UiT The Arctic University of Norway

Faculty of Health Sciences, Department of Psychology

Terrains of Uncertainty

Communicative Challenges of Medically Unexplained Illness in Youth

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Preface

In 2012, three different departments at UiT The Arctic University of Norway, the Department of Psychology, the Department of Community Medicine (General Practice Research Unit), and the Department of Social Sciences (Visual Cultural Studies), started research collaboration on medically unexplained symptoms (MUS) in young people. Professor Mette Bech Risør had been working in the field of functional illness and medically unexplained symptoms from a medical anthropological perspective for several years and had seen the particular challenges these cases represented for communication in clinical encounters in general practice. Associate Professor Trond Waage had been researching youth cultures from an anthropological perspective, and had developed the visual methodology called "youth gaze", consisting of courses in self-reflective filmmaking for adolescents as a methodological tool to promote dialogue that could provide insight into their daily lives and personal experiences. Professor and specialist in clinical psychology, Catharina Elisabeth Arfwedson Wang, had both scientific and clinical experience in the fields of depression and chronic fatigue, prevention of mental health problems, low-threshold help and self-help for adolescents, and evidence-based and alternative treatment approaches. The three of them decided to apply for funding for a research project that would benefit from their combined experience in anthropology, visual methodologies and psychology in order to enhance knowledge of a specific group of adolescents that health professionals were struggling to understand and treat, namely those with persistent MUS.

In order to join this group, I wrote a research proposal for the position of PhD research fellow, and in September 2014 I started on my PhD journey. My plan was to explore communicative challenges in the understanding and treatment of medically unexplained symptoms in youth. Encouraged by cultural psychological conceptions of adolescents as active in transforming and constituting themselves (Carpenter-Song, 2009; Hauge, 2009; Jansen, 2010; Kofoed, 2008; Staunæs, 2003, 2005; Søndergaard, 2002), I was particularly interested in how young people experiencing dropout from school and isolation from social activities due to persistent MUS attached meaning to their experiences, how communicative practices could either assist or hinder important developmental trajectories, and how these practices appeared in health encounters and in everyday life.

In addition to the three senior researchers and myself, the research group included another PhD research fellow, Maria Fredriksen Kvamme. Her background was in social anthropology, supplemented with visual anthropology, and she had been working in low-threshold services for adolescents for several years, including offering film courses based on the youth gaze methodology developed by Trond Waage. Maria Kvamme and I worked together in organizing collaborative film courses for adolescents. Later in the project, clinical psychologist and professor emerita Hanne

Haavind, whose research was in interpersonal relationships and developmental change, joined the research group. She had extensive experience of developing and applying interpretational qualitative methods within psychology and related fields and had a particular interest in children and young people growing up in the context of their families and processes of change during psychotherapy. In addition, two students from postgraduate clinical psychology programs joined the research group briefly to explore the perspectives of health professionals working with MUS as a basis for their master's thesis.

Before starting my work as a PhD research fellow, I had been working as a clinical psychologist for some years, and had encountered several young people in the transition between childhood and adulthood struggling with persisting symptoms of fatigue or pain. They retreated from social settings and expressed difficulties with emotions, relationships with others and in finding out who they were and could become in increasingly demanding and uncertain social contexts. I had for some time been especially interested in identity development and the role of language and narrative in creating meaning and a coherent sense of self (Bruner, 1990), and for my master thesis I had written about how people create meaning in the aftermath of traumatic life events through interpersonal, societal and personal narrative reconstruction (Østbye, 2009). In addition, my clinical work had opened my eyes to relational and non-verbal aspects of psychotherapy and meaning-making processes (Abbas & Schubiner, 2018; Grzybowski, Stewart & Weston, 1992; Mitchell, 1988). My clinical approach could be termed a broadly relational psychoanalytical approach (Greenberg & Mitchell, 1983; Mitchell, 1988), one that emphasizes relational aspects in illness and healing, and sees the intersubjective co-construction of meaning in the analytic relationship as an important ingredient of therapeutic change. However, my clinical work with adolescents had shown me that it could be challenging to develop a therapeutic alliance and co-create a coherent narrative by relying on verbal expression alone. Existential meaning making in contexts of uncertainty could also entail finding other modes of shared expression such as the use of play, images, drawing and body language. The question of how to support the narrative work of young people with difficulties expressing themselves was what first sparked my interest in the use of ethnographic fieldwork and visual qualitative methodologies. I believe in the importance of coming close to, listening to and enabling "thick descriptions" (Geertz, 1973) of lived experience in order to improve clinical services and understand how to support adolescents in their developmental processes. Over the years of this research project, I have been able to map out and come close to the research participants' lived experiences and their attempts at creating meaning within terrains of uncertainty – existential, embodied, epistemic, ontological, and communicative. This dissertation is the result of my exploration of some of these terrains.

Acknowledgements

First of all, I would like to thank all the young participants that shared their stories, their creativity, their sincere enthusiasm and their time despite long-term struggles with fatigue, pain and illness. It has been a rich and valuable learning process for me to be able to glimpse the lives of so many brave and open-hearted souls. I would also like to thank all of the health professionals that have shared their wisdom, their insights and their time in order to give the research community more knowledge of how to understand and meet the challenges of medically unexplained illness in youth. The work you do is invaluable, and it is admirable that despite all the struggles, pressures, demands and difficulties in this field you maintain an attitude of curiosity and empathy in your everyday clinical encounters with young patients.

I would also like to thank the staff, leaders and patients in Birch Hill[1] rehabilitation facility. Without the opportunity to conduct fieldwork and participatory observation in a naturalistic setting, I would not have been able to understand so much of what actually takes place in a clinical context where the communicative challenges of MUS are most apparent. Thank you for making this happen, and for your openness and warmth in receiving me.

My gratitude also goes out to the Department of Psychology of UiT The Arctic University of Norway who gave me the opportunity to do this PhD. These years have enabled me to grow personally and academically. The clinical psychology research team has been a safe haven during the years I lived in Tromsø, and I have much appreciated the lunches, wine lotteries, coffee breaks and seminars with good colleagues. Thanks also to the Department of Psychology of the University of Oslo, my base during the final years of my PhD. Having an office to go to and seeing some familiar faces each day has surely kept me sane in my satellite existence.

My research group of Mette Bech Risør, Catharina Elisabeth Arfwedson Wang, Hanne Haavind, Trond Waage and Maria Fredriksen Kvamme also deserves my heartfelt gratefulness. I have really appreciated all of our stimulating discussions, and your analytical knowledge and theoretical reflections have been invaluable. Without the creative minds of Trond, Mette and Catharina and the idea of joining forces from medical anthropology, psychology and visual cultural studies, this research project would never have seen the light of day, so to you I am forever grateful. In that respect I would especially like to thank my supervisors Mette, Catharina and Hanne for each in their own way letting me find my analytical direction and always offering time, knowledge and helpful guidance. You have

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[1] Birch Hill is a fictional name I created in order to secure the anonymity of the research participants.

all given me support and have expanded my horizon in countless ways, and you have stood by me and encouraged me to continue my work even when my motivation fluctuated, pushing me to perform at my best and believing in myself. I would also like to thank Trond for his innovative visions, creativity and generosity, introducing me to the potentials of ethnographic filmmaking as well as the youth gaze methodology, and offering creative and nuancing comments from the anthropological perspective. I would also like to thank my fellow PhD student Maria whom I collaborated closely with in the initial planning of the project, in parts of the fieldwork and in the organizing of the film course for adolescents. Maria has been a curious, reflective and humorous partner in crime, that has made my journey in unfamiliar and uncertain terrains more enjoyable and less lonely. Thanks also to the psychology students Ida Pauline Granheim and Kjersti Kristensen for contributing to the study and conducting many of the interviews with the health professionals.

Last but not least, I would like to thank close friends and family for humorous and insightful reflections, interesting conversations, comfort, encouragement, practical help and welcoming breaks of laughter and fun. You know who you are.

Oslo, April 2020

Silje Vagli Østbye

Abstract

Background: Medically unexplained symptoms (MUS) are symptoms for which a treating physician or other health care providers have found no medical cause, or whose cause remains contested. Typical symptoms are persistent headaches, musculoskeletal pain, gastrointestinal problems, and fatigue. MUS are common in all areas of primary care as well as in specialty medicine. In children and adolescents, MUS have been found to cause substantial impairment in multiple domains of everyday life, as well as creating many layers of uncertainty both for the individual experiencing symptoms and for health professionals that try to understand and treat them. Dimensions of the relationship and communication between clinician and patient are shown in primary care studies to be decisive for subsequent illness pathways, potentially leading to adverse effects. However, further studies of communicative challenges for adolescents with MUS in specialist health care are needed in order to understand young people's experiences and needs, and to direct attention to consequences like falling out of school or giving up social life.

Aims: The overall aim of the present study was to explore communicative challenges in the understanding and management of MUS in adolescence in specialist health care operating in the interface between biomedical and biopsychosocial discourses of health and illness. More precisely, the aims were to investigate how adolescents and health professionals construct meaning by creating narratives and explanatory models, and by positioning themselves within discourses and social structures, in three different sites where uncertainty arose and had to be handled.

Methods: In order to elicit the lived experiences of the participants and enable a deep exploration of the meaning-making activities of adolescents and health professionals, a multi-sited ethnographic approach and a triangulation of traditional and more innovative and participatory qualitative methods were used. This resulted in three sub-studies:
For the first study, eight adolescents with MUS were interviewed about their participation in different social contexts using life mode interviewing. Five of them participated in the collaborative film course "Youth Gaze", making individual films about their experiences. Discussions and explorations of the film topics and footage led to joint reflections on important life events. The study resulted in the presentation of one case that demonstrated how a young male made sense of his experiences of illness and disruptions of social life and future aspirations through a combination of personal and cultural themes, which he named "Derailment 1" and "Derailment 2".
In the second study, 16 health professionals with extensive experience of working with adolescents with MUS in outpatient settings in secondary health care were interviewed. Ten of them were

interviewed individually, and six participated in a focus group discussion. The study resulted in a conceptual model of methodological and epistemological paradoxes.

The third study was based on fieldwork over two months in an inpatient rehabilitation setting. I observed clinical encounters and took part in a range of activities, as well as interviewing eight adolescents diagnosed with chronic fatigue (CFS/ME). Further, I talked with the nine health professionals whose job was to provide the adolescents with methods to cope with their affliction. The results highlighted different ways of handling communicative challenges. The professionals categorized cases on the basis of different dialogues and engagement in rehabilitation processes. This was demonstrated by the presentation of two “classic” and two “complex” cases.

Results: Adolescents with MUS struggle to reorganize their developmental aims and domains for social participation. In the process of dialogically constituted meaning, the participants challenged and expanded the social categories and the discourses made available for them, seeking to create their own subject positions by engaging in narrative work. For the young participants, the search for meaning was not contingent on clinical settings and medical labels, but rather a continuous process of everyday life in which they sought accountability and future prospects. This process was dependent not only on the subject’s own individual efforts but was to a large degree restricted and affected by various discourses. The communicative challenges in each study illuminated discursive terrains marked with uncertainties that could not be solved or removed. Therefore, health professionals were caught between different knowledge regimes and paradigms of thought that created paradoxes and dilemmas in their clinical work. These findings resonate with previous studies demonstrating the discrepancies between the ideal of holistic and integrative approaches and the reality of everyday clinical practice.

Conclusions: Drawing attention to the different value systems and knowledge regimes that underpin clinical reasoning may lead to a more reflexive practice in line with principles from patient-centered care. An examination of how meaning is ascribed, how categories intersect and how experience is accounted for in everyday activities in specific contexts offers a nuanced and contextualized understanding of the possibilities, challenges and limits among the subjects involved. The problem of explanation should be recast not in terms of its representational, objective ‘truth’ but rather in terms of the quality of its clinical effects. Finally, the research context in study one could be used as a template for how professional helpers might stay engaged and supportive of adolescents with MUS in finding alternative developmental processes and suitably adapted forms of everyday functioning.

List of papers

Paper I

Østbye, S. V., Kvamme, M. F., Wang, C. E. A., Haavind, H, Waage, T. & Risør, M. B. (2018a). 'Not a film about my slackness': Making sense of medically unexplained illness in youth using collaborative visual methods. *Health, 0*(00), 1-21.

Paper II

Østbye, S. V., Wang, C. E. A, Granheim, I. P., Kristensen, K. E. & Risør, M. B. (2018b). Epistemological and methodological paradoxes: Secondary care specialists and their challenges working with adolescents with medically unexplained symptoms. *International Journal of Mental Health Systems, 12*, 52.

Paper III

Østbye, S. V., Wang, C. E. A., Haavind, H. & Risør, M. B. The makings of 'classic' and 'complex' patients – an ethnographic study of clinical rehabilitation for adolescents with medically unexplained long-term fatigue.

This paper is ready to be submitted.

1. Introduction to the thesis

1.1 Communicative challenges of medically unexplained illness – the struggle for meaning

“Meaninglessness inhibits fullness of life and is therefore equivalent to illness. Meaning makes a great many things endurable - perhaps everything.” — C. G. Jung

This thesis is about the struggle of negotiating and creating meaning in a phenomenon that cannot be explained objectively; it explores communicative challenges in the understanding and treatment of medically unexplained symptoms (MUS) in youth. In three sub-studies involving multi-sited fieldwork and various participatory methods, I have been able to demonstrate how youth with MUS actively engage in meaning making and developmental processes within a context marked by biomedical and psychological discourses of what illness, health and development entail. With this thesis, I aim to enhance understanding of the lives of young people with unexplained illness, and to gain insight into how they create meaning and negotiate possible ways of being in a context that typically views them in terms of categories and problems. Such a view runs the risk of ignoring knowledge of lived lives and personal experience and can mask the complexities in the young persons’ efforts to manage and make sense of their lives (Holland, 2009). Within what has been termed contextual-relational developmental psychology, it is considered essential to gain knowledge of adolescents’ own perspectives on their lifeworlds, presenting them as subjects with important insights and views (Sommer, Samuelsson & Hundeide, 2010). Moreover, such an approach necessitates a focus on the young person’s own engagement in developmental processes (Haavind, 2007; 2014). To understand developmental processes and communicative challenges for youth with MUS, there is a need for knowledge of their daily lives and their perspectives on their own lifeworlds, as well as knowledge of the sociocultural and discursive contexts in which their developmental efforts are taking place.

In this thesis I will offer descriptions of the discursive terrain (Youdell, 2005) where adolescents and health professionals navigate in attempting to alleviate suffering and cope with the uncertainty of unexplained illness. I will outline a frame of knowledge that differs from conventional developmental psychology and builds on sociocultural notions of development, identity and symptom formation. Instead of considering these concepts as the product of inert biological or psychological processes which exist ontologically in and of themselves and take place without the intention or active participation of the actor, I am interested in the construction of meaning as a social, intentional and active process relating to discursive practices and overall cultural structures. As such, my epistemological position is situated within a broadly defined social constructionist framework (Burr, 2003).

The papers presented here draw on theory and research from a number of overlapping disciplines. The common feature of all the disciplines is their foundation within critical applied medical anthropological and cultural psychological research, inspired by perspectives from sociocultural approaches and post-structural theory. Theoretically, the project touches upon themes such as language, narratives, subjectivation processes and illness constructions, adolescence and development, health encounters and patient-centered practice.

The thesis is based on a theoretical framework that understands children and adolescents as participants in their own developmental processes and considers transitions and development as something the growing person actively engages in and negotiates within multiple contexts and in social interaction (Jansen & Haavind, 2011). In order to focus on the growing persons' own engagement in such processes, it is necessary to employ methods that elicit their stories and make their voices heard (Thomson, 2008). I was able to accomplish this by engaging with the adolescents over time, talking to them in repeated interviews and making use of alternative modes of expression such as visual methods. The discursive terrain within which the adolescents navigate was revealed through separate fieldwork in everyday and clinical contexts and an interview-based study on health professionals' experiences and understanding of the adolescents and the relevant clinical work.

In line with a sociocultural position, I understand illness as created in a communicative, relational and sociocultural field between positioned actors (Burr, 2003; Frank, 1995; Garro, 1994; Good, 1994; Good, Fischer, Willen & Good, 2010; Good & Good, 1993). Additionally, all the papers in this thesis address the category of MUS by focusing on how this concept is construed through medical discourse and by emphasizing the role of language and intersubjective meaning making in processes of subjectivation and healing (Buchbinder, 2015; Kirmayer, 1988, 2000; Kirmayer, Grouleau, Looper & Dao, 2004; Kleinman, 1980, 1988, 1994). As such, I have not been interested in finding the "true" cause of medically unexplained symptoms, or in describing the adolescents' illness experiences merely as an expression of problematic lives. Neither has it been my aim to suggest the most efficient interventions or approaches to healing. Instead, my analytical focus has been the communicative and discursive practices through which these young people constitute themselves and are constituted as adolescents and as patients with illness of unknown etiology. The three articles of the thesis illuminate in different ways the communicative challenges of adolescents and health professionals in their efforts to understand, explain and give meaning to a phenomenon that is medically defined as unexplained.

2. Background

2.1 An overall presentation of the field

Although considerable variation exists in terminology and classification procedures (Rosendal et al., 2017), it has been estimated that 20-30% of patients in primary care (Rosendal, Olesen & Fink, 2004) and up to 25% of children and youth in specialist care (Eminson, 2007) present mild to severe symptoms such as headaches, musculoskeletal pain, gastrointestinal problems and fatigue, without receiving a medical explanation. If such symptoms are persistent and are not given a full medical explanation despite medical consultations for more than six months, they are often referred to in the literature as medically unexplained symptoms (Peveler, Kilkenny & Kinmonth, 1997). MUS represent major challenges to public health care in European and other industrialized countries, and the US National Institute of Health has identified MUS as the most common problem in medicine (Hellhammer & Hellhammer, 2008). There is even greater concern about MUS in children and adolescents, due to potential adverse consequences of long-term illness and drop-out from school, including negative effects on employment, lifetime earnings, physical health and social participation later in life (Terrence et al., 2018).

