and as interesting resources in new paths of realisation. Fatigue and dizziness appear as interesting “*dreamlike*” states, a term Peter sometimes applied to his own symptoms. Trying to express and at the same time influence and regain control over his embodied experiences, Peter used this knowledge as an interpretive and symbolic layer of his own filming.

2.4 Emplotting a character on a forward-oriented path

As the editing phase of our workshop began, Peter imported as many as 223 “*symbolic*” and “*aesthetic*” single clips to his editing timeline, of two hours duration in total, in the chronological order of their filming. We began to explore the significance of what he had filmed, positioned as film instructors and researchers with previous experience in social work and clinical psychology, motivating him to make a selection for a much shorter film with a clear message or theme. Pressured to cut back, he gradually reduced the two hours to a structured 12-minute long film. His favourite clips kept some of their chronology in this process, but were emplotted into three distinct acts, representing “*phases*” that Peter identified that he had gone through since receiving a camera.

Through dialogue on the filmed material, his storyline gradually transpired, and our mutual understanding and interpretations were adjusted until a partial language or description was achievable. The way Peter approached and later re-interpreted the image of an empty moving swing, for example, was informed by his, as well as our, efforts at making and creating sense:

P: *It looked a bit dramatic... and I don't know if it was very personal but I thought it was nice, it was like it aroused emotion. (...)*

I: *But in the context it's in now, has it got (yes) new meaning?*

P: *Yes, there's a certain time, doesn't have to be childhood, just the end of activity in normal life. There, that wasn't what I did then but ...(...)*

I: *No... But when you're editing you add meaning to the clips.*

P: *Yeah, I do. It's that 'one plus one is three' (Yes!) (both laughing) (...) I think it's like a having to grow up type of film. (...). I can't say if I've grown up but I have a totally different opinion since I got ill."(...)*

Peter first filmed in an attempt to express and perhaps adjust embodied emotional states that may be interpreted as pre-reflective (Csordas 1990), and to communicate indirectly with a filmmaking role model by imitating symbolic language and music from his films. As Peter reflected with us upon different layers of meaning, his own embodied perceptions and practices were reinterpreted in ways that may have supported his process of knowing himself in new ways, using representations of passage into adulthood available in his sociocultural context.

2.5 New rails: redefining the illness experience

Despite his suffering, Peter explained in interviews that his situation was “*not all bad*”. He smiled when recounting some ways in which his lengthy period of isolation had also opened up possibilities “*to be alone and explore oneself*”, to develop “*interests you didn't know you had*” and to mature compared to his old self as well as compared to his peers. In the film workshop setting, he negotiated a presentation of self where his absence from school and social life may have been legitimate and valuable in bringing him forward on his path to adulthood. Emphasising his new active engagements, he provided an alternative story about himself to the otherwise available illness or dropout narratives represented by the self-presentations of other young participants.

Another example of Peter's continuous efforts at redefining his illness experiences was seen in dialogue over the last few sessions about a title for his film. Peter was inspired by one of the films he had seen more recently, where Tarkovsky uses “*waiting at a railway station*” as a metaphor for a life on hold. Peter reflects upon life being “*like a train journey moving forward between periods of time*”, and he placed a video of a train moving forward on its

rails as connecting clips between the three acts. “Wait!” he suddenly exclaimed during the last session, after playing with titles connected to his illness and to youth:

“I think I’m on to something! Derailment... Life passes ... begins and ends at the last station, sort of. And now, I’ve fallen off, or I’ve derailed. The connections have loosened. And I’m sort of trying to catch up with the locomotive by the force of my hands (...) (He smiles, laughs a little and pretends to be gripping a huge lever) I’ve fallen off the physical rails, and then I’ve found thought, another pair of rails. Ideas, relaxation. I must have had it in me, but I’m a bit unsure if I would have found it or maybe found it later.”

Seen in this way, Peter’s “derailment” from an acknowledged path to adulthood may entail a temporary space for morally legitimate work in reorientation. In the film workshop, as in everyday life, Peter experimented with new understandings, moral judgments and interpretations of the challenges he was experiencing.

2.6 Uncertain endings

Trying to accommodate our mutual communicative process of making sense, Peter temporarily entitled the three chapters in his film “*Inwards*”, “*Outwards*” and “*Free*”. These chapters came to symbolise dominant themes in his experience at the time, narrated into in a chronological process with a desired future ending of attaining recognition of who he was. He made it clear, however, that the title “*Free*” also came with an implicit question mark, a strong “*mood of insecurity*”.

Still in the process of making sense and hoping to effect an outcome, Peter suffered as much from the psychosocial consequences of his illness as from the actual bodily symptoms, a point made by multiple qualitative researchers (e.g. Frank 2016). As he worked his way out of isolation, strong feelings of uncertainty were mixed with hopes and desires for a solution. As we collaborated on the film narrative, the insecurity expressed by Peter became more visible to us, emphasised by the theme of gradually returning from a long period of isolation:

“That is if anyone can relate, they can think how this is an insecurity in coming out of the world. Like moving away from home for the first time (...) or coming out of prison (...) but when you come out of that zone you had - that phase you had – it’s not always easy or amazing to come back out.”