The research literature on medically unexplained symptoms in youth can be grouped into studies based on a biomedical understanding of disease or on a sociocultural understanding of illness. The former typically focus on establishing clear guidelines for management (olde Hartman, Woutersen-Koch & van der Horst, 2013), investigating outcomes of various interventions (Wortman, Lokkerbol, van der Wouden, Visser, van der Horst & olde Hartman, 2018), developing clear symptom criteria for these illnesses, focusing on comorbidity, nomenclature and diagnostics (Smith & Dwamena, 2007), or discussing etiology in terms of predisposing or maintaining factors (Price & Okai, 2016). These studies can all be summed up as asking the question: "What is it really about and what should we do about it?" In these studies, the problem of MUS is interpreted as an empirical matter, to be solved by the medical field through similar work and methods applied to other diseases. In this view, more observational data, randomized controlled trials, symptom counts and classification could ultimately lead to a clearer understanding of these conditions (Eriksen, Kerry, Mumford, Lie & Anjum, 2013).

Alternatively, it is suggested by researchers within sociocultural approaches that the lack of explanation in MUS reflects the limits of medical knowledge and the epistemological difficulty of assigning a clear cause to subjective complaints like pain and fatigue (Kirmayer, Groleau, Looper & Dao, 2004). This would mean that the problem of MUS is a symptom of deeper ontological issues such as the nature of pain, fatigue or illness itself (Eriksen, Kerry, Mumford, et al., 2013; Buchbinder, 2015). In this perspective, it is suggested that MUS show the limitations of the evidence-based approaches of biomedicine (Deary, 2005; Soler & Okkes, 2012; Ulvestad, 2008). In extension of this position, the biomedical conceptualization of diseases as specific ontological entities has been argued to lead to a reductionist, mechanism-oriented way of thinking about the body and its felt malfunctions, removing the experiential aspects of *illness*. In order to understand these aspects - the psychosocial experience and meaning of perceived disease (Kleinman, 1980) - recent decades have seen a burgeoning of the literature on illness experiences in the social sciences (Bell, 2000; Bury, 2001; Hydén, 1997; Kirmayer, 2000; Nettleton, 2006; Nettleton, O'Malley, Watt & Duffey, 2004; Riessman, 2003). Within these approaches, it is argued that both illness and disease exist only as constructs in particular configurations of social reality; they are explanatory concepts and not entities, and as such they can be understood only within defined contexts of meaning and social relationships (Kleinman, 1980: 72-73).

This would mean that in order to understand medically unexplained symptoms in youth, one should shift focus towards the social and cultural realm of illness experience, towards communicative practices and interpersonal interaction in both clinical and everyday contexts. The present study falls within this second paradigm, in which the main question asked is "What is it like and how are different contexts made relevant for the experience of illness?" The knowledge produced by asking this question has not only importance for descriptive purposes, but also implications for our understanding of who these young people are, what challenges they face and how they engage in their own processes of development, healing and recovery. By extension, this knowledge may have implications for clinical practice and policy making.

2.2 The problem of medically unexplained symptoms in youth

2.2.1 Classification problems

Symptoms that have no definite medical diagnosis are common in all areas of primary care as well as in specialty medicine (Nimnuan, Hotopf & Wessely, 2001). Many different labels for the medically unexplained have been proposed, such as somatoform disorders, bodily distress syndrome, functional somatic syndromes, medically unexplained physical symptoms, or complex somatic symptom disorders (Fink, Rosendal & Olesen, 2004; Fink & Schröder, 2010; Schulte & Petermann, 2011; Ware, 1992).

The problem of reaching a consensus in classification and diagnostic criteria is evident in the vast variation in prevalence estimates, and some have pointed out that without such consensus, prevalence figures necessarily become advanced guesswork (Eriksen, Kirkengen, & Vetlesen, 2013). In the research literature and overall field there are heated debates on taxonomy, nomenclature and etiology, where different parties from the medical community, patient organizations and the research community confront the problem from different angles, with different agendas and based on different epistemological realities (Banks & Prior, 2001; Greco, 2012).

The conditions that qualify as medically unexplained are in themselves a subject of controversy, but some that have been commonly referred to as such are chronic fatigue syndrome, irritable bowel syndrome, low back pain and fibromyalgia. All areas of medicine have their own functional somatic syndromes: irritable bowel syndrome and non-ulcer dyspepsia in gastroenterology, premenstrual syndrome and chronic pelvic pain in gynecology, fibromyalgia in rheumatology, chronic fatigue syndrome in neurology, and somatization disorder in psychiatry (Nimnuan, Hotopf & Wessely, 2001). These different labels can all be said to be examples of fuzzy concepts (Horowitz & Malle, 1993), with no clear-cut answers as to which clusters of symptoms to include, with significant overlap and no specific boundaries between concepts, and with a great deal of heterogeneity among patients and in symptom manifestations (Norregaard, Bulow, Prescott, Jacobsen & Danneskiold-Samsoe, 1993; Prescott, Kjoller, Jacobsen, Bulow, Danneskiold-Samsoe & Kamper-Jorgensen, 1993; Wessely, Nimnuan & Sharpe, 1999; Wysenbeek, Shapira & Leibovici, 1991).

2.2.2 Distressing consequences

Medically unexplained symptoms are seen in all age groups, but early adolescence is considered a critical period for the development of chronic and recurrent physical symptoms (Wilson, Moss, Palermo & Fales, 2014). According to a review by Eminson (2007), MUS have been very little studied in children and adolescents, which is partly due to the difficulties involved in studying children in general. However, because symptoms often start in childhood and later develop into chronic conditions, there is now increasing focus on adolescents and even young children, where MUS is also prevalent (Berntsson, Kohler & Gustafsson, 2001; Eminson, 2007; Rask et al., 2009; Schulte & Petermann, 2011). Diagnoses like somatoform disorder, chronic fatigue syndrome or irritable bowel syndrome also exist in the younger population and some epidemiological studies point out that MUS is quite common in childhood and adolescence (Berntsson, Kohler & Gustafsson, 2001; Hoffart & Sherry, 2016; Konijnenberg et al., 2005; Rask et al., 2009; Zuckerman, Stevenson & Bailey, 1987). Medically unexplained symptoms are reported to be more common among females, younger age groups, and people of lower socioeconomic backgrounds (Nimnuan, Hotopf & Wessely, 2001).

For patients, the uncertainty of MUS has been shown to have both physiological and psychological consequences. For example, heightened sensitivity to pain, negative psychosocial outcomes, reduced coping skills, psychological distress and reduced quality of life have been noted (Edwards, Thomson & Blair, 2007; Kornelsen, Atkins, Brownell & Woollard, 2016; Lian & Hansen, 2016; Neville, 2003; Wright, Afari & Zutra, 2009). Adolescents with MUS seem to be at risk for developing problems later in life, and studies demonstrate that they experience significant impairment in a range of social and functional domains (Karterud, Haavet & Risør, 2016; Konijnenberg et al., 2005; Moulin, Akre, Rodondi, Ambresin & Suris, 2015a; Winger, 2015). Studies have linked childhood MUS with anxiety and depressive symptoms and disorders, both at first presentation (Campo, Bridge, Ehman et al., 2004) and in adulthood (Campo, Di Lorenzo, Chiappetta et al., 2001). In addition, qualitative studies have demonstrated that suffering from conditions that are not considered "legitimate" often leads to feelings of identity confusion, alienation and loneliness (Fisher & Crawley, 2013; Karterud, Haavet & Risør, 2016; Karterud, Risør & Haavet, 2015; Winger, Ekstedt, Wyller & Helseth, 2013).

It has been pointed out that these patients risk increased morbidity because of extensive testing and medical procedures resulting from over-investigation and treatment, frequent visits to doctors and emergency wards, and prolonged hospital admissions (Geist, Weinstein, Walker & Campo, 2008). Since mind-body dualism and the body-as-machine metaphor are still prominent paradigms of thought in Western medicine, health systems are organized in a way that encourage us to consider the human body as consisting of separate entities instead of a coherent whole (Page & Wessely, 2003). Consequently, many patients end up being thrown back and forth between different specialties within the health care system, with limited attempts at an integrated understanding of their symptoms. This in itself represents a problem in terms of chronicity, leading patients on an endless search for explanations and treatments, in some instances leading to serious iatrogenic effects such as secondary complications after invasive medical procedures (Fink, 1992; Page & Wessely, 2003).

2.2.3 The clinical encounter

Although physicians recognize MUS as health problems, studies show that they often feel ill-equipped to deal with affected patients (Wileman, May & Chew-Graham, 2002). Health professionals report feeling pressured into continual examinations, referrals and treatments (Salmon, Ring, Dowrick & Humphris, 2005), and generally refer these patients to specialists for evaluations aimed at ruling out disease rather than managing the patient's distress. Most doctors recognize the importance of a therapeutic relationship and feel responsible for it when it is difficult (olde Hartmann, Hassink-Franke, Lucassen, van Spaendonck & van Weel, 2009). However, they vary in their willingness and capacity to engage with patients' emotional cues (Salmon, 2007), and lack confidence in their ability to meet their patients' needs (Dowrick et al., 2008; Hahn, 2001; Hahn, Kroenke, Spizer, Brody, Williams, Linzer & deGruy, 1996; Stone, 2014).

In describing patient-doctor relationships, "battlefield", "minefield" and other warfare metaphors have been used (Lian & Hansen, 2016; Thompson, Isac & Rowse, 2009; Werner, Isaksen & Malterud, 2004). Studies have demonstrated that many general practitioners (GPs) think that persistent MUS are associated with personality or psychiatric disorders; their attitude is that the patients fail to see that their symptoms are an expression of psychological distress (Reid, Whooley, Crayford & Hotopf, 2001; Sharpe, Mayou & Walker, 2006). Attitudes among GPs towards patients that present symptoms with no physical cause are often marked by skepticism, and the use of terms such as "difficult" (Steinmetz & Tabenkin, 2001), "hateful" (Groves, 2009) or "heartsink" (O'Dowd, 1988) can serve as examples of how negative emotions can be triggered in the doctor.

A number of studies have demonstrated that doctor-patient communication during consultations with MUS patients is even poorer than previously thought (Epstein, et al., 2006; Ring, Dowrick, Humphris, Davies, Salmon, 2005; Salmon, Ring, Dowrick, & Humphris, 2005). In contrast to consultations with patients with explained symptoms, one study found that GPs explored the symptoms, feelings, concerns, opinions and expectations of the patient less adequately in consultations with patients with MUS (Cegala, 1997; Salmon, Dowrick, Ring & Humphris, 2004). Most of these studies have investigated communicative challenges in consultations with adult MUS patients in primary care, but a few studies have found similar results in consultations with children and young people (Geist, Weinstein, Walker & Campo, 2008; Moulin, Akre, Rodondi, Ambresin & Suris, 2015b).

2.2.4 Incompatible epistemologies?

It is apparent from this literature review that there exist major tensions and contradictions in both research and clinical practice with regard to MUS. Some of these issues relate to terminology, etiology, implications of medical uncertainty and potential stigma for patients, and management and treatment issues for practitioners. The literature describes difficulties in the diagnostic process and in clinical encounters, as well as many problems on the part of the individual young person with debilitating symptoms. Many of the studies describe young patients as struggling with comorbid symptoms of anxiety and depression (Campo, Bridge, Ehman et al., 2004; Geist et al., 2008), and several studies point out the difficulties young MUS patients have in functioning in a range of social domains (Karterud, Haavet & Risør, 2016; Konijnenberg et al., 2005; Moulin, et al., 2015a; Winger, 2015). Some studies describe the young patients as lacking basic social skills and using passive or avoidant coping styles, and several point out that they risk further impairment in adulthood (Ax, Gregg

& Jones, 2001; Hareide, Finset & Wyller, 2011; Moss-Morris, 2005; Trigwell, Hatcher, Johnson, Stanley & House, 1995).

In sum, these studies point towards discursive terrains (Youdell, 2005) marked by a problematizing and categorizing understanding of adolescents with MUS, as well as several conflicts and tensions between epistemological positions and paradigms of thought represented by dominant biomedical and psychological discourses. This might lead to a positioning of youth with these kinds of symptoms in potentially troubling subject positions (Wetherell, 1998) that might negatively affect their developmental processes and possibilities for being and becoming.

As pointed out by Greco (2012), the MUS debate is fueled by etiological conflict between the medical and the psychological. She describes both doctors' and patients' resistance to psychological attributions and a persistent disavowal of a psychological dimension and locates this situation within wider political fields in which epistemological privilege is still awarded to the visible (Foucault, 1973). In line with this argument, Tucker (2004) and Werner and Malterud (2003) find that patients have to position themselves as physically ill, constructing their symptoms as socially visible, real and of a biomedical origin when consulting their doctors in order to be considered to suffer from a legitimate illness and avoid the stigma of a psychological disorder. Likewise, Horton-Salway (2007) describes a moral ordering by patients and GPs that places physical symptoms above mental illness in terms of genuineness, and Nettleton et al. (2005) describe the marked concern of neurology patients that their unexplained, undiagnosed symptoms might be viewed as psychological in origin by their doctors. These studies exemplify some of the tensions and polemical positions between patients and health professionals, and as Greco (2012) has pointed out, a resulting deadlock between the positions of "dismissive doctors" and "delegitimized patients".

To address the problem of terminology and disputed etiology, attempts have been made to develop integrative approaches to better account for the complexity of MUS (cf. Brown, 2007; Creed et al., 2010; McFarlane et al., 2008). These approaches are offered as a solution to difficulties in bridging the two different perspectives of illness and disease, to overcome communication challenges by better accounting for patients' illness experiences in the understanding of disease, and to contribute to a more patient-centered clinical practice (Engel, 1977; Mead & Bower, 2000).

Integrative approaches seem to make sense in the light of the many problems relating to MUS and are in tune with the increasing understanding that bodily symptoms reflect the brain's integration of multiple etiological factors (Damasio, 1994; Sharpe, Mayou & Walker, 2006). However, they fail to recognize that models, approaches and terminology are constructed within wider structures and limited by existing discourses and epistemologies.

If one of the fundamental issues is that existing structures and related discourses cannot accommodate a complex biopsychosocial problem, then developing new models, approaches and terminology alone will not resolve this (Eriksen, Kirkengen, & Vetlesen, 2013). If illness is socially constructed, then MUS need to be explored within their wider social context, including the discourses within which they are located.

2.3 Discourses of health, illness and disease

Phenomena such as diseases are from a positivist viewpoint considered as observable, steady and true entities, with epistemological assumptions of universal, objective facts to be identified and predicted by standardized, deductive approaches and research methods where controlled observations yield objective certainty (Malterud, 2016). In line with this way of thinking, the paradigm of evidence-based medicine is widely accepted as a way to support practitioners in their decision-making in order to eliminate the use of ineffective, inappropriate, overly expensive and potentially dangerous practices by finding, appraising and applying scientific evidence to the management of health care (Hamer, 2005).

Within a social constructionist framework, by contrast, medicine is understood as a cultural system: a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions (Kleinman, 1980). Even the language of medicine is culturally shaped. For example, the metaphor of the body as a machine, a widely accepted explanatory model in contemporary biomedicine, reflects a shared cultural model of the body as made up of interchangeable and thus potentially fixable parts (Kirmayer, 1988).

Both clinicians and patients use particular causal models to explain symptoms, aimed at new self-understanding and better adaptation, and providing a rationale for particular kinds of treatment. The way people perceive, interpret and respond to suffering is mediated by cultural and social contexts, as well as the illness or disorder itself. The term “explanatory model” was introduced by Kleinman (1980), who defined it as the complex, culturally determined process of making sense of illness, ascribing meanings to symptoms, evolving causal attributions, and expressing suitable expectations of treatment and related outcomes. Explanatory models provide a conceptual framework that allows clinician and patient to make sense of suffering and suggests possible solutions, and as such they do not only aim at conveying objective knowledge of truth and objective certainty, but are created to emotionally engage, support, motivate, change and empower the patient (Kirmayer, Lemelson & Cummings, 2015). The exploration of explanatory models in the clinical encounter provides information about the significance of the illness for the patient in his/her social context and allows for a richness of the patient's world view to emerge in narrative form (Dinos, Ascoli, Owiti & Bhui, 2017). Explanatory models are not only for the use of patients but also clinicians, and the construction of explanatory models can be understood as a collaborative and negotiated intersubjective process taking place both within and outside the clinical encounter. From this argument, it follows that the language of medicine is not a mirror of the empirical world, but rather shaped by cultural values and different modes of knowledge, including empathetic, emotional and contextual knowledge (Good, 1994).

In the reality of clinical practice, a simple and unified diagnosis and explanation for the causes and mechanisms behind illnesses, in addition to a curative treatment approach, is often difficult to find (Mol, 2008). In the case of MUS, the patients' illness cannot adequately be assigned to conventional disease taxonomies and the exclusion of underlying biological pathology does not necessarily help to alleviate the patient's suffering. Furthermore, feeling ill and seeking help in response to illness appear to bear little relation to the type of condition or its clinical "severity" (Hahn et al., 1994). Such findings challenge a key assumption of the 'biomedical model': that illness and disease are coterminous. This has, in part, led to the claim that an alternative model where illness is understood as consisting of a dynamically intertwined and hierarchical system of mental and physiological components, the *biopsychosocial* model, is needed (Engel, 1977). This model is a cornerstone in *patient-centered care* (Mead & Bower, 2000), a framework that can be said to differ from the biomedical model in its biopsychosocial perspective, its emphasis on the personal experience of the patient and on the importance of egalitarian doctor-patient relationships where doctors regard patients as experts on their own illness, and where power and responsibility are shared with the patient through mutual participation (ibid.).

Critics have argued that despite good intentions, the biopsychosocial model is still caught in the reductionist analytic philosophical tradition of Cartesian dualism (Butler, Evans, Greaves & Simpson, 2004; Eriksen, Kerry, Mumford, et al., 2013). As a response, an alternative interpretive approach where the goal is to understand the whole experience as a complex unity, embedded in a specific context or frame of reference, has been suggested as a more satisfactory philosophical rationale for a patient-centered clinical method. In this view, the patient's complaints are not seen as objective facts, but as phenomena to be interpreted, and the clinician's role is to help patients make sense of their symptoms and reflect on the meaning of these in their lives (Butler et al., 2004). This framework has involved a movement away from a *"one-person medicine"* where the application and therapeutic techniques are a fundamentally objective issue, to a *"two-person medicine"* where the subjectivity of both doctor and patient is an integral aspect of any satisfactory clinical descriptions (Balint, Courtenay, Elder, Hull & Julian, 1993).

In this thesis, in the context of specialist health care systems operating within ideals from patient-centered care and evidence-based practice, I explore communicative challenges in the understanding and treatment of MUS in adolescence. In the interface between biomedical and biopsychosocial discourses of health and illness, I study how constructions of MUS affect adolescents' meaning making, developmental and subjectivation processes. Meaning does not exist out in the world waiting to be discovered or accurately conveyed, but rather is created within language. In line with a social constructionist position, language is in this thesis understood as a historically generated collective tool that mediates the world as people use it in their everyday concrete practices (Berger & Luckman, 1966; Burr, 2003). It is essential for providing perspectives on reality, but it is also the principal mechanism through which our knowledge of the world comes into existence. Patients and medical personnel alike cannot simply report on what they see; inevitably they will produce different versions of persons, actions, events and things (Goodman, 1978; Hacking, 1999; Shotter, 1993).

The term discourse refers to "a set of meanings, metaphors, representations, images, stories (…) that in some way together produce a particular version of events" (Burr, 1995 48). An instance of discourse articulates one possible version of things, but there are always other possible versions (Potter & Wetherell, 1987). To assert one version rather than another has specific effects: articulating, maintaining or opposing particular power relations or "regimes of truth" (Foucault, 1977). A central aspect of discourses for Foucault is that they have the effect of producing truths about what is considered "normal", "common", "unnatural" or "deviant" (Hauge, 2009). Discourses in this sense might be understood as "bodies of ideas that produce and regulate the world in their own terms, rendering some things common sense and other things nonsensical" (Youdell, 2006a, p. 35). Similarly, discourses such as those of adolescence, health and illness or families can be understood as producing "normalizing truths", i.e., expectations regarding what is "common" or even "moral" with regard to the behavior of a specific group of people.

All cultural systems are framed by power as embedded in discourses, and this also applies to health care systems. Within these discourses there lies knowledge of what is expected, common, abnormal or deviant within any given context, and discourses are therefore involved in processes of categorization and creating hierarchies (Foucault, 1973, 1976, 1977, 1988). Power is not a concept explicitly mentioned in the three articles of the thesis, but all of the articles point towards discourses that influence claims to knowledge and normative ways of thinking in the cultural fields that adolescents with MUS come into contact with, and thus have significance for their understanding of themselves and their developmental possibilities. Discourses that are in play in the contexts that I have described in this thesis are those of adolescence, of families and of treatment personnel, but also those of illness and health and of sociocultural categories like gender and class. All of these discourses create various subject positions and spaces of being and mediate the process in which adolescents come to understand themselves and the possibilities they hold. In order to understand medically unexplained symptoms in youth, it is therefore important to make these various discourses visible.

2.4 Discourses of adolescence

In the last couple of years, Norwegian media have increasingly focused on adolescents' problems. Several headlines have proclaimed that adolescents of today "stress themselves sick", that more and more adolescents drop out of school, that increasing numbers of adolescents use painkillers daily, and that many young people struggle with unexplained bodily or mental problems (Amundsen, 2014; Ertesvåg, Wallenius & Huuse, 2016; Hotvedt & Aardal, 2014; Huuse & Ertesvåg, 2016; Johannessen & Kreutz-Hansen, 2014; Knapstad, 2013). In these headlines one can trace different and contrasting discourses of what adolescence entails. Adolescents are portrayed as incomplete adults in a phase in which they need special protection in order to develop into worthy and productive citizens. They are further described as struggling to fit into society because of individual problems, as struggling with mental and physical symptoms and distress, but also as clever, adaptable and well-behaved, spending more time with their parents and using drugs less than previous generations (Bakken, 2018; Madsen, 2018).

Research on adolescents and young people is also framed by these various discourses. Mørch (2010), with inspiration from Foucault's genealogical discourse theory, writes that research on young people today can be thought of as an archeological field in which several discourses operate at the same time, layered on top of each other. He describes some discourses in play in the understanding of adolescents today as the *problem discourse*, in which adolescents are understood primarily as a source of problems for society or for themselves, the *resourceful discourse*, in which adolescents are seen as competent and innovative, or the *vulnerability discourse*, in which adolescents are understood as in a vulnerable transitional phase in need of special protection and support. All of these discourses can be said to be present in the understandings of adolescents with MUS.

Critical perspectives have pointed out that conventional psychology has had a tendency to produce normative and universal discourses of development (Jenks, 1996; McNaughton, 2005; Prout & James, 1997), relying on methods which posit children and adolescents as objects (Thorstenson-Ed, 2007) and holding an ontology of children and adolescents as passively developing according to biologically fixed stages or “natural” maturation (Burman, 1994; James, 2009; Morss, 1990). The dominant view of adolescence in many Western societies can be dated back to the psychologist Stanley Hall and his description of adolescence as a period of “storm and stress” (1904). Psychoanalytic theories and the psychosocial stage theory of Erik Erikson (1950) have also been influential (Arnett, 1999). These theories describe the passage from childhood to adulthood as an unsettling period in which the child undergoes significant transformations, a period in which either hormonal flux or detachment from parents prepares the child for becoming a “proper” adult. Within these studies, there has been a focus on problems in adolescence, such as conflict with parents, mood swings and risky behavior (Arnett, 1999). The problems of the “storm and stress” discourse, however, are that it asserts that adolescents are incomplete adults-in-the-making (Thorne, 1993), and that it construes problems and upheaval in adolescence as something universal and inevitable, mainly due to biological or intrapsychic processes (Griffin, 2010; Lesko, 2001). In contrast to frameworks included in conventional developmental psychology, research emerging from adjacent disciplines such as education and childhood studies have to a larger extent developed frames of knowledge that emphasize the social contexts through which children and adolescents become who they are (Halldén, Änggård, Markström, & Simonsson, 2007). As pointed out by several youth studies researchers, adolescence must be understood as more than a transitional phase from childhood to adulthood; children’s and adolescents’ perspectives and subjective experiences of their life situation, relationships and cultures are worth studying in and of themselves (Hauge, 2009; Sletten, 2011).

An important conceptual pairing within these kinds of studies is the dichotomy of “being” and “becoming” (Uprichard, 2008). The “being” child is seen as a social actor in his or her own right, who is actively constructing his or her own lifeworld, and who has views and experiences about being a young person; the “becoming” child is seen as an adult-in-the-making, who is lacking universal skills and features of the adult that he or she will become (James & James, 2001; James & Prout, 1997; Jenks, 1996; Qvotrup, 2009). Being and becoming perspectives have implications for epistemological positions and research interests: producing research that has an interest in explanations and control or, on the other hand, critical understanding and emancipation (Habermas, 1987; Radnitzky, 1970). The problem-oriented transition studies of adolescents have tended towards a “becoming” perspective; research is directed towards finding ways to support adolescents in succeeding in their transitions towards adulthood. Within cultural studies, however, there is a long tradition of viewing adolescents as competent actors, and research attention has been directed towards the cultural practices and various subcultures in which youth engage, studying youth as social actors that generate their own norms and values in their interaction with peers, often in opposition to the norms and values of the majority culture (cf. Drotner, 1991; Drotner & Bay, 1986; Gudmundsson, 2006; Willis, 1977).

Perceiving the young person as “being” or “becoming” tends to involve conflicting approaches to what it means to be a child or adolescent. However, as several researchers have argued, these seemingly incompatible perspectives can fruitfully be used together in complementary ways (Hauge, 2009; James & James, 2001; Mørch, 2010; Uprichard, 2008). Perspectives that focus on embodied lived experiences, meaning-making activities and negotiating practices that children and adolescents engage in here and now can be combined with developmental perspectives and theories, accounting for both continuity and change in developmental processes and providing an understanding that includes both individual and contextual conditions. To look ahead, plan and dream of the future is undeniably an important feature of being a child or adolescent in the here and now (Uprichard, 2008). Which futures can be imagined and which possible selves the subject can adopt represent a process of positioning (Davies & Harré, 1990), depending on actual and comprehensible discourses, practices and distributions of power, as well as the compositions of the actors involved (Staunæs, 2003). As such, children and youth are always and necessarily both being and becoming. In this thesis I study adolescents as both beings and becomings. I am interested in adolescents as competent and active actors, engaged in meaning-making activities and subjectivation processes here and now, but at the same time I understand these processes as ongoing and as constrained and influenced by contextual conditions as well as ideas about future possibilities.

2.5 A narrative approach to self-making, illness and healing

In this thesis I explore meaning-making processes with the assumption that meaning is created intersubjectively and dialogically through the creation of coherent narratives. A basic tenet of narrative theory is that we create stories in our efforts to create meaning about what happens in our lives, in our attempts to understand other people and ourselves (Bruner, 1990). Moreover, this theoretical position is concerned not only with how we understand ourselves, but with how the self comes into existence. People construct and constitute themselves through the stories they tell (Bruner, 1990; Crossley, 2000; Gergen & Gergen, 1986; McAdams, 2003). We mediate and make sense of our self through talk, and identity is a constantly negotiated, social and contextual construct. A narrative approach allows for taking into consideration the individual’s own engagement in these self-making processes. This enables a perspective that considers the individual as an agent, and regards the self not as a unitary, essentialist entity, but as multiple, flexible and negotiated and constituted in an interactional space (Jansen, 2011). This also implies that stories are not something you *are*, but rather something you *do*, which represents a performative focus (Riessman, 2003).

A performative approach to narrative theory emphasizes narrative as social action and as an intentional project in which individuals negotiate how they want to be known in the stories they create collaboratively with their audiences (Bakhtin, 1981; Mishler, 1995). A performative approach in addition implies greater awareness of how the empirical data are situated and the researcher's own role in the co-creation of narratives (Hollway & Jefferson, 2000; Holstein & Gubrium, 1995; Riessman, 2003). Narratives are always told to someone, in a specific context. Stories are fundamentally social creations. They are embedded in cultures, and in the patterned dispositions and the social structures that each and every one of us carry with us through the "habitus" (Bourdieu, 1977), or "bodily performatives" (Butler, 1993). For example, people from different cultures create narratives that are distinct in how they connect events causally, and in the associated emotions felt by characters (Miller, 1994).

In addition to the self-making properties of the narrative, people also order their experience of illness, i.e., what it means to them and to significant others, as personal narratives. The illness narrative is a story that the patient tells, and significant others retell, to give coherence to the distinctive events and long-term trajectory of suffering. The plot lines, core metaphors and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. The personal narrative does not merely represent illness experience, but rather contributes to the experience of symptoms and suffering (Bell, 2000; Bury, 2001; Hydén, 1997; Kirmayer, 2000; Kleinman, 1980).

One common criticism of narrative theory is that its frequent reliance on a phenomenologically informed analysis renders it too "near-sighted" in its focus on the subjective, the idiosyncratic and the personal experiences of the individual (Crossley, 2000). Despite the advantage of this analytical method in giving rich and detailed descriptions, there might be a danger of losing sight of the importance of social structures and available discourses for creating diverse constraints and possibilities for the individual. To highlight the contextual conditions in which the individual's personal narratives are created, I have found it fruitful to include theories and concepts from discourse theory and poststructuralist theories such as performativity (Butler, 1995), subjectivation (Foucault, 1977; 1988; Kofoed, 2008; Staunæs, 2003, 2004, 2005; Søndergaard, 2005), and positioning (Davies & Harré, 1990).

The subject is in Foucauldian terms a speaking subject, one who chooses to speak, but who necessarily speaks in discourses that constrain what can be spoken. The subject knows itself through knowledge formulated in discourses. Narrative is one genre within which discourse is expressed. According to Frank (2016), to understand an ill person as a "narrative subject" requires identification of the specific narratives within which this person is able to know herself:

"The subject is, foremost, one engaged in processes of knowing himself or herself through available discourses, expressed in narratives." (Frank, 2016, p. 14)

As stories are always located within a number of different discourses, and thus vary in terms of the language used, the concepts, issues and moral judgements made relevant, and the subject positions made available within them, discourse theory and poststructuralist approaches can be said to overlap with narrative theory (Davies & Harré, 1990:46). Although some scholars would argue that narrative theory and the different discourse analytical approaches from critical discourse analysis to discursive psychology are incompatible and refer to different research traditions, I will in this thesis follow the lead of those that promote a synthesis of these approaches (e.g., Jansen, 2010, 2011, 2013; Jørgensen & Phillips, 2002; Wetherell, 1998; Willig, 2001).

2.6 Development and subjectification

In the theoretical framework of this thesis, development is understood as transformations of subjectivities between categories of age (Hauge, 2009). In contrast to universalizing and biologizing theories of development in which the subject is seen as passively developing according to maturation or fixed stages, the developing subject is seen as actively engaged in his/her own process of becoming, constantly negotiating, leaning on, expanding or rejecting accessible discourses (Haavind, 2007, 2014; Staunæs, 2003; Søndergaard, 2002; Wetherell, 1998).

Subjectivity is the post-structural concept for a person's effort to create or sustain a sense of self. In contrast to the concept of identity, subjectivity is built upon a certain understanding of the relation between a sense of self and the social context, seeing the process of subjectivation as an ongoing process of becoming (Hauge, 2009; Søndergaard, 2002). The process of subjectivation is in Foucauldian terms described as a process in which the human actor is both acting upon contextual conditions, and being subject to such conditions (Foucault, 1977, 1988). Researchers within post-structuralist and critical traditions have further developed this concept to include descriptions of how people take up, ignore or resist accessible discourses, being actively engaged in their own process of becoming (Butler, 1993; Haavind, 2007, 2014; Staunæs, 2003; Søndergaard, 2002; Wetherell, 1998, Youdell, 2005, 2006a, 2006b). This indicates the duality in processes of subjectivation; the subject is seen as both structured and structuring, created and creating, affected and affecting. Butler (1993) discusses the notion of the performative and elaborates on the productive power of discourse in relation to the production of subjects. According to Butler a performative is "that discursive practice that enacts or produces that which it names" (Butler, 1993, p. 13). With this understanding of the performative, the "functionally disabled", the "mentally" or "physically ill" or the "difficult patient" is such because he/she is designated as such. Butler argues that the subject must be performatively constituted to make sense *as* a subject. Performatives might constrain the sorts of subjects that adolescents with MUS can be, and at the same time they constitute the young persons with MUS *as* subjects. Discursive performatives are often considered as they are deployed through spoken and written language, for example through direct naming of social categories (boy, girl, student, high-school drop-out, disabled, ill), or supposed characteristics (clever, gifted, having mental or physical problems, being badly or well behaved). However, Butler points out that they might also be deployed through bodily gestures, postures and accents, clothing and embellishments, as well as through silences, what is unspoken and what is not done. In extension of this, Butler suggests that we rethink Bourdieu's concept of bodily *habitus* as a "bodily performative", at once productive and constrained.

The duality of subjectivation means that even though the subject is understood as actively engaged and as socially competent with creative and agentive force, this does not preclude the fact that different contextual conditions create different possibilities and limitations. The theoretical concept of positioning indicates which subject positions are available at any given time in different social contexts, and describes the process in which subjects negotiate, challenge or accept the positions they are offered in an attempt to create a sense of self (Davies & Harré, 1990). Which subject positions are possible, which narratives are heard, and which are silenced, and thus how the subject understands him/herself and others, is dependent on power as embedded in discourses. The way in which subjects position themselves within discourses, and the subject positions available, must be understood as highly context-driven (Youdell, 2005). Youdell (2006a) uses Butler's theorization of productive power and the performative constitution of subjects, to illustrate the processes through which young students come to be particular subjects in schooling. She demonstrates that how students are subjectivated biographically and as learners are dependent on how they make use of and position themselves within several intersecting discourses. Students are, according to Youdell, "inaugurated into subjecthood" through various discourses, for example gender or developmental discourses, and they "must continually cite (be it tacitly or knowingly) the rules of these discourses, if they are to remain intelligible as subjects" (p. 37). In this way, the concepts of discursive performativity and positioning can be used to understand how classed, gendered, and otherwise marked subjects continue to be produced and constrained in the ongoing process of being marked as such subjects, thereby enabling us to comprehend the endurance of particular configurations of inequality and exclusion. In Youdell's writings she uses the example of education and schooling, but these concepts are just as applicable to other contexts, such as that of health care.

In the clinical and everyday contexts that the participants of this study come into contact with in their illness careers (Freidson, 1988) there are a limited number of subject positions they can occupy, take up and make their own. The concept of troubled subject positions (Wetherell, 1998) covers interactions and negotiations where subject positions become inappropriate, destabilized or difficult: positions that challenge the normativities at stake in certain contexts of lived experience. Whether subject positions become troubled is an ongoing process depending on actual and comprehensible discourses, practices and distributions of power (Wetherell, 1998).

The various discourses of health, illness and disease as well as the discourses of adolescence that I have outlined thus far create the fabric from which the adolescents in this study construct their subjectivity and illness narratives, thereby creating meaning for themselves. The way they position themselves in relation to these various discourses is what creates possibilities and constraints for their developmental and subjectivation processes. In order to understand MUS in youth, it is necessary to describe how various actors position themselves and are positioned within this web of discourses, not only to describe illness in relation to the experiences and the narrative work of individuals, but also to place these narratives within the wider communicative space and the sociocultural context in which MUS is constructed.

3. Research focus and aim of thesis

To sum up, the overall aim in this thesis is to examine medically unexplained symptoms in youth as a socially constructed phenomenon and therefore as an issue of communicative challenges, and to investigate the way people construct meaning by the use of language, the creation of narratives and by way of positioning themselves within discourses and social structures. Communicative challenges were used in the project as a preliminary lens through which to approach my field of research, a broad concept that could be used for many different layers of interpretation. I used this concept to help me to be open and inductive in my investigation of the research questions, but as the research transpired, the concept was broken down into more precise theoretical terms that could be applied for specific analytic purposes.