Each experiment in a new social context exposed Peter to radical insecurity (Arendt 1958), and provoked critique from others as well as self-critique (*ibid*: 311). In the end, Peter was

ambivalent about showing his film to his family and friends, worried that they might not understand what he was trying to communicate. This strong feeling of ambivalence about coming back out from isolation, between a fear that bridging the communicative gap between himself and his social context might be difficult, and a slight hope that this might succeed, is perhaps illustrative of the existential task that Peter was facing. Although narrative time featured Peter as a protagonist empowered to intentional action outwards and forward, it was also marked by suspense (Mattingly 1994). Would he overcome his obstacles? Because of this indeterminacy, Peter's story might be said to contain subjunctive elements, described as the dual and suspenseful nature of uncertain endings; this includes hope and possibilities, but also fear, ambivalence and uncertainty (Good 1994, Whyte 2005). Nevertheless, 'being in the subjunctive mode' might have also functioned as a coping strategy that allowed him to keep hope for recovery, by leaving several plots and interpretations open-ended.

Discussion

In our findings, we have presented a continuous, collaboratively made narrative of the life of Peter, his illness-induced "*derailment*" from his expected developmental path towards adulthood, and the process of re-interpretation through the research interviews and the making of a film. The collaborative process of filmmaking and interviews gave us insight into Peter's own understanding and handling of his life situation, showed us what was at stake for him at this particular trajectory in his life, and demonstrated Peter's active engagement in his process of coping. From the outside, the existential meaning of this work may be invisible. The collaborative nature of our methods, however, allowed us to come close to Peter's particular embodied experiences, highlighting the active work being done and making the complexity of his attempts of coping more visible.

In the first theme, "Derailment 1", an important finding is that Peter was less concerned with the symptoms in themselves than with their consequences. He described how his illness "*put his life on hold*", isolating him from social life with friends and family, and leaving him uncertain of himself and his future. Despite his intense symptoms and their consequences for his life, he was not concerned with the process of diagnostics, feeling that what health professionals decided to call his problems was of little relevance to him. He believed that the diagnosis would not provide him with answers to the questions of how long the symptoms would last and what significance they would have in shaping his future. This lack of interest in finding the cause of the symptoms and framing them within diagnostic language makes

Peter somewhat atypical as a patient with persistent MUS. A diagnosis typically “validates what counts as disease; offers explanations and coheres patients’ symptoms; legitimates illness, enabling patients to access the sick role; provides a means to access resources and facilitates their allocation; and forms the foundation of medical authority” (Jutel and Nettleton 2011: 793). Studies have found that patients experience medical labels as beneficial in terms of validating the sick role (Ogden *et al.* 2003) and as an essential precondition for coping (Woodward *et al.* 1995), although the picture is somewhat more complex in the long run with regard to contested illness conditions (Undeland and Malterud 2009). What our findings demonstrate is that Peter’s project was more about building a future for himself that he and others could acknowledge than about finding the cause and a name for his suffering. The health professionals he met on his way were unable to help him in this project, as they were more concerned with their own projects of labelling his symptoms. This finding suggests that in order to be able to help young people in their struggle to find meaning in their illness experiences and to support them in their transitional tasks, it is important to take into account their motivations, interests, and ongoing projects. This resonates with clinical research that has demonstrated the importance of a therapist being sensitive to the patient’s own efforts, or ‘plan’ for mastering her or his problems (Binder *et al.* 2008).

The theme “Derailment 1” further describes that an important aspect of what Peter was trying to achieve was to make people around him understand how isolating and existentially difficult his experience of dropping out from social arenas was for him: “*to really feel how he feels*”. This can be interpreted as a need for empathic understanding from those around him. Empathy has long been held to be a crucial element in helping relationships. Contemporary mental health practitioners rely on empathy to understand patients’ experiences and to maintain the interpersonal relatedness that facilitates helping and healing (Kirmayer 2008). Diagnostic language generally did not capture the existential and embodied aspects of Peter’s experiences, and therefore failed to facilitate empathic understanding; he therefore had to find alternative ways to communicate. There were thus two reasons for his eagerness to participate in our study. Firstly, the finished film, the process of filmmaking and conversations with researchers gave him an opportunity to communicate the embodied and existential aspects of his suffering to those around him, evoking the sought-after empathic response in his audience. Secondly, participation provided him with a possible new identity and an avenue to something he could see himself doing in the future.