The term communicative challenges is understood in the context of MUS in youth as generally relating to problems of taxonomy, explanation, and dialogue and rapport between health professionals, adolescents, family members and researchers. From my literature studies, I expected to find communicative challenges in many different forms and on many different levels, and assumed that they would probably come into play in individual lives, in clinical and relational encounters and in institutional settings, but I did not know the specifics of these challenges and how they appeared to specific young people in particular contexts. In order to explore communicative challenges from different angles, I have applied various methods in multiple contexts, looking at the interaction between positioned actors within discursive terrains, and their respective knowledge constructions and meaning-making activities.

Inspired by cultural psychological conceptions of adolescents as actively engaged in their own process of becoming (Carpenter-Song, 2009; Hauge, 2009; Jansen, 2010; Kofoed, 2008; Staunæs, 2003, 2005; Søndergaard, 2002), the particular focus of the overall study is how adolescents navigate and negotiate complex health problems when communicating with health professionals and significant others, what might cause the perceived communication challenges, and how the challenges might be approached to benefit the adolescents. This has produced the definition of three interrelated research aims, as presented in the three papers.

1) The aim of the first paper was to examine the consequences of medically unexplained illness in youth and to explore the processes of meaning making for the young person experiencing symptoms. Specifically, the paper aimed at exploring social and relational aspects of the understanding and handling of illness in youth by looking at the process of creating social accountability and meaning through dialogic-performative narrative emplotment during the

research process (Bakhtin, 1981; Mattingly, 1994). A related methodological aim in the study was to find ways to combine collaborative visual methodologies with data gathered through interviews in order to access multiple aspects of the illness experience.

2) The aim of the second paper was to examine the challenges experienced by health professionals in their attempts at understanding and supporting adolescents with MUS in their developmental trajectories. Specifically, this paper explored the explanatory models and rationales for clinical action that highly experienced and engaged professionals constructed in order to overcome clinical uncertainty.

3) The aim of the third paper was to explore communicative challenges in a rehabilitation setting in which adolescents with medically unexplained long-term fatigue were offered tools for coping with their affliction. I was particularly interested in exploring how adolescents and health professionals explained and gave meaning to unexplained long-term fatigue by looking at how different categories of adolescent patienthood were produced in the talk-in-interaction between patients and health professionals.

4. Methods

4.1 The present study

The present thesis draws its empirical data from a qualitative multi-sited study that took place in Norway. The study has had an explorative approach to research, emphasizing the continuous interplay between preconceptions, epistemological positions, theory, methods and interpretative work (Alvesson & Sköldberg, 2018; Haavind, 2000). My focal point for the study was medically unexplained symptoms in youth understood as communicative challenges, and I wanted to explore this phenomenon from the perspectives of individual MUS sufferers and of health professionals. One of my goals has been to describe and understand the meaning-making processes and communicative practices related to MUS in the interaction between positioned actors within the cultural system of secondary health care in Norway. In order to explore how communicative challenges were expressed and experienced by differently positioned actors within a complex cultural system such as health care, I had to gather data from a range of different settings, such as everyday activities, various relational encounters and institutions. In order to come close to the lived experiences of the participants and allow for a deep and meaningful exploration of the adolescents' and health professionals' meaning-making activities, an ethnographic approach and a triangulation of traditional and more innovative and participatory qualitative methods were applied. The ethnographic approach places the research participants at the center of the research as "experts in their own worlds" (Abebe, 2009; Thomson, 2008; Tickle, 2017), and this methodological approach is often seen as the "natural choice" when conducting research with children and adolescents (James & Prout, 1997). In this study, I interviewed adolescents in different contexts and followed them closely over time using participant observation and collaborative and participatory visual methods. I also observed the work of health professionals in an inpatient rehabilitation setting, and interviewed and explored interactional aspects of the work of various health professionals in different outpatient settings in secondary health care. I have gathered data from both northern and southern Norway.

4.2 Multi-sited ethnography

The basic methodological approach in this project can be defined as multi-sited ethnography. Ethnography is an eclectic methodological choice, which privileges an engaged, contextually rich and nuanced type of qualitative social research (Falzon, 2009). It entails a combination of methods, for example note-taking, visual methods, audio and visual recording, qualitative interviews, informal conversations and observations. The approach is rooted in the ideal of participant observation and the idea that data are produced in "thick" descriptions emanating from prolonged interaction between researcher and researched (Geertz, 1973). Conventionally, ethnography has involved an intensively-focused-upon single site of ethnographic observation and participation (Marcus, 1995). A less common mode of ethnographic research, first coined *multi-sited ethnography* by Marcus (1995), moves out of the single sites and local situations of conventional ethnographic research designs to examine the circulation of cultural meanings, objects, and identities in diffuse time-space (Marcus, 1995, p. 96). In terms of method, multi-sited ethnography involves a spatially dispersed field through which the ethnographer moves between two or more places, or conceptually, by means of techniques of juxtapositions of data (Falzon, 2009, p. 2). Multi-sited ethnography is useful for obtaining knowledge of a phenomenon that resides in and is configured in several different arenas, in this case the phenomenon of MUS as experienced by adolescents and negotiated in different health encounters and everyday settings. For the approach to be called multi-sited ethnography, it has been argued that it is insufficient for the ethnographer to focus on two or more conceptual sites, but that there must be an actual movement across time-space. Most settings I used in this project were located in Northern Norway, in different departments of the University Hospital, and in the everyday environments of the adolescents such as school or home. The setting in Southern Norway was an interdisciplinary rehabilitation center. In this way, I moved spatially and temporally, not merely conceptually.

The multi-sited ethnographic approach has been criticized for the loss of nuanced and rich observations and deep understanding of a field when ethnographic fieldwork is conducted over a long period of time. It has been claimed that to observe a phenomenon in different contexts in a shorter time does not allow the ethnographer to gain the insider perspective that is necessary to truly understand the world of those you observe, in other words: many superficialities do not necessarily provide depth (Falzon, 2009). This might be a fair critique. However, long fieldwork does not guarantee in-depth understanding of the field, it also depends on e.g., the characteristics of the field itself, one’s research focus, methodological skill, interaction and analytic insight of the researcher. Concentrating on a limited number of well-defined questions and a select number of in-depth case studies and having a clear theoretical orientation are some ways to counter the challenges of depth in multi-sited fieldwork (Horst, 2009). Some have also suggested that working in a team of researchers might contribute to more in-depth multi-sitedness (Stoller, 1997). Moreover, as many ethnographers have described, the process of insight into a phenomenon does not only entail being in the field for a stretch of time and almost “going native”, but it also means detaching oneself from the field, thereby gaining more of an outsider perspective on the experiences one had while one was in the field. This implies that in order to broaden one’s perspectives one needs to move not just temporally in the same field, but also spatially, away from the field. The alternations between outsider and insider perspectives have been described as the process in which one gains new insights into the workings of a particular cultural system. One could argue that this is exactly what I have been able to do during the time the data acquisition for this thesis took place. I followed the phenomenon of MUS in different settings, being in the field for a period of time and then removing myself from the field for a time, which enabled me to reflect upon the experiences and stories that were shared.

4.3 Analysis using interpretive methods

This thesis is grounded in critical applied medical anthropological and cultural psychological research. In choosing my methodology and data analysis, I have been inspired by perspectives within sociocultural approaches: social constructionism, discursive psychology, post-structural theory and strands of narrative theory (Bakhtin, 1981; Davies, 2000, 2006; Haraway, 1992; McDermott, 1993; Staunæs, 2004; Søndergaard, 2002; Wetherell, 1998). I have analyzed the material using different reading strategies, but throughout the project I have consistently maintained a perspective on narratives as performative events (Butler, 1990; 1993) and focused on the collective and collaborative aspects of storytelling. I see stories as socially situated actions that are identity giving (Bakhtin, 1981), drawing on overarching cultural frameworks that include notions about ontology, epistemology and morality. Stories do not only take place under particular social conditions, but are social actions that construct, legitimate and maintain social realities (Davies & Harré, 1990). A postmodern constructivist understanding that involves a conversational approach to social research implies that knowledge is not just given, but is co-constructed in the stories told and in the process of reflection that follows from the storytelling in the researcher, the researched and the audience (Kvale, 1996). Meaning is interactive and develops through relational interaction and language representations (Bruner, 1990; Haavind, 2000; 2007).

The data in this study derive from a series of encounters between researcher and researched, such as observations, informal conversations, interviews and explorations of film footage. All the interpretations of the researcher are based on the relationship between the researcher and the researched, and this is what makes the communicative work of creating intersubjectivity so important in interpretive methods (Haavind, 2007). Intersubjectivity is a prerequisite for interpretations of what something means to another, and there are therefore no clear boundaries between the interview/observation phase and the interpretation or analytical phase of the data acquisition. Analysis and interpretive work start even before going out into the field through formulating research questions, preparing interview guides and reading literature, and are based on one's previous experience of the field (Hammersley & Atkinson, 1995; Emerson, Fretz & Shaw, 2011; Tavory & Timmermans, 2014; Wolcott, 1999).

When the hermeneutic circle method of analysis is used, with its continual review and analysis between the parts and the whole of the text, the hermeneutic interpretivist tradition acknowledges that pre-understandings cannot be eliminated (Reiners, 2012). Researchers cannot detach themselves from the meanings extracted from the text, but instead become part of the phenomenon studied. Our perceptions are always already structured by preconceptions and presuppositions, and this applies to both researcher and researched. Life is lived through "language games" (Derrida, 1976, 1978; Wittgenstein, 1953), and language is an approximation of the material world, rather than an exact equivalent. Language is culturally determined and meanings change over time and from place to place. Thus, we cannot understand human behavior or experience fully and once and for all; understanding the world of others will always be a fusion of horizons (Alvesson & Sköldberg, 2018; Finlay, 2003; Finlay & Evans, 2009). Since concepts and ideas vary with the context and must be seen as socially constructed, notions such as "objectivity", "truth" and "fact" are undermined.

Despite this rejection of the notions of objectivity, truth and fact, this position still necessitates engagement in a reflexive and dialogical dialectic with our own preconceptions, i.e., we reflect upon what our own history, experiences and the way we place ourselves in the research field all add to the understanding of a phenomenon. I understand this as a general attitude that must permeate everything we do as researchers: our formulation of research questions, the way we approach our research participants, our interpretations of the data and our writing of research reports. I have attempted to acknowledge this attitude throughout the project, engaging in a continuous reflexive process and dialogue in the research group by discussing my role as a researcher, my previous experiences, values, beliefs and knowledge, and the way these might have influenced my interpretations and my positioning in the field.

4.4 Descriptions of the three sub-studies

Study I: Making sense of medically unexplained illness in youth using collaborative visual methods

4.4.1 Site, sample and procedure

The adolescents experiencing MUS

The adolescents that participated in this first ethnographic study that Maria Fredriksen Kvamme and I conducted were sampled from several different health and everyday settings in Northern Norway: school services, public health nursing, general practice, the division of child and adolescent health, and the division of rehabilitation services.

The adolescents that we sought contact with were defined as aged 12 to 23, having experienced persistent medically unexplained symptoms for at least six months, which had made them seek out health care services. The age group was that of the target group for secondary child and adolescent health services in Norway, in addition to being the age group often described as adolescents in the literature on the developmental phase between childhood and adulthood (Neinstein, 2002). The names and ages used to describe this transitional phase, however, vary between contexts and cultures. We decided to use the term adolescence, understood in a broad sense to encompass psychological, social and moral terrains as well as the strictly physical aspects of maturation in puberty.

Informants for the study were found after several rounds of recruitment using criteria-based purposeful sampling (Patton, 2007). The term medically unexplained symptoms was used to describe and sample the group of adolescents that we sought contact with. This term was selected because we believed it to be the most neutral and self-explanatory of many of the descriptions used in the literature, although as I will elaborate on in the discussion, we soon discovered that the naming and framing of which adolescents to include were not without problems.

Descriptive criteria for MUS that were used in the sampling of adolescents were: a) the person suffers from physical symptoms, b) the symptoms cause him/her distress and possible negative life outcomes such as dropping out of school and other social settings, and c) the person has consulted his/her GP without receiving a satisfactory explanation/diagnosis by the GP or other health professionals (Peveler, Kilkenny & Kinmonth, 1997; Salmon et al., 2004). By using this definition, we hoped to avoid some of the discussions surrounding contested diagnoses, as the definition only states that health professionals were unable to provide the individual with a satisfactory explanation without placing responsibility on him/her and without presuming anything about etiology.

Both health professionals and professionals from schools were asked to conduct the sampling of the adolescents. Initial contact was established with leaders of different units in health facilities and schools, followed by several meetings to provide information about the study to professionals working in schools and different health care contexts. In these meetings, the professionals were given information letters and informed consent forms which they distributed to adolescents they encountered in their practice. It was up to the professionals to evaluate whether the adolescents fit the descriptive and sampling criteria and whether they might be possible candidates interested in participating in the study. The adolescents themselves, their legal guardian or the professional that they had regular contact with typically made the first contact with the researchers, and from there we arranged meetings in which further information was given and a final participation agreement was made. In this meeting the adolescents could decide whether they wanted to participate in full fieldwork, in the film course that we arranged, in one or more interviews or in a combination of these approaches. Consent had to be given by both the adolescents and the legal guardian if the adolescents were under the age of 16.

After several rounds of sampling procedures, we had established contact with eight adolescents that had agreed to participate in some variation of the methods used. Some of them were particularly interested in filmmaking, while others were motivated by the prospect of meeting peers in similar situations or by the opportunity to share their stories with researchers and eventually health professionals. All of the adolescents had had experience of different physical and mental symptoms that had negatively affected their everyday lives, and the majority had dropped out of school and leisure activities due to their symptoms. Typical symptoms included fatigue, recurring headaches, muscle pain, dizziness, cognitive symptoms such as concentration problems, emotional problems and sleep disturbances. Some had received a diagnosis such as CFS/ME but still found a lack of clarity in the explanations they were given by health professionals, while others had not yet received a diagnostic label. Five of the adolescents participated in a group making self-reflexive films and in several individual interviews held concurrently with the filmmaking. Three of these dropped out during the film course before they had finished making their film. In addition to the five that participated in the group setting, three participants were followed individually and given private film sessions as well as individual interviews. One of these dropped out before her film was finished. This meant that we had a varied amount of data for each of the adolescents that participated in the study. Some had made a film that was eventually screened for a selected audience, some had been involved in self-reflexive filmmaking but had not finished making a film, and some had been interviewed once while others had had several interviews over the course of some weeks or even months.

4.4.2 Methodological approach and analysis

Participatory visual methods – the youth gaze methodology

The youth gaze methodology, first developed by anthropologist Trond Waage (2013), was inspired by methods from social anthropology in the actor-oriented tradition of Goffman (1971, 1981) and Barth (1969), and the craft of ethnographic filmmaking (MacDougall, 2006; Rouch, 1967; Rouch & Morin, 1961). This research has emanated from the emerging field of participatory research as well as what has been termed "the visual turn" in social sciences. These perspectives arose from critical and feminist studies that suggested that dominant forms of knowledge needed to move from center stage and make room for more diverse meanings and ways of meaning making (Lather, 2007; Thomson, 2008; Weiler, 2001). The idea of voice was taken up into research methodologies in ongoing efforts to find ways to bring previously unheard voices into scholarly and professional conversations: "giving voice to the voiceless" (Visweswaran, 1994). As part of these more general shifts in research practice, social science research on children and young people widened its search for ways to solicit their views and voices and to represent them in publications. As scholars in the "new" childhood studies argue, children and young people are capable of providing expert testimony about their experiences, associations and lifestyles. Children and young people are seen as competent "beings" whose views, actions and choices are of value (Thomson, 2008). There has been considerable discussion of the kinds of methods that could most adequately elicit the voices of youthful participants; this sparked an interest in visual research, as it seemed to offer different ways to elicit the experiences, opinions and perspectives of children and young people, as well as new means of involving them as producers of knowledge. Voice does not only mean having a say, but also refers to the language, emotional components and non-verbal means used to express opinions. A commitment to hearing marginalized voices does not permit the censoring of particular views and modes of expression. Thus, to make visible the complexity, partial truths and multiple subjectivities of local worlds, it is necessary to make use of different methods that elicit different voices.

Based on previous studies demonstrating the many potentials of collaborative and visual methodologies when researching children and adolescents (cf. Chalfen & Rich, 2007; Mitchell & Sommer, 2017; Rich, 2004), we wanted to explore how these methods could be combined with more traditional qualitative methods to gain access and insights into otherwise hard to reach aspects of embodied life experiences and the personal social worlds of adolescents living with contested illness. In previous studies applying this methodology, young filmmakers had transformed visual representations of everyday events and personal experiences into films, which allowed researchers to study contextualized meaning-making processes and to overcome communicative barriers (Waage, 2016). Dialogue during the filmmaking process aims to create a momentary common ground by communicating otherwise unavailable or hard to reach aspects of participants' experiences (Pink, 2006, 2007), and enabling reflective processes where individual interpretations and dilemmas may be explored (Carlson, Engebretson & Chamberlain, 2006; Johnson & Alderson, 2008).

Against this backdrop, and to gain insight into the everyday lives of adolescents living with MUS and understand the ways in which they gave meaning to their experiences, I worked with Maria Fredriksen Kvamme to arrange collaborative film courses with inspiration from the youth gaze methodology. By using the film course and its film products, we wanted to supplement data gathered through interviewing with a method of dialogical interpretation of visual representations. Five adolescents were invited into a small workshop setting, given camcorders and asked to make individual films about a topic close to their experiences. Conversations and exploration of film topics and footage led to joint reflection on important life events for the participants. Three of them were also followed individually due to their health concerns and difficulty in participating in the group setting. The visual methodology was applied flexibly to account for each individual's health challenges and different life circumstances. At the end of the workshop, we arranged a screening of the finished films for a selected audience. This audience included family members, friends and health professionals that had close contact with the adolescents. The adolescents themselves chose whom they wanted to include in this screening. The screening of the films was hypothesized to enable new modes of communication and to create dialogue, mutual understanding and pave the way for empathetic encounters in the adolescents' social contexts, which would hopefully benefit both the adolescents and those around them in coping with the uncertainty of unexplained illness.

Life mode interviews

In addition to participation in the film workshop, some of the adolescents were interviewed individually to gain a deeper understanding of their everyday life with illness. The interview format used was the life mode interview, first developed by Hanne Haavind (1987). There are a number of different approaches and techniques broadly referred to as qualitative interviews; their common feature is that they are conversations with a clear structure and a purpose, and that they are determined by the person responsible, i.e., the researcher (Kvale, 1996). The qualitative interview goes beyond the spontaneous exchange of views of everyday conversation and becomes a careful questioning and listening approach with the purpose of obtaining thoroughly tested knowledge. The strength of the interview conversation is that it is able to "capture the multitude of subjects' views on a theme and to picture a manifold and controversial human world" (Kvale, 1996, p. 7). As Kvale (1996) points out, the interview is literally an "inter view", an inter-change of views between two persons conversing about a theme of mutual interest, and as such it is a construction site for knowledge. The skills needed to perform research interviewing can be said to overlap with the skills involved in psychotherapy, although the goals of each type of interview differ (Finlay, 2003; Finlay & Evans, 2009; Kvale, 1996). Both practices require an ability to form an accepting relationship, skill in active listening, and a focus on the other's experiential world, thus creating space for intersubjective relatedness (Finlay & Evans, 2009). However, different kinds of interviews invoke different forms of interaction that produce different kinds of knowledge.

The life mode interview format has in several studies demonstrated its usefulness in providing data on how young people make sense of themselves and their environment (Andenæs, 1996, 2000; Gulbrandsen, 1998, 2000, 2003, 2006; Haavind, 2003, 2007; Hauge, 2009; Søndergaard, 1996). This interview format seeks out everyday events, with an emphasis on how these events are included in the routines and meaning-making activities of the individual's life. The overall idea of the life mode interview is that the previous day or the previous week is used to structure the dialogue. This format may lead to the exploration of other research issues of interest such as experience of symptoms, illness experiences, youth cultures or interactions with friends, family and health professionals. The dialogue provides an intersubjective focus on the narrator as a participant in events that are significant for him or her. The basic idea of the life mode interview is a focus on comprehensions that may seem self-evident and often appear as taken for granted in the participants' descriptions. The aim of the interview format is to maintain an open focus while also focusing in depth on selected topics. By asking participants to elaborate on descriptions of everyday practices and everyday life, the researcher is able to steer the conversation from general descriptions towards more detailed accounts ('thick descriptions'). By returning repeatedly to the structuring aspect of the previous day or week, one is able to regain the initial focus and to obtain detailed descriptions of everyday life (e.g., "I see but let us return to when you got back from school...").

Many of the adolescents that I interviewed initially rushed through the descriptions of their day, and it was apparent from the way they presented their stories that they were used to talking to health professionals and others about their illness and their daily routines. However, the difference of the life mode interview format is the dwelling on certain topics and the expanding of themes through focus on details. For example, when asked about the previous morning, the participants often started by saying that they woke up, went to school, had some classes and then went home. However, detailed questioning can elicit rich accounts of everyday life and embodied experiences of illness. Examples of such questions are: How did you wake up? Was there anybody with you? How did you feel when you woke up? What clothes did you put on? Who had chosen the clothes? Did you take a shower? What did you have for breakfast? Who made the food? For some of the adolescents, the interview format was used in repeated interviews, and after a while, they became quite familiar with the format for the conversation, and the recognizable and familiar structure allowed them to be more open in their reflections. The focus on everyday practices is simple and understandable even for younger participants, and because the interviewer does not introduce concepts before the participants themselves name them (such as the diagnosis of CFS/ME), the format is advantageous from an ethical perspective as it does not impose perceptions or views on the participants. By being open to what the participants bring to the table and the concepts they use to describe their own experiences, the format is able to provide data which might not have been generated if the interview had been more specific. Thus, what might be considered a weakness of the interview, i.e., its broad scope, also represents the potential and strength of the method. The openness to issues that participants bring into the interview provides rich and extensive data and analyses that are more grounded in the empirical material than is often the case in the analysis of qualitative interview data (Hauge, 2009).

Analysis

The initial questions that took form during the participant observation and ethnographic fieldwork led us to conduct a case study in which we focused on one of the eight participants. We followed him over one year during his participation in 14 film workshop sessions and six interviews held concurrently with the filmmaking process. Peter was purposely selected for in-depth analysis because the initial steps of our analysis showed us that his case provided extensive and specific answers to the question we were interested in exploring, namely, how a young person might make sense of the experience of bodily symptoms and suffering that defy explanation from medically approved notions of disease, and the disruptions of social life and future aspirations that follow. The way he enthusiastically took part in exploring the film footage and in dialogic exchanges with us as researchers in interviews and in film workshop sessions with other adolescents powerfully demonstrated the process of narrative work that entailed agency, seeking accountability and future aspirations, but also sociocultural constraints and discursive limitations. The film process and the interviews were analyzed together using an explorative narrative and performative approach, emphasizing the co-constructed and dialogical search for meaning during the research process (Bakhtin, 1981; Frank, 2010; Holquist, 2002; Riessman, 2008; Shotter & Billig, 1998). This meant that our own roles as researchers also became an integral part of the analysis. A performative narrative analysis asks not only what the elements or prevailing themes of the narrative are, but also why this narrative is produced at this specific time, in this specific context and for this specific audience. It asks what positions the narrator occupies in telling the narrative, and to what purpose (Riessman, 2003). These performative dimensions make the contextual nature of narratives more visible and indicate some aspects of the discursive terrains in which the individual tells his/her story. This case study is presented in the first article that anthropologist Maria Fredriksen Kvamme and I wrote in collaboration.

Study II: Secondary care specialists and their challenges working with adolescents with medically unexplained symptoms

4.4.3 Site, sample and procedure

Health professionals in secondary care

The second study of this thesis was an interview-based study with highly experienced and engaged health professionals working with adolescent MUS patients in secondary health care in Northern Norway. Health professionals with different occupational backgrounds were purposively selected. They were recruited from different units of the University Hospital, specializing in child psychiatry or mental health, pediatric pain, chronic fatigue, pediatric rheumatology and adolescent medicine. The health professionals recruited had an average of 13 years of experience of treatment and/or assessment of patients aged 12-23 with MUS.

The health professionals were, as already mentioned in the description of study one, our partners in the recruitment and sampling of adolescents. In the information provided about the adolescents we also included that we wanted contact with health professionals who had experience of clinical encounters with adolescents with MUS, were professionally engaged in this field, and were interested in sharing their experiences and thoughts in individual interviews and/or focus group discussions. Initial contact was established with leaders of the various units, followed by several meetings to provide information about the study to possible participants. Those interested in participating gave us their names and contact details, and further arrangements were made via e-mail or phone.

The sample consisted of 16 health professionals, three men and 13 women: six physicians, six psychologists, one nurse, two physiotherapists, and one occupational therapist. Six of these participated in the focus group discussion and ten were interviewed individually.

4.4.4 Methodological approach and analysis

Focus groups

In order to capture performative aspects of health professionals' knowledge construction, I decided to use both a focus group discussion and individual interviews. As I was interested in the interaction between health professionals and their joint knowledge production as representatives of the health care system understood as a cultural system (Kleinman, 1980), I found the focus group to be an appropriate format that could supplement data gathered from individual interviews. The individual interviews and focus group discussion both represented interactional contexts for storytelling that highlighted collective and collaborative constructions of social realities. Focus group discussions have been described as located midway between structured interviewing and observational fieldwork (Barbour, 2010; Powney, 1988), and have been argued to provide concentrated and detailed information in a much shorter time span than is possible through ethnographic fieldwork (Bloor, Frankland, Thomas & Robson, 2001). The group situation allows the participants to step back from taken-for-granted behaviors and assumptions and provides space to problematize concepts and ideas to which they usually pay little attention. I therefore felt that this format could give me valuable insight into communicative challenges, not only as these were consciously interpreted and understood by individual practitioners, but also as related to shared discursive and cultural practices in health care systems.

As I had learned from reading methodology literature that the moderation of focus groups could be demanding and that it required the researcher to be especially well prepared, I paid careful attention to the designing and planning of the focus group. In this process, I concentrated on the sampling and composition of group participants including occupational backgrounds and gender, the development of topic guides and the selection of stimulus materials. I tried out several different approaches beforehand, developing different elicitation stimuli such as newspaper clippings and different constructed cases. The guide that I ended up with consisted of two constructed clinical cases and a list of topics and questions following each case. Prior to the meeting, the participants were given information on the study and encouraged to recall memories of particular clinical encounters with young patients with medically unexplained symptoms that they had perceived as challenging or illuminating. I moderated the group, while Mette Bech Risør, who had more experience in conducting focus group research, functioned as an observer and assistant who could intervene if the discussion became stuck in an unconstructive path or if important topics were missed or overlooked. The discussion ended after 90 minutes and the moderator and observer then compared notes and observations, and discussed some preliminary interpretations.

The focus group consisted of six participants from different occupational backgrounds: two medical doctors, one occupational therapist, one physiotherapist, one nurse and one psychologist. There were two men and four women. The health professionals selected to participate in the study had several years of experience and were highly engaged in their clinical work, as I thought these would be able to give rich and detailed accounts and nuanced insights into the workings of the health care system. The choice of different occupations and both sexes mirrored interdisciplinary groups in secondary health care, and allowed for conflicting or differing views.

The focus group data were combined with data obtained from subsequent individual interviews, and provided me with some important insights into the interactional dynamics of medical knowledge production, positioning and discursive production of professional actors in a simulated micro-cosmos that mirrored the workings of the health care system. It also gave me insight into how to understand communicative challenges in the health care system and triggered some preliminary thoughts on the most interesting topics for further exploration in the individual interviews.

Qualitative interviews with health professionals

Whereas the life mode interview was particularly well suited to the exploration of everyday life and meaning making of the adolescents, the interviews with the health professionals had a more specific research focus and therefore had to follow a different format. The interview guide developed consisted of four sets of questions regarding health professionals and 1) their understanding of MUS in adolescence, with a focus on explanations of symptoms, 2) their experience of clinical encounters with this patient group, with special emphasis on one specific recalled case, 3) their perceived challenges concerning the management of this patient group, specifically focusing on communication and interaction with patients, family members or other health professionals, and 4) their positive experiences in encounters with this patient group, specifically focusing on relational aspects and experiences of mastery of the professional role.

The qualitative interviews with the health professionals were conducted by two clinical psychology students, who used the interviews as a basis for their master's theses. The interview guide and research questions were developed in collaboration in the research group. The interviews were audio recorded and transcribed verbatim.

Analysis

The analysis can be said to have started with the development of research questions and the interview guide, and continued with the interpretative work in developing common themes across cases, the use of theoretical concepts as a lens for understanding how health professionals discursively and performatively constructed MUS, the writing of the research report and finally, in my representation of the research participants through my story about them. The analysis of qualitative data always implies making choices: "carving out unacknowledged pieces of narrative evidence that we select, edit, and deploy to border our arguments" (Fine, 2002, p. 218). The transcripts were read and reread several times and analyzed in conjunction with the focus group data using an explorative approach, initially following general principles for thematic analysis as developed by Braun and Clarke (2006). In later stages of the analysis, I also focused on performative and structural elements, such as how the participants positioned themselves in relation to their roles as health professionals and representatives of the health care system as a whole as well as in relation to each other in the focus group context (Barbour, 2010; Riessman, 2003). The analysis evolved from a curiosity to understand more of how MUS was constructed among representatives of the cultural system of health care, and how they approached communicative challenges and dilemmas in their practice. This curiosity stemmed from the aim of making visible the discursive terrain (Youdell, 2005) in which the adolescents with MUS navigated. The analysis revealed paradoxes and contradictions in the health professionals' statements, which were interpreted in light of the research literature and theoretical concepts in the MUS field on inherent epistemological tensions between biomedical and integrative biopsychosocial discourses. The results of the analysis are presented in the second article of this thesis.

Study III: An ethnographic study of clinical rehabilitation for adolescents with medically unexplained long-term fatigue

4.4.5 Site, sample and procedure

The rehabilitation center

In view of how the study transpired and because I wanted to know more about how clinical encounters and communicative practices actually appeared in a specialist health care setting, I later established contact with a tertiary health care arena that allowed me to conduct participant observation in a naturalistic context, namely a rehabilitation center (Birch Hill) to which many adolescents suffering from MUS are referred. The rehabilitation center was chosen as a site because it was an inpatient unit that enabled me to gather rich and detailed data on clinical communication over a relatively short but intense time. Here I was able to observe encounters between health professionals and patients in many different contexts at all times of day for several consecutive weeks, which allowed me to gather more data than would have been possible in participant observation in an outpatient setting.

Contact with the center was made after a meeting at the University with some of the leaders and the head of research activities at the center. Arrangements were made to give information to a group of adolescents diagnosed with CFS/ME who were to take part in a four-week rehabilitation program at the center, their family members and the professionals working there. This information was to be given at a pre-screening that was to take place before the adolescents' actual stay at the center. Information letters and informed consent forms were sent out by our partners at the rehabilitation center to all eight of the adolescents enrolled in the rehabilitation program.

In the information letter I explained that I wanted to gain knowledge of a) how adolescents with complex health problems describe and understand their symptoms, illness experiences and illness paths, b) the experiences of their family, friends and school and health services and the adolescents' various encounters in their social environment, and c) the significance of different social encounters for the adolescents' experiences, coping and managing of symptoms and daily lives. The adolescents could decide whether they wanted to be interviewed, and they were informed that they had the right to refuse to be mentioned in descriptions based on participant observation. Both legal guardians and adolescents had to give their consent. All eight of the adolescents in the group that received the information letter agreed to participate.

The health professionals working with adolescent patients at the center were given information about the study in a separate meeting, and they could also refuse to be mentioned in the data gathered from participant observation and to abstain from taking part in interviews. Nine health professionals that had more individual responsibility and/or more of the day-to-day contact with the adolescents in the CFS/ME program were followed more closely, and could be defined as key informants, since they were the professionals I had most extensive contact with during the fieldwork. Two of these key informants did not have direct contact with the adolescents but gave me insights into the general workings of the center. Seven of the key informants were in daily contact with the adolescents in the CFS/ME group, supervising their treatment and being in charge of activities, organizing daily schedules, individual follow-up care and therapy sessions and arranging meetings between family members, patients and partners in the treatment and planning of discharge. The health professionals who were responsible for the adolescents in the day-to-day treatment program either had a physiotherapy background with various specialties in physical activity or rehabilitation, were social educators, social workers or had nursing degrees. Two of the nurses had specialized in mental health and had responsibility for the therapy groups and some individual therapy sessions with the adolescents.

The nine health professionals and the eight adolescents with CFS/ME on the rehabilitation program at the center were the key informants of my fieldwork. The adolescents were aged from 12 to 18, had on average been ill for two years, and experienced moderate to mild symptoms. They were a heterogeneous group in terms of social function. Some of them were still taking all classes at school, while others had dropped out of school completely. They also differed in terms of social contact with peers and their ability to participate in after-school activities. Some of them had quit all after-school activities, while others had tried to maintain some activities. They were of diverse socioeconomic backgrounds, some from middle to upper social classes while others had a working-class background. Their symptoms also differed significantly, although they all had received the same diagnosis of CFS/ME. The main concern for some was fatigue, for others pain was their main symptom, others struggled with nausea and some had epileptic-like seizures and tremors. Despite these variations, the treatment approach was more or less the same for all, focusing on balancing activity and rest and establishing good routines for meals, physical activity and sleep. Cognitive-behavioral principles were the basic approach in therapy groups. The treatment approach is described in further detail in Paper III and will not be repeated here.

4.4.6 Methodological approach and analysis

Fieldwork and participatory observation in different contexts

Conducting fieldwork over two months, I was able to observe and take part in a wide range of activities at the rehabilitation center, such as physiotherapy, climbing sessions, archery, yoga classes, various outings, meals and therapy groups for the adolescents and their parents, in addition to interviewing the adolescents and having informal conversations with parents and health professionals about their experiences. I also observed the health professionals in backstage talk discussing patients during treatment meetings or in casual conversations amongst themselves and I sat in on individual conversations between the adolescents and staff. Participating in a broad range of activities and observing directly the interaction between health professionals and patients in an inpatient setting gave me the opportunity to describe communicative practices and challenges in detail. I was able to make audio recordings during treatment meetings and therapy groups and in some of the individual encounters between patients and staff, as well as during the interviews with adolescents. These recordings were later transcribed verbatim. When recording was not possible, I was careful to take detailed notes during my observations or as soon as possible afterwards.

A typical day of fieldwork at Birch Hill could be as follows:

My day often started eating breakfast at a separate table observing who came and went in the breakfast hall and the social dynamics between patients, family members and staff, having a chat with some of the employees, e.g., the psychologist or the leader of research activities, before the morning staff meeting. In this meeting the plans for the day were discussed, potential difficulties brought up, logistics laid out and tasks assigned to the team members. Here I could arrange to join or sit in on therapy groups, individual therapeutic sessions, parent groups, school classes, yoga classes, outings or other activities planned for the day.

After the morning meeting I would typically take part in two team sessions in which the patient, his/her mother or father and two of their main contacts in the team usually participated. In these sessions, progress or obstacles in the treatment process were discussed and plans were laid for how to incorporate the routines they had learned at the center in their home situation. Here I would usually just sit and listen, most of the time being able to record and take notes during the sessions. After these sessions, I would typically be able to have a chat with the team members and ask them about their work and their thoughts on the patient group in general, or the specifics of individual cases and the session that had just taken place. These conversations with the health professionals did not follow any specific interview format, as they were more informal and ad-hoc talks in between more formalized meetings and activities.

If I was conducting interviews, I typically had arranged these the day before directly with the adolescents and made sure to fit them in with their daily schedule at the center. Each patient followed a preset schedule that was open to individual adjustments. If I had arranged interviews the day before, these would typically take place in the time normally reserved for individual sessions between patients, family members and team. The interviews with the adolescents were life mode interviews, i.e., the same format as described in the methods section of the first study.
Lunch normally followed the interviews or team sessions. During meals I was able to observe the adolescents in a more casual setting, how they interacted with each other and how social groups and bonds eventually formed between them. During meals I would also get impressions of who these young people were and what backgrounds they came from by observing their interactions with family members and by overhearing their conversations.