The second theme, “Derailment 2”, describes Peter’s process of redefining his illness experience. We find that for Peter, the handling of symptoms was only one small part of what he was trying to achieve. Claiming his own voice in a reflective process of sense making seemed to be an important part of his ongoing project. The film workshop, conversations and negotiations with researchers and other young participants, and the reflective process in interviews, can be understood as different experiments in a moral laboratory (Mattingly 2013). Participants can try out new meanings and new identities in their ongoing project of making sense of a biographical disruption, constructing a new, meaningful and coherent narrative. Other studies have also pointed out that an important part of coping with chronic illness is to redefine one’s experiences, to find ways to live a meaningful life and to belong to and uphold an identity separate from illness (Davidson and Chan 2014, Good 1994, Risør 2010). In research on recovery, healing processes are understood as taking place beyond clinical contexts, as an active process of meaning making in everyday life. The collaboration with us as researchers seemed to facilitate and support this active process of meaning making, making room for relational and existential aspects in the process of coping with illness. This finding resonates with clinical research that suggests that in order to help patients cope with chronic illness, a holistic approach that supports the process of meaning making is a more valid approach than a strictly medical focus emphasising symptom reduction (Conrad and Barker 2010, Davidson and Chan 2014, Wampold 2001).

Our findings demonstrate that Peter was an active subject trying to make sense in a challenging situation, choosing, negotiating with, and responding to available social and cultural resources. Some studies have argued that adolescents with MUS have a tendency to use a passive or avoidant coping style (Hareide *et al.* 2011). The way Peter actively engaged in his own process of creating accountability and meaning demonstrated the opposite in his case. Gradually moving from chronological to narrative time, and emplotting phases symbolising an intentional movement outwards, Peter’s film came to reflect the themes and processes most crucial in his everyday life at the time. On the one hand, Peter experienced the psychosocial consequences of an illness anomalous to the diagnostic system as a “*derailment*” from his contextually expected path into adulthood, as a sort of rift in intersubjective life (Jackson 2002) or a biographical disruption (Bury 1982). On the other hand, as a narrative subject (Frank 2016), Peter was adapting this plot to be able to know himself within it. Actively involved in a narrative re-construction (Williams 1984), both outside and within our encounters, Peter’s disruption was re-interpreted into a space of

possibility and growth, providing his isolation with new meaning. Coming back “*out of the comfort zone*” is a concrete physical effort, but also involves necessary and valuable liminal work in preparing for reintegration after illness-induced isolation. According to this narrative plot, Peter was perhaps not even derailed, but simply reorienting into a better set of rails, more adapted to his strengths and weaknesses.

In his ongoing narrative work, it became important for Peter to communicate that his absence from school and social activities was a justifiable and valuable means to bring him forward in his dawning developmental project. In the history of film, Peter discovered new masculine role models that replaced the sports-related role models he used to have, showing him a way to handle the transitional tasks he was facing in becoming, despite his illness, an accountable young man still in line with cultural notions of masculinity. Instead of being a young boy who had failed, he constructed himself as an active agent with clear motivations and interests. In this light, Peter’s isolation need not be understood in terms of a pathological and inappropriate tendency for withdrawal and a passive coping style (Hareide *et al.* 2011), but rather as a morally legitimate need for a private space to rework and reorient himself in his new developmental project.

In the midst of his own narrative plot, Peter was in what can be understood as a subjunctive mode (Good 1994). Peter expressed considerable insecurity as to whether he would succeed in becoming an accountable young man, given his perceived faults and weaknesses. The finished film strongly expresses this feeling of suspense, especially in his final chapter “Free”, with its implicit question mark as an underlining of the strong uncertainty that Peter felt, but also a cautious hope and a feeling of excitement at the prospect of succeeding in his project. To Peter, the use of nature, music and dreamlike imagery was a way to both express and alleviate the feelings of suspense, existential loneliness and isolation. The creative and reflective process of visual, collaborative methodologies supported Peter in his subjunctive mode, and these methods therefore hold promise not only in research, but also in a therapeutic context, providing the participant with a language for multiple aspects of the embodied experience of illness (Furnman 1990, Johnson and Alderson 2008). The process of establishing a therapeutic bond in work with adolescents is commonly regarded as a challenging task (Binder *et al.* 2008). Visual methods have been shown to be especially fruitful when trying to engage children and adolescents (Chenhall *et al.* 2013, Gamlin 2011). We suggest further research on the potential in these and other experience-near methods for

overcoming communication barriers in everyday life and clinical encounters and producing a more person-centred practice, thereby helping patients in recovery from chronic illness.

Conclusion

Our study presents experience-near insights that may prove transferable to other cases and encounters with young people experiencing contested illness, despite obvious limitations to generalisation on the basis of a single case. By focusing on a single case, we are able to provide a thick description of subjective experience, capturing embodied experiences and processes of dialogically constituted meaning. The analysis brings forward a narrative of suffering, hope, and intentionality that is configured by the immediate limited possibilities of agency due to Peter's medical condition. It is, however, configured to an even greater degree by aspirations, i.e. to move on, to become an accountable person through social experiences and to meet sociocultural and moral expectations of being an adolescent. This could be used as a template for how adolescents with contested illness conditions might be met and understood. Also, because Peter is a boy exploring ways to become an accountable young man that are in line with cultural notions of masculinity, the case demonstrates that adolescents that struggle with long-term illness also grapple with identity issues and cultural values that are (among other things) highly gendered. Attention to these issues is important for health professionals as well as others that work to understand and support adolescents with long-term contested illness.

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