After lunch, I would typically have some time to write up some field notes in private, before joining a therapy group or an activity for the adolescents. As I often sat in a shared office for this writing, I sometimes would inadvertently become an observer of the dynamics between staff members and the various dilemmas and difficulties they faced during their working day, as they often would use the office space for ad-hoc conversations between themselves.

On some days there were treatment meetings where patients were discussed in more detail. During these meetings, all the health professionals working with children and adolescents in the center were usually present, not only the ones working specifically with the group of adolescents with CFS/ME. This included the physician, the speech therapist and usually one or two teachers, as well as the professionals working with adolescents in individual treatment programs for different symptoms, illnesses and injuries, whose backgrounds were in physiotherapy, social work, animal-assisted therapy and nursing. At these meetings, cases were discussed in terms of progress, general understandings of triggering and maintaining factors and the etiology of symptoms, plans for discharge and potential solutions to problems. I always tried to be present during these meetings, which often took place in the afternoon, and was able to record and write notes as patients were brought up and discussed.

On some days there were social activities or physical activities planned for the adolescents, like board games in the evening, karaoke, swimming, yoga or climbing. I took part in these activities as often as I could, and here I would try to get to know the adolescents and interact with them in a more casual way than was possible during group treatment sessions or in interviews. The adolescents were forthcoming in taking me in and giving me a role in their social groups, often sharing thoughts and experiences in a more spontaneous manner than in other settings. Here it could be more difficult to write notes while participating and interacting with the adolescents, but sometimes I would be able to do a drawing or write down some keywords that would prompt my memory when writing my notes later in the evening. On most days I would eat dinner alone in the apartment where I stayed, but sometimes I ate in the cafeteria in the main building. In the evenings I usually spent much time writing up field notes from the day, writing reflexive memos and developing preliminary research questions.

Analysis

Initially I went to the fieldwork with an open mind, without specific research questions that I wanted to answer other than the general aim of observing and describing meaning-making processes and communicative challenges as they played out in a rehabilitative context. I had a general idea of wanting to understand more of how adolescents gave meaning to their experiences, how health professionals working in this context understood their work and how they supported the adolescents in their processes of meaning making and how health encounters appeared. Therefore, I tried to gather as much data as possible, taking part in a broad range of activities that either patients, staff or both engaged in together. Each day during fieldwork I wrote extensive notes and memos that over time gave rise to preliminary analytic ideas and more specific research questions. During this process I became interested in exploring the informal categorization processes that health professionals and adolescents seemed to engage in over the course of treatment.

After fieldwork had ended, these preliminary questions and research interests lay the foundation for further explorative analysis. Mette Bech Risør, Catharina E. A. Wang, Hanne Haavind and I listened to raw data from interviews, treatment meetings and different clinical encounters, and reviewed the field notes and interview transcripts, exploring how the categorization process appeared. In the group, we discussed and explored analytical approaches, and developed emergent ideas and interpretations. During this process we selected four cases from the material that illustrated two patient categories that could be described as opposite ends of a spectrum, which were constructed in the talk-in-interaction in the clinical encounters. In reading research literature, I came across the theoretical concepts of positioning (Davies & Harré, 1990) and troubled subject positions (Wetherell, 1998), as well as the concepts of categorization and intersectionality (Staunæs, 2003). Several ethnographic studies from medical anthropology were also major inspirations (e.g., Buchbinder, 2015; Desjarlais, 2000; Gremillion, 2003). Moving between phases of reading the empirical material, discussing it in the research group and looking for analytical entry points by reading theoretical and empirical literature in a hermeneutic circle of interpretation, I became aware of how the communicative and categorization processes in the clinical context affected the adolescents' meaning-making processes in what could be understood as the creation of either troubling or untroubling subject positions. I saw that the subject positions made available to the adolescents were closely connected to a categorization in which some were labeled “complex” patients whereas others were named “classic” patients. The names that I selected for describing these two categories were based on the staff’s own descriptions of their patients and their explanatory theories regarding etiology, maintaining factors and relevant treatment approaches for different patients, as well as their understanding of what created problems during treatment for some patients and not for others. When analyzing the research material and drawing on the talk-in-interaction between staff and adolescents, I came to understand the construction of these two categories of patienthood as related to shared discourses of development, family life and illness. In addition, I became aware of how, in the meaning-making processes that both patients and staff engaged in during treatment, several sociocultural categories such as gender, age and class were interwoven with local perceptions and ideas of “factitious”/“complex” and “real”/“classic” illness.

The results of the analysis are presented in the third article of this thesis.

5. Findings: Summary of papers

Paper I

Title: 'Not a film about my slackness': Making sense of medically unexplained illness in youth using collaborative visual methods.

The presentation of a continuous, collaboratively made narrative from Peter about living with MUS includes both his illness-induced 'derailment' from his expected developmental path towards adulthood, and the process of reinterpretation through the research interviews and the making of a film. Such a narrative demonstrates what is at stake for the person in the particular trajectory in his life, and his active engagement in processes of coping. In the case of Peter there is an emotional tension between two central themes, as exemplified by 'Derailment 1' and 'Derailment 2'. According to 'Derailment 1', 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. However, he did not believe that a diagnosis would provide him with answers to the questions of how long the symptoms would last and what significance they would have in shaping his future. According to 'Derailment 2', Peter's process of redefining his illness experience moves beyond symptoms and is directed at a future filled with uncertainties. However, this is also about claiming his own voice in a reflective process of sense making. In his ongoing efforts to live a life for himself he is constructing a new and meaningful narrative that seeks to make sense of his biographical disruption. In this process he is actively engaged in trying out new meanings and new identities. We came to see him and other young people living with MUS as intentional and active creators of their own subject positions, with their own projects of becoming. These projects are not just restrained and confined by the symptoms they were experiencing but contained much more, such as searching for accountability, acknowledgement and future aspirations. The creative and reflective process of the visual, collaborative methodologies and life mode interviewing over the course of one year allowed us to come close to each person's particular embodied experiences, highlighting the active work being done and making the complexities of their attempts at coping more visible. In addition, these methods supported the ongoing narrative reconstruction of subjective experiences, providing each person with a language for multiple aspects of the embodied experience of illness. We found that these methods might have potential not only in a research context but also in overcoming communication barriers in everyday life and clinical encounters.

The paper was published in 2018 in *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, after receiving an extensive editorial review.

Paper II

Title: Epistemological and methodological paradoxes: secondary care specialists and their challenges working with adolescents with medically unexplained symptoms

In the second paper I bring attention to the contextual conditions and discursive terrain in which adolescents with disabling symptoms navigate. By talking to highly engaged health professionals aiming to offer treatment and understanding to adolescents with MUS, I gained insights into the workings of the health care system as a whole, as a sociocultural context highly relevant and influential for the developmental processes of adolescents with contested illness. Invited to tell about their experiences from clinical encounters with adolescents living with MUS, the health professionals emphasized several communication challenges in consultations. These challenges followed from their efforts to navigate between discourses of evidence-based medicine and sociocultural dimensions of clinical practice, and the ways in which both discourses intersected with their efforts to reach out to and stay engaged with the patients. By taking a closer look at the explanatory models and rationales for clinical action that the health professionals constructed in order to overcome clinical uncertainty, I gained an impression of shared discursive practices and conflictual epistemological realities that underpin medical reasoning and the logic of care. The findings point out that, although the health professionals were highly invested and engaged in their work with these patients, they were caught up in different knowledge regimes and paradigms of thought that created paradoxes and dilemmas in their clinical work. A conceptual model of two different but interconnected themes combines the professionals' different responses to these dilemmas in individual encounters with patients: the epistemological paradox and the methodological paradox. Within these paradoxes, the professionals tried to find solutions by being creative in their communicative strategies, by applying metaphors and other rhetorical devices to explain complex ideas, by creating clinical prototypes as a way to explain symptoms and guide them in clinical action, by relying on principles from patient-centered care involving empathy, and by trying to balance expertise and humility. The communicative strategies and the explanatory models the professionals created worked as mediators to understand symptoms and create meaning for themselves and their patients; however, these practices were not value-free but instead infused with normative ideals and morals. By drawing attention to the different value systems and knowledge regimes that underpin clinical decision-making and reasoning, the results of the study might contribute to a more reflexive practice in line with principles from patient-centered care.

The paper was published in 2018 after peer review in *International Journal of Mental Health Systems*.

Paper III

Title: The makings of 'classic' and 'complex' patients – an ethnographic study of clinical rehabilitation for adolescents with medically unexplained long-term fatigue

Ethnographic fieldwork in a multidisciplinary rehabilitation center that offered intensive treatment for young people diagnosed with medically unexplained long-term fatigue highlighted ongoing challenges for communication across different treatment settings. Such challenges were also prevalent in the efforts to understand and assess the same client across different arenas for participation in treatment activities. Following the talk-in-interaction of four cases, I demonstrate in my findings that for adolescents diagnosed with medically unexplained long-term fatigue and following a rehabilitation program based on a biopsychosocial understanding, the process of negotiated and co-constructed meaning might take two rather different directions. These two directions are presented through the two categories of "classic patients" and "complex patients": Either the adolescents' understanding of their suffering and future prospects in life is confirmed in the ongoing communication in the clinical encounters, or the encounters bring up contested issues about being a proper patient and an accountable person. In my analysis I paid attention to the ways in which established sociocultural categories such as age, gender and class interwove with local perceptions of "classic" and "complex" versions of illness, showing how institutional ideologies and discourses produce norms of patienthood that might be hidden within generalizing terms of health and illness. All of the adolescents in the study struggled to achieve credibility and validation of being legitimately ill and to define their subjectivities as adolescent girls or boys with plans and dreams for the future in their trajectory toward adulthood. However, the analysis indicates that several intersecting categories might be involved in the subject positions made available to the adolescents, creating either opportunities or challenges in their developmental processes. In closing I discuss the implications of such categorization for adolescents' illness paths and subjectification processes. The study suggests that the concept of intersectionality can be a useful analytical tool to understand the production of (un)troubled subject positions in clinical contexts. By examining how meaning is ascribed, how categories intersect and how experience is accounted for in mundane activities in a specific context, one can understand more of the possibilities, challenges and constraints among the subjects involved, possibly paving the way for a more reflexive clinical practice.

This paper is ready to be submitted.

6. Discussion

By being a participant in three sub-studies I have entered social fields that differ somewhat in how young MUS sufferers express themselves and encounter professional helpers and experts who try to understand them and reduce the burden of their symptoms. I will summarize and discuss the results in terms of the discursive terrain where challenges are pointed out, and where some uncertainty prevails. Challenges and the uncertainty that follows may take on different forms. I have seen how the tensions between the quest for explanations and cure could be handled in different ways according to the engagement and the positioning of the communication partners and what they viewed and produced as challenges and suitable approaches.

The results will first be discussed in terms of certain methodological and ethical issues. These include validity and reflexivity in studies where definitions of the phenomenon in question (MUS in young people) are a concern in themselves, in addition to whether the researchers can claim they have privileged access to this phenomenon as real. Further, I will present some considerations on the persons that may, or may not, be included and have their voices heard in studies like these. This leads to the specific asymmetries involved in defining power between the adolescents and health professionals, as well as between adolescents and researchers. This section ends with a discussion about generalizability: How far-reaching are the models for representing uncertainty in contexts where everyone is authorized to speak just for themselves?

Taken together, the three sub-studies document specific qualities in communicative challenges from different social sites. The second part of this section will discuss the three sets of results in conjunction. The overarching theme here is models for understanding developmental processes for young people that experience constraints and challenges due to fatigue, pain and embodied symptoms. Here I will also draw attention to moral and existential aspects of narrative work, as well as pointing out that in the subjunctive mode these processes are incomplete and ongoing.

The third part of the discussion will dig a little deeper into the implications of these results. I will address some consequences of being in the role of a professional helper for young people with MUS. The role of the helper is, however, only one aspect of realities in health care systems. The discursive handling of ideals and realities will be in constant focus.

Finally, there is a brief paragraph about the need to slow down efforts to reach firm conclusions, be it through research or through treatment. The point is to pay attention to the ways in which categories like MUS intersect with membership in other categories in ways that should not be predetermined.

6.1 Methodological and ethical considerations

6.1.1 Internal validity: Quality and reflexivity in qualitative methods

Scientific quality is not tied to a specific research method, but to how knowledge is collected and handled. Internal validity describes whether the choice of methodology is appropriate for answering the research question, the design is valid for the methodology, the sampling and data analysis are appropriate, and finally if the results and conclusions are valid for the sample and context (Malterud, 2011). In this project I have sought to achieve internal validity by a triangulation of methods, by discussing analytical approaches, methodological choices and theoretical positions, and by reflecting upon my own role as a researcher within an interdisciplinary research group. I have also sought to achieve craftsmanship in the gathering of data by conducting practical exercises, pilot interviews, trial and error learning and apprenticeship. In addition, I have reflected a great deal on my double role as clinical psychologist and researcher and how this has affected my presence in the field and the data that I have co-constructed with my research participants.

According to Alvesson and Sköldberg (2018), determinants of good quality research are that the ontology and epistemology on which the research is based are made transparent, drawing attention to the complex relationship between processes of knowledge production and the various contexts of such processes, as well as the involvement of the knowledge producer, i.e., the researcher. This implies a reflective mode involving strict attention to the way different kinds of linguistic, social, political and theoretical elements are woven together in the process of knowledge development, during which the data are constructed, interpreted and written. Reflexive empirical research implies that the researcher rejects the notion that research data have an unequivocal and unproblematic relationship to the outside world; there is no simple mirroring between "reality" or "empirical facts" and the research results (Alvesson & Sköldberg, 2018, p. 11). However, through systematic and critical reflection and awareness on several different levels, one can still make important points about the world we live in. By focusing on the person of the researcher, the relevant research community, society as a whole, intellectual and cultural traditions and the central importance of language and narrative in knowledge production, one can open up opportunities for understanding and endow the interpretations with a quality that makes the empirical research of value (ibid.). In order to honor such an engagement, I have dedicated some space in this thesis to reflections on my own preconceptions and position in the field as well as those of the research group to which I belonged. I believe that it is only when I make these positions explicit that other researchers can evaluate my interpretations and findings following my participation in the field.

Researching adolescents that can be said to be in a particularly vulnerable and marginalized position creates specific challenges in ethical reflection and awareness. Ethical reflection implies the ability to present the results in a balanced and nuanced way that takes into account the complexities of adolescents' and health professionals' unique struggles, contextual conditions and dilemmas. I have tried to adhere to such an engagement throughout the realization of this project. In spite of this engagement, there are several limitations connected to the recruitment of participants and data collection and handling that are worth dwelling on.

6.1.2 The researcher's classifications and reality construction

As researchers, we encountered the problems of nomenclature and classification when we first started planning our project and setting out to recruit participants. We encountered problems when we initially described the project in the information letter, seeking out informants of the "right" category of adolescents and deciding on which term to use in our description: medically unexplained physical symptoms, functional symptoms/syndromes or complex health problems? We also faced the problem of which adolescents we should include in or exclude from our study. For example, how long should the symptoms have lasted for us to consider them persistent enough? What did it mean that symptoms were physical, and did this mean that we should exclude adolescents with mental health problems from the study?

These questions all seemed to exemplify some of the current issues in research on MUS regarding mind/body dualism, interpretive and cultural dimensions of the relationship between bodily signs and symptoms, and the role of language and discourses in creating and maintaining social realties. Even though our field of interest was not to investigate causes of the symptoms or to find the right or the wrong way to describe and understand symptoms, we had to consider these issues in our approach. As social scientists, we have a responsibility to pay critical attention to how our terminological choices, often underpinned by specific methodological or even political commitments, can performatively feed into the conflictual dynamics that we have set out to describe (Greco, 2012). The term performativity entails that our choices of wording and our statements do not merely represent or describe a phenomenon, but rather enact and perform its reality (Butler, 1990; 1993). The perspective of performativity addresses what a representation and description *does*, and what it adds to the world in terms of possibilities or constraints, what reality it performs. This perspective necessarily applies not only to the medical profession or the individual experiencing symptoms, but also to the researcher. We all engage in different forms of reality construction through our representations. To be conscious of these performative aspects is especially important for us as researchers.

6.1.3 Whose “voice”?

Several adolescents dropped out before they could finish their films, which might suggest that the format was too demanding, despite all the adjustments and consideration taken to attend to their needs. Many of the adolescents that we encountered had been struggling with fatigue and pain for years, and most of them had dropped out of school and leisure activities due to their symptoms. One of our presumptions in the research group was that the film course could provide the adolescents with something to focus on apart from their illness, an opportunity to share their experiences with interested and engaged researchers and eventually with health professionals, as well as providing them with a social setting where they could meet others with similar experiences. We assumed that the visual methods would have some important secondary benefits for the adolescents in terms of dealing with the consequences of long-term unexplained illness. Indeed, this seemed to be an important motivation for some of them, but the health challenges and long-term social isolation might still have made it too difficult to participate for some of those we encountered during the recruitment stage. With this in mind, I see that the collaborative visual methodology might be beneficial in terms of eliciting the voices of some adolescents, but may still be too demanding to reach those with more severe health challenges. One might ask if this issue led to an unequal distribution of research participants, and that we were unable to get in touch with and make the stories of those with more severe marginalization experiences heard. It might be that the methods have potential secondary and therapeutic effects for those of the adolescents that already had some resources to make use of in their coping attempts, or a specific interest when it came to film, and the method therefore is not necessarily useful when it comes to understanding and supporting all adolescents with health challenges. The key to using alternative research methodology such as visual methods and the youth gaze does not necessarily lie in the specific tools themselves, but in approaching research participants with creativity, openness and reflexivity, thus offering them subject positions in which they are made experts on their own lives. It is by scaffolding people’s unique ways of expressing themselves and enabling narrative emplotment that one may access hard to reach aspects of individual experiences and understand what might support individuals in their subjectivation and developmental processes.

There are also some aspects of conducting the qualitative interviews that might be worth mentioning. The life mode interview format was tried out beforehand by conducting several pilot interviews with adolescents without health challenges. This was to familiarize myself with the interview format and ensure that I could conduct the interviews as intended using the life mode form of questioning. However, despite attempting to remain consistent and faithful to the interview format, I sometimes found that I became more interested in the participants’ illness narratives as they were presented through their first experiences of symptoms, their initial contact with health professionals and the consequences of their illness for their lives. This might have made me more specific and less open than the intention of the interview format. I also recognized that for some of the participants, especially those that I interviewed several times, my background as a clinical psychologist might have influenced the interview to a significant degree. Despite being conscious of the pitfall of problem-focused encounters with adolescents and the gaze of concern from care professions, the "psy-diciplines" and researchers (Barnhart, 2017; Holland, 2009; Madsen, 2018), as well as the potential danger of reinforcing a discourse of victimization rather than one of empowerment, I sometimes found it difficult to distance myself from the role of clinical psychologist. For example, I caught myself contemplating over diagnostic issues and even trying to offer support and helpful comments when the adolescents were sharing particularly difficult experiences and emotions in the conversation. Some of them also seemed to be confused about my role, sometimes referring to me as "one of their therapists". This might have affected what they were willing to share in the conversation, as well as how they approached me and my questions and their reasons for wanting to participate. My role as a clinical psychologist might also have affected which topics came up in the conversations and which ones I chose to pursue. Narratives never come into existence in a vacuum, but are the result of who is listening, which questions are asked and the context in which these questions are asked (Riessman, 2003). My own "bodily performatives" (Butler, 1993), or *habitus* (Bourdieu, 1977), as a young female researcher and therapist with my own relational, physical, emotional and cultural history, experiences, and ways of deploying myself through my appearances, gestures, acts, ways of speaking and dressing, surely affected the interaction with the research participants and what stories we were able to collaboratively create in the social space of the research context. The question of whose voice is heard and represented through the research is therefore a pertinent question. Lather (2007) makes the point that there might be a danger in romanticizing the idea of giving voice to the voiceless and allowing for marginalized groups to speak for themselves, and thus to indulge in "confessional tales, authorial self-revelation… the reinscription of some unproblematic real" (Lather, 2007, p. 136). Through the facilitation and co-construction of these kinds of stories, there is a risk of reinforcing a rhetoric of victimhood. To give voice to some of the moral and existential concerns of patients experiencing marginalization and delegitimation due to illness that the medical community has tended to classify as "not real" has been an important contribution of social research on MUS, and this research has been compared to research on the medical side of the story in its infancy. However, it is important to bear in mind that what is represented is just one of many possible truths, and to be mindful of the complexity, partial truths and multiple subjectivities that might be presented in narratives.

6.1.4 Asymmetrical power relations between adolescent and health professional and between researcher and researched

In this research project I have been interested in how adolescents with MUS navigate and negotiate complex health problems when communicating with health professionals and with significant others, what the perceived communication challenges might be a product of, and how the challenges might be approached to benefit the adolescents. As such, the focal point in the study is the adolescents in their health pathways and in their navigations in different contexts, even though I also included health professionals' struggles and perspectives in the interview-based study. The often asymmetrical power relations between health professionals and adolescents in the medical encounter was one reason why I chose to represent the side of the adolescents, which may have made me more conscious of possible faults and problems on the side of the medical profession. The perspective of health professionals was included in the study to explore the discursive terrain: what the communication challenges might be a product of and how clinical practice could improve to benefit the adolescents in their developmental trajectories. The idea was that demonstrating possible challenges might result in a more reflexive and empathetic clinical practice; to give something back to the clinical field in terms of the development of tools for reflection and dialogue has been a goal throughout the project.

My double role as a clinical psychologist and researcher involved some challenges, not only when I was interviewing adolescents as already mentioned, but also in my encounters with health professionals and during my fieldwork in clinical settings. To avoid some of these problems, I outsourced some of the interviewing of health professionals for the interview-based study to two undergraduate students. However, I decided to have sole responsibility for the fieldwork and participatory observation. I found that when doing fieldwork in a clinical setting, it was sometimes difficult for me to find ways to blend in, making my presence non-conspicuous and being free of the expectations usually attached to social roles. Since I had a background as a clinical psychologist, I sometimes felt that the health professionals expected me to take on the role of the clinician instead of that of the observer. Some were reluctant to allow me to observe therapy groups without making myself useful. This is understandable, and probably also an expression of the uneasiness they sometimes must have felt at being observed. They often commented on my notepad and asked me about what I had found out or what I was writing. The challenge for the researcher is to become an insider so that one can understand the positions and perspectives of the actors in the field one is trying to describe, while at the same time being able to maintain the outside observer perspective that enables new analytical perspectives (Fangen, 2010). I tried to overcome this challenge by spending as much time as I could with the different actors in the field, both health professionals and adolescents, coming close to their experiences by immersing myself in the field, but at the same time seeking to maintain the analytical gaze by discussing my observations with the other members of the research group as well as writing up field notes and reading methodology literature that helped me lift my gaze and broaden my perspective.

To avoid being an advocate of just one perspective is also a challenge, since it is easy to identify with one group over the other rather than seeing them both as purposeful actors with intentions and unique struggles. Working as a clinical psychologist in a specialist health care setting for many years, I experienced myself some of the struggles that the health professionals described. The interviews with the health professionals and the literature review on clinical challenges in the management of MUS further substantiated my impression of a difficult field with many contradictions and demands. To be able to give something back in terms of new insights or reflections has been important to me, especially because of the participants' willingness to share their experiences and thoughts on difficult topics and their openness in receiving and accepting me. Despite being critical of some of the clinical practices I describe, I understand the dilemmas and difficult positions facing health professionals working in this challenging field as they try their best to balance different roles and tasks in the clinical encounters, working under pressure from both patients, collaborative partners and family members, and to show treatment results in a very limited amount of time.

As Greco (2012) points out, social science research has tended to address MUS in abstraction from medical debates on diagnostic taxonomy and nomenclature, creating sociologically defined categories and concepts such as "contested", "controversial", or "debatable" illness (e.g. Dumit, 2006; Horton-Salway, 2007; Tucker, 2004), "illegitimate illness" (e.g. Cooper, 1997; Ware, 1992) or "illness without a label" (e.g. Nettleton et al., 2004; 2005). By doing so, social science research supposedly adopts a position of epistemological neutrality, leaving it up to the medical community to deal with questions of representation and definition. However, as Greco points out, aside from the broadly social-constructionist methodological commitment that these descriptive terms encompass, they also reflect a political commitment towards validating "lay" narratives. By avoiding the medical concepts that many patients find to be loaded against them, an alternative and parallel nomenclature that patients can recognize and accept and that doctors cannot argue with is proposed. However, this validation of the lay perspective often implicitly constructs "medicine" as a singular and internally cohesive *other* (cf. Mol, 2008), downplaying the fact that nomenclature and classification is not only a controversial and much discussed topic among patients, but also among the medical profession itself.

By adding the voice of academic analysis to that of lay experience and of organized activism, there exists a danger of reinforcing the conflictual dimensions between the medical profession and patients, contributing to a cementation of the positions involved and a stagnation of the debate along unproductive lines. To avoid such a polemicist position that sees only one side of an issue and views the other side as an enemy that threatens the one and only truth, I have explored communicative challenges from the perspectives of both health professional and patient. To represent both in a respectful way, seeing both as intentional and purposive actors with their own projects of accountability and meaning making in complex and demanding contexts has been a goal throughout the realization and writing up of the project. The different epistemological realities that rule medical and lay communities might be one reason for challenges in communication. These must be highlighted in order to make visible the struggles, dilemmas and paradoxes governing this field, and allow for reflection on the taken-for-granted discourses that rule medical reasoning.

6.1.5 External validity: Generalizability of the results

The practices that I describe are not necessarily meant to be descriptions of a specific context with no further relevance to health care practices in other domains. I hope that the cases presented in the three articles can be illustrative of some general tendencies in Norwegian health care and of how the rationalizing cost-effectiveness logic of managed care models is applied in day-to-day clinical work. The manualized treatments standardized by diagnosis that are implied by these models seem to lead us on a path where we rely on simplified explanatory models of human behavior, losing the more complex and unquantifiable nuances of human interaction in the process. To account for the role of interpersonal and relational meaning making in individuals' illness experiences, it is necessary to have contexts that allow for collaborative reflection and exploration over time. An important aspect of what I wanted to achieve by describing clinical practices has been to demonstrate health professionals' need for spaces for reflexive exploration of relational and emotional aspects of clinical encounters with challenging cases as well as reflections on norms and values that underpin certain clinical decisions and thought processes.

Generalizability is an issue that is often raised in qualitative research. I believe that the value of the research does not necessarily relate to whether or not it can be generalized across a variety of situations, individuals and contexts, but whether the research can suggest valuable insights that can expand the field of knowledge in terms of theoretical or methodological advances. In postmodern approaches, the quest for universal knowledge is replaced by an emphasis on the heterogeneity and contextuality of knowledge, and the potential of generating new and desirable alternatives for thought and action (Kvale, 1996). For example, case studies can be used to encourage readers to envisage possibilities, to expand and enrich the repertoire of social constructions available to practitioners and others, and to demonstrate the rich varieties of human behavior and possible ranges for our society (Donmoyer, 1990; Gergen, 1992).

Andenæs (2000) argues that the contribution of the results of a qualitative inquiry can be evaluated in two ways: as state-of-affairs pictures or as models for understanding. The transferability of the results must be discussed in light of the characteristics of each of these types of results, and one must consider the meaning-making processes in which the results are to be included. The results of this thesis can be understood as offering both state-of-affairs pictures and models for understanding. One of the arguments in the papers is the importance of elaborating new theoretical concepts and methodological and analytical tools to better account for the complexity in subjective experiences of illness and health and in developmental processes. Ethnographic fieldwork and varied methodology such as visual methods, participatory observation, life mode interviewing, focus groups and interviews with health professionals enabled access to thick descriptions of the individual adolescents' embodied and lived experience, and a description of the cultural contexts with which they come into contact. These descriptions cover several different events, come closer to the field and make the complexities and the contextualization of the experiences more explicit than if we had used a single, one-sided methodology. In this way the thesis offers a state-of-affairs picture that describes medically unexplained symptoms as they are constructed, experienced and enacted by individuals within a specific cultural field.

On the other hand, the thesis offers a model for understanding that seeks to challenge biomedical ontological truths about bodies and subjectivities, demonstrating how the experience of symptoms, the language used for describing these symptoms and the explanatory models used for understanding causes and processes of recovery are inextricably linked in complex ways. Illness and recovery do not exist in and of themselves, but are made real and are deeply affected by the way human beings understand, name and encounter them. Illness therefore comes into existence in a communicative, relational and cultural field between positioned actors. In such an understanding of illness, the relevant field of exploration is communication, meaning making and discursive practices.

6.2 Discussion of results

To sum up and to introduce the discussion of the results, I will repeat the overarching aims of this thesis. The first overarching aim was to describe and explore what happens when developmental processes go awry due to illness that is defined as biomedically unexplained. When adolescents' behavior or experiences in this way break with our cultural expectations of normal development at that age, what do the adolescents make of it and how do they give meaning to their experiences?

By exploring how a young person engaged in his own developmental process of creating a narrative configured by the contextually determined limitations of his illness, but also by intentionality, agency and hope and dreams for the future, the first paper of the thesis offers a model for understanding how adolescents who experience contested illness might be understood, and makes visible the narrative work involved in recovery and developmental processes. To better account for the complexity in these processes, to emphasize adolescents' agency and to elicit the nuanced and different versions of their stories, it was necessary to involve the adolescents over time and in ways that enabled them to give voice to their experiences, not only by vocal expression, but also through other means that could capture embodied and sensory aspects of their experiences. In order to engage the individual adolescent in the research process, and to do research *with*, rather than *on*, the adolescent, an ethnographic approach using a variety of participatory methodological tools, visual methods and life mode interviews was particularly well suited. These methods made it possible to explore how adolescents actively engaged in their own development by creating narratives that positioned them within prevailing discourses of illness and health and of growing older. Getting to know the adolescents through interviews and film workshop sessions over a long period also gave me a sense of different aspects of the illness experience and enabled me to see the active, relational, gradual and suspenseful nature of narrative emplotment.

The second and third articles further support the findings of the first article by offering answers to the question of how adolescents with MUS seek to establish new subject positions that give meaning to their experiences and offer some hope of recovery, as well as describing the challenges of health professionals in trying to support the adolescents in these processes. The second article focuses on health professionals' dilemmas and struggles within the health care system, while the third article demonstrates how the process of meaning making might appear in a clinical setting where health professionals and adolescent patients continually engage in negotiations over available subject positions; it also points out how several intersecting categories might be involved in creating troubled or untroubled subject positions in health encounters.

The second overarching aim of the thesis has been to illuminate how dominating discourses impact the lives of the young people in question and to describe the discursive terrain (Youdell, 2005) in which they navigate. In order to gain knowledge of the discursive terrain, we talked to health professionals who represented the cultural system of health care, and as such were managers and enforcers of knowledge on how illness in youth should be handled and understood. In addition, to gain further knowledge of the contexts that these young people encountered in their illness careers (Freidson, 1988), I found a clinical site that enabled me to observe what actually took place when health professionals and young patients, each with their own projects and systems of knowledge, embarked on the journey of finding meaning and means of coping. The ethnographic approach and participatory observations provided me with deep and detail-rich descriptions of the communicative practices that were difficult to elicit through interviews alone and provided me with a check on the contrast between what our subjects claimed to do in interaction and what they actually do.

I will now elaborate a little on some of the main points made in the three articles and discuss them in light of research literature that has inspired me in the writing of this thesis in terms of theoretical positions and analytical entry points.

6.2.1 Developmental challenges for adolescents with MUS

Adolescence is often thought of as a vulnerable and difficult stage in which rapid psychological and physical changes involve a risk of developing various mental health problems (Kessler et al., 2005). A report from Norwegian Social Research (NOVA) states that adolescents in Norway in general are well adjusted, have good relationships with their parents and are satisfied with school (Bakken, 2018). Nevertheless, the report also finds that a large proportion of adolescents struggle with emotional and mental problems; they report feeling stressed, worrying a great deal and thinking everything in life is difficult. This report reflects the lives and mental health of Norwegian adolescents in general and could be interpreted as a sign of the many developmental challenges that young people face at this time of their lives. Important developmental tasks in the transition from childhood to adulthood have been described as developing more autonomy and independence from parents, and negotiating an identity in social interaction with peers and family members (Frønes, 1995; Øiestad, 2011).

The young participants involved in this research project might be understood as having even more developmental challenges than most young people, struggling with unexplained illness in addition to the “normal” transitional issues of adolescence. MUS in adolescence might be said to involve more burdens than illness symptoms with clear biomedical explanations in other periods of life. Given that symptoms of illness as such involve a certain degree of suffering, illnesses without a diagnosis, or with a contested or illegitimate diagnosis, will involve an additional burden of suffering that may stem from profound uncertainty, social stigma or difficulty in accessing health services or benefits (Greco, 2012). Much of sociological and anthropological research on these conditions has focused on making this additional burden visible (cf. Lian & Robson, 2017; Nettleton, 2006; Sowinska, 2018). However, this literature has mainly described the challenges of adults. With a few exceptions, research on the experiences and challenges of adolescents with MUS is still scarce (cf. Hareide, Finset, Wyller, 2011; Jelbert, Stedmon & Stephens, 2010; Karterud, Risør & Haavet, 2015; Karterud, Haavet & Risør, 2016;

Konijnenberg et al., 2005; Moulin, Akre, Rodondi, Ambresin & Suris, 2015; Richards, Chaplin, Starkey & Turk, 2006; Winger, Ekstedt, Wyller & Helseth, 2013). As information obtained from research into the adult population is not necessarily applicable to young people, it is important to study children and adolescents on their own terms, engaging with their lives and with the questions that are important to them (Christensen, 2004).

The articles that make up this thesis have used methods aimed at taking adolescents' own agency into account, eliciting their voices and positing them as experts on their own lives in order to highlight some of the specific challenges of MUS in adolescence with regard to meaning-making processes, subjectivation and developmental processes. The stories of Peter, Alicia, Grace, Zach and Madeleine have shown us that not only do they have to make sense of the serious and enduring violations to their self-respect and embodied self-control that follow the symptoms, they also have to find ways to reorganize their developmental aims and domains for social participation. Their stories describe that when the capacity to recover from illness is reduced or disappears, this might have specific psychosocial consequences in terms of posing a threat to their ability to participate in settings for socialization and identity development. No longer being able to take part in leisure activities and losing contact with previously important social communities pose a threat to subjectivation processes. The subject positions previously available and important for the young person's sense of self are no longer accessible. This finding is in line with other studies that have investigated the experiences of young people with MUS in terms of the impact of MUS on their everyday quality of life (Moulin et al., 2015a; Winger, 2015).

When the young person falls away from what can be characterized as a normative developmental path due to symptoms that escape classification and understanding, this breaks with expectations of what development at certain ages should entail, possibly creating marginalized and troubled subject positions (Stevens et al., 2007; Wetherell, 1998). Typical aspects of adolescent life such as exploring life outside the home, social contact with peers, individuation and separation from parents and learning environments such as school and leisure activities become more difficult because of the symptoms (Jelbert, Stedmon & Stephens, 2010). In this way, young people who are struck by unexplained illness might invoke a particular "moral panic" (Cohen, 1972) in today's knowledge society where education and social participation are seen as highly important for development into well-functioning adult citizens. When young people experience illness that does not recede, they risk being led into a path of passivity and social isolation (Blakely et al., 1991; Hareide, Finset & Wyller, 2011; Moss-Morris, 2005; Nater et al., 2006), ultimately leading them to regression and making them unfit as productive participants in society. As described by several studies on MUS in youth, such symptoms are linked to depression and anxiety (Campo et al., 2004), other health-related issues and to malfunctioning in a range of domains both at first presentation and later in life (Campo et al., 2001; Karterud, Havet & Risør, 2016; Konijnenberg et al., 2005; Moulin, Akre, Rodondi, Ambresin & Suris, 2015; Winger, 2015). These studies all point towards a problem discourse in the understanding of medically unexplained illness in youth.

6.2.2 Moral laboratories and narrative work

In this thesis, I have not merely been interested in describing what might be understood as "problematic lives", but on how the stories these adolescents tell about themselves from their specific positions can provide us with knowledge about processes of development and change among these young people, as well as how contextual conditions and discourses regulate possible ways of being. In this way, I have been interested in eliciting the adolescents' own voices and projects, and in describing different social contexts and interactions that they take part in and negotiate with in the process of making their experiences intelligible. The first article of the thesis presents a theory-building case that nuances the problem discourse and the prevailing understanding of adolescents with MUS. The case demonstrates that in spite of challenges and difficulties and exclusion from some arenas for development, young people can still continue their developmental and subjectivation processes, but may need support in finding alternative arenas and projects and help to understand how to enhance subjectivation. As the study suggests, these processes take place both within and outside the clinical context, in everyday interpersonal interactions.

Previous studies have found that patients with MUS engage in narrative work when talking about their illness and state of health, actively seeking meaning in their experiences by constructing coherent narratives with a past, present and prospective future and seeking explanations for their distress (Kirmayer, 2000; Nettleton, 2006; Nettleton, Watt, O'Malley, & Duffey, 2005). The way a person constructs this narrative is always closely connected to the individual's social lifeworld and cultural context, and the explanations that people rely on in their narrative configurations have been shown to depend on the listener to the illness story (Dalsgaard, 2005), and they also change according to the phase of illness (Whitehead, 2006).

Several previous studies have demonstrated the narrative work that adolescents in marginalized positions engage in to make their experiences intelligible and provide them with ways to manage their situation, and with alternative subject positions, future prospects and ways of being (Jansen, 2010, 2011, 2013; Jansen & Andenæs, 2013; Jansen & Haavind, 2011). The narrative work involved in opening up new possibilities and developmental trajectories might be supported in social interaction to scaffold the exploration and creation of new plots and storylines. The theoretical term “moral laboratory” (Mattingly, 2013, 2014) became an analytical entry point for understanding and describing the process that the research participants in study one engaged in with us as researchers: trying out new meanings, subject positions and creating new plot lines and narratives in reflective conversations in the film workshops and interviews. In study three, we found the theoretical concept of positioning (Davies & Harré, 1990) to be useful to describe the process of negotiated meaning making that took place in the clinical context of Birch Hill.

The results of these two studies showed us that the laborious and experimental narrative work of creating meaning in one’s illness experiences is not necessarily achieved in clinical encounters, but is rather a continuous process in everyday social interaction. Further, it is not only dependent on the subject’s own efforts, but is to a large degree also affected and restricted by various discourses. This is in line with structural theory (Bourdieu et al., 1993) which elaborates on how social structures of inequality constrain lives and possibilities for narrating them. Subjects are never completely free in their performances represented in narrative. In the studies in this thesis, the discourses that restrict what can be narrated by the individual include those of adolescence, gender, and illness and health. In study one, over the course of the negotiations and the gradual emplotment of a storyline that could make sense to Peter, we could trace moral and sociocultural expectations and demands. One example of this was the “duty to be well” (Greco, 1993), to regulate and handle risk according to internal and external demands.

Peter’s story demonstrated that the diagnostic language and the search for the true cause of his symptoms were not major concerns. Instead, he expressed a need to find existential meaning and accountability in his current situation. However, the study demonstrated that, in order to succeed in the forward-oriented narrative work of becoming an accountable person, a young person needed to position him/herself in a way that met sociocultural and moral expectations of being an adolescent with unexplained illness. This has also been demonstrated in other studies of illness narrative. For example, Catherine Riessman (2003) analyzed and compared the narratives and identity performances of two men diagnosed with MS. By drawing on Bourdieu’s work on class and the body’s relationship to social space, she demonstrated how the two men’s illness narratives and identities were colored by their different social structural contexts. The possible ways that the two men had to perform masculinity within their social contexts were distinctly different, which also had implications for their illness narratives.

Peter was a boy who explored ways of being accountable that were in line with cultural notions of masculinity, and the study can therefore serve as an example of how adolescents with long-term illness also struggle with identity issues and cultural values that are (among other things) highly gendered. In study three, we also saw that the ways in which young people were positioned and positioned themselves in relation to various discourses and social categories affected their illness narratives in terms of future prospects, accountability and legitimacy. Both studies thus concur with other research on how illness narratives might be configured and molded by various social categories.

6.2.3 Relational and existential meaning making in processes of development and subjectivation

The first article focused on how adolescents, despite the various challenges of their health concerns and of their encounters with health professionals, can reorient themselves into a developmental path that supports their subjectivation process. The article demonstrated that this reorientation does not only imply getting rid of symptoms, but is about finding relational and existential meaning, trying out new identities and finding developmental projects that support the individual in its sense of self as an accountable person. This finding resonates with other studies that have demonstrated how patients with chronic illness of diagnostic ambiguity actively seek meaningful identities for themselves over time (Davidson & Chan, 2014; Grue, 2016; Rossen, Buus, Stenager & Stenager, 2019). One study found that patients with MUS use different explanatory idioms for their distress depending on time, space and situation (Risør, 2009). Risør argues that the “symptomatic idiom” that focuses on bodily experience, assuming that the distress is caused by a physical disorder and trying to find a cure for the physical symptoms, is only one of many possible idioms people use when trying to find meaning in their illness experiences. She also describes a personal, a social and a moral idiom that patients use in meaning making, mentioning elements such as personal history, identity struggles, relational issues, psychosocial stresses and existential concerns as aspects that shape illness experience. In line with this way of thinking, several clinical studies have suggested that a holistic approach that supports the process of meaning making, making room for relational and existential aspects of healing, might be a more valid approach than a strictly medical focus emphasizing symptom reduction (Conrad & Barker, 2010; Davidson & Chan, 2014; Wampold, 2001). This concurs with the findings in the articles of this thesis, demonstrating that meaning-making processes are a gradual and suspenseful activity that takes place in interpersonal and everyday contexts as well as in health encounters, and involves social and moral aspects just as much as concerns over etiology and cure.

The story of Peter tells us that in some ways adolescents with unexplained illness are not so different from other young people. Rather than being concerned with finding a definitive cure or a cause of the symptoms, Peter was interested in understanding himself, his future and his social world. In collaboration and interaction with others, including us as researchers, he constructed a narrative in an effort to make sense of his experiences. The analysis showed us that although his narrative was configured by immediate limited possibilities of agency due to his medical condition, it was to a greater degree configured by his aspirations: to become an accountable person through social experiences and to meet sociocultural and moral expectations of being an adolescent. In this way, the story of Peter highlights general features of adolescence and development that may not only be relevant to adolescents with MUS but also to other domains. Peter's story might be recognizable to other young people who encounter struggles and challenges in their lives or who in different ways need to figure out who they are and might become in interpersonal interaction in more or less demanding social contexts.

Also in study three, it was apparent that the adolescents struggled to create meaning for themselves and to position themselves in a way that supported their ongoing projects of accountability and subjectivation, which could provide them with future prospects and a way of dealing with their illness. The way they positioned themselves in relation to dominating discourses of illness, adolescence and health had implications for the way they were understood by those around them and in clinical encounters, and for whether their ongoing projects were supported in the relevant communicative spaces. Other studies have also found that the ways in which adolescents make use of social categories and position themselves within dominating discourses will affect their subjectivation processes (Jansen, 2010; Kofoed, 2008; Staunæs, 2003, 2005). The ways in which social categories intersect will mute, nuance or exaggerate the understanding of possibilities and constraints among the subjects involved, thus creating troubled or untroubled subject positions, and this might ultimately also have consequences for healing and coping with illness.

Fields as diverse as disability studies (Bekken, 2014), studies of children with various functional impairments (Gulbrandsen, 2014), studies of children placed in out-of-home care (Jansen, 2010, 2011, 2013), studies of youth with minority backgrounds (Roth, 2017; Youdell, 2006b), and studies of children and young people in developmental transitions in everyday and school settings (Hauge, 2009; Staunæs, 2003; 2005) have shown how children and young people in various contexts take on and negotiate subject positions that they are offered, and how various discourses of difference, ethnicity, gender, family and development mediate this process. All of the above studies have inspired me in writing this thesis, and have expanded my analytical gaze through concepts in narrative theory (Bruner, 1990; Gergen & Gergen, 1986; Riessman & Quinney, 2005) and poststructuralist theories of subjectivation (Davies, 2006; Staunæs, 2003; Søndergaard, 2002; Youdell, 2006a).

6.2.4 In the subjunctive mode: Open endings and future prospects

Narratives are understood as consisting of elements of past, present and future, tied together in a temporal order. However, a focus on past experiences and meaning making has dominated the field of narrative psychology. Using the concept of narrative emplotment, Mattingly (1994) made the point that narratives are not only configured by recollecting past events but are open-ended and created in the midst of action in an interactional space. I found this concept useful when analyzing the process of meaning making that our participants engaged in with us as researchers (Bakhtin, 1981).

The story of Peter illustrated that created narratives are not final, but that their creation is an ongoing process in which elements of the past, the future and the present are tied together in dialogue with actual and imagined audiences. In addition, images of the future are manifested in the present (Cole, 1995), which means that narratives of the future and what might happen are part of meaning-making processes (Jansen & Andenæs, 2013). An important point for us in our representation of Peter was to emphasize that his story was not finalized, but ongoing and with an open ending. The subjunctive mode (Good, 1994) implies a feeling of suspense that lies in not knowing exactly what might happen in the future, but still remaining open to possibilities.

Frank (2005), referring to the writings of Bakhtin (1981), has written about the danger of finalizing our research subjects when we write about them and represent them in research. Research is, in the simplest terms, one person's representation of another.

Frank writes: "In Bakhtin's dialogical ideal, the research report must always understand itself not as a final statement of who the research participants are, but as one move in a continuing dialogue through which those participants will continue to form themselves, as they continue to become who they may yet be." (p. 967)

Jansen and Andenæs (2013) use the term "prospective narratives" to illuminate how youths create and negotiate drafts of the future, and how these drafts interact with their understanding of who they are today and what actions they might take. Other related concepts are Bamberg's (2004) "emergent identities", and Markus and Nurius' (1986) "possible selves". Peter's images of what he might be doing in the future were altered by his experience of physical constraints. An important part of dealing with the illness was to figure out what the illness might mean in his life and for his future. This is in accordance with other studies that have demonstrated that children and young people often engage in prospective narrative work that involves creating stories containing elements of aspirations and future scenarios in order to present solutions and deal with difficult life situations (Jansen & Andenæs, 2013; Øverlien, 2011; Øverlien & Hydén, 2009). For Peter, the world of films played an important part in creating a forward-oriented and meaningful activity, thereby playing an existentially significant role in managing his hopes and fears for the future, as well as playing a part in his developmental process here and now, pushing him towards action. Watching and learning about films, Peter was trying out a new interest, practicing for a potential new role as someone knowledgeable about films as a way of "narrative re-envisioning" (Mattingly, 2013). For other young people, there will be other projects and interests of importance for this narrative work.

A major cultural expectation of adolescents is that they have plans for the future, and they are assigned increasing responsibility to take charge of their own development and transition to adulthood (Andenæs, 1995; Haavind, 2003). Wyn and White state that "becoming somebody" is the most important and consuming activity of young people (1997). However, this forward-directed movement typical of adolescence is threatened by unexplained illness without answers as to how long the symptoms will last, what can be done to treat them or what might be expected in the long run. The illness disrupts the future plans and ideas that are such an important signifier of youth. It therefore makes sense that an important part of dealing with the symptoms in the present is to gradually emplot a storyline in which important themes and experiences are narrated in a chronological process with a desired, but still open future ending.

Peter used the metaphor of a train moving forward on its rails as a way to redefine his experience of a life on hold. Alicia, Grace, Zach and Madeleine in study three also had to redefine who they were and could become with the onset of MUS. Some of them had to significantly alter their future plans, while others adjusted some of their goals but could still maintain certain future plans and aspirations. The literature on illness narratives describes how the process of creating meaningful and coherent narratives often becomes difficult when people experience crisis, trauma or illness (Bury, 2001; Frank, 1995; Radley, 1997; Williams, 1984, 1993). Illness is often understood as a "rift in intersubjective life" (Jackson, 2002), which removes the individual from its connections with others. To create meaning and reconstruct the narrative of who one is and where one is headed is an important part of the recovery process that does not happen in isolation, but in relational and intersubjective sociocultural contexts. To support adolescents in this creation of prospective narratives can therefore be understood as an important part of clinical work.

There might be a danger in interpreting Peter's process as a "quest narrative" (Frank, 1995), in which the solution to his problems and illness experiences can simply be found in his creating a positive and future-oriented narrative for himself. Such an interpretation involves a potential for feeding into a normative discourse of illness experiences and healing. It is important to keep in mind that there is no universal way to understand healing, and that meaning making is a complex process with no definitive answers. The process of meaning making and the narratives that are constructed will change according to different contexts and situations, over time and with different audiences (Risør, 2009). However, despite not giving universal or recipe-like answers to the process of recovery and healing, the studies that make up this thesis support other research within sociocultural approaches to adolescence and development, which implies that seeking out subject positions that offer accountability and future prospects is important in helping many young people to cope with adversity and marginalization.

6.3 Implications for health care and clinical practice

6.3.1 The role of the helper in encounters with adolescents with unexplained illness

If recovery is about meaning making and enabling the construction of narratives that offer untroubled subject positions, future aspirations and accountability, this will influence our perception of the role of the helper in clinical encounters with young MUS sufferers. As described in the literature, the uncertainty and moral ambiguity associated with the lack of diagnosis and explanation that accompanies MUS can leave sufferers in a state of embodied doubt and permanent “narrative chaos” (Frank, 1995; Nettleton, 2006).

To evade the chaos and moral panic of unexplained illness, the deviance that these adolescents represent is typically channeled into the medical domain, where health professionals try to fit their suffering into categorical terms in an effort to find explanations and a cure, as they interpret and adapt individual lifeworlds into the biomedical expert language of diseases and diagnoses (Jutel, 2009). As demonstrated by a large body of research on communication in clinical encounters relating to MUS, however, the health care system often does not relieve the burden of these symptoms, but rather amplifies them by failing to support the patients in their moral and existential concerns or to find a common language that makes sense of suffering and indicates possible solutions (Ring et al., 2005; Salmon, 2007; Salmon et al., 2004, 2005). Some studies have even found that clinical consultations can have “somatizing effects” (Ring et al., 2005), and that doctors fail to recognize their patients’ emotional and psychosocial “cues” in consultations (Salmon et al, 2004), thereby overlooking the story of the lifeworld (Mishler, 1984).

The story of Peter in article one and those of the complex patients Alicia and Grace in article three support this body of research, and suggest an alternative model for how adolescents with MUS might be understood and supported. By failing to support patients in their efforts to create meaning in their experiences and offering no assistance in the patients’ narrative re-envisioning, health care professionals are perhaps making themselves redundant, or possibly even doing more harm than good.

In a recent book by the Norwegian psychologists Flor and Kennair (2019), the potential harmful side-effects of psychotherapy are discussed, referring to recent research on the topic. In the literature on doctor-patient interaction, the potential of communication in clinical encounters to have either healing or harmful effects has long been a topic of interest.

Much of the research on MUS in childhood and adolescence deals with whether the symptoms should be understood as a result of psychological or physical causes, and which explanatory models and approaches to treatment are the most valid. One such explanatory model often emphasized in discussions of MUS in the literature and in clinical contexts is, as already mentioned in the introduction, the biopsychosocial model (Engel, 1977), in which symptoms are understood as the result of a complex interplay between biological, psychological, social and cultural factors. This model was also mentioned as foundational for the clinical practice of the various health professionals that participated in the studies of this thesis, both those working in specialist health care that were interviewed in study two, and those followed in the fieldwork at Birch Hill in study three. The biopsychosocial model is claimed to be a cornerstone of patient-centered care (Mead & Bower, 2000), an approach that emphasizes the personal experience of the patient and the importance of egalitarian doctor-patient relationships where doctors regard patients as experts on their own illness, and where power and responsibility are shared with the patient through mutual participation (ibid.).

In the second and third articles, we found that in the local forms of clinical practice, the biopsychosocial model created locally emergent forms of social categorization that influenced how the individual adolescent was received and understood in clinical encounters. The categories used by health professionals were based on the practical knowledge they had acquired through many years of experience, and these local categories were the ones that guided their understanding and treatment. In the second article, two such categories that the health professionals used were “the trauma victim” and “the good girl”. These categories were tied to discourses of what constitutes a normal adolescence, how family relations are supposed to work, and which roles different family members are supposed to adopt. In the third article, we also found that in the local understanding and interpretation of the biopsychosocial model, the health professionals developed local categories of patienthood, which affected communication in the clinical encounters. These categories were the “complex” and “classic” patients and were constructed with a basis in underlying biomedical and psychosocial discourses. Whether a young person was classified as complex or classic was in article three interpreted and analyzed as a result of how the young person positioned him/herself according to several intersecting social categories. The descriptions and analysis of the talk-in-interaction in the clinical context of Birch Hill indicated that the recovery process might take somewhat different directions depending on how the young person was classified. The categories used in the context of Birch Hill constituted a framework for describing these young people and their possibilities, which also affected their subjectivation and developmental processes. In this way, the study concurs with research within critical and poststructuralist frameworks that demonstrates the powerful effects of communicative practices not only in representing reality but creating it. As formulated by Thomas and Thomas as early as 1928: “If men define situations as real, they are real in their consequences”.

A recurrent theme in this thesis is that a key factor for recovery and development is whether adolescents in their encounters with health professionals and significant others are able to find an understanding and to create a narrative that supports subjectivation processes and future aspirations. This seems to require a more finely tuned and creative adaptation of diagnoses, explanatory models, metaphors and experience-based knowledge that incorporates the particularities of each individual’s unique history and situation than that offered by a general and broad-spectrum model such as the biopsychosocial model. What the third article of the thesis demonstrates is that the translation of such a model into everyday local practices might also lead to a rigidity and inflexibility in the health professional’s perspective that makes a common exploration and understanding more difficult. If the health professional becomes too concerned with the idea that there is a right and a wrong way of handling illness instead of seeking to support and explore the individual’s meaning-making process, this might jeopardize the goal of helping adolescents cope with their illness.

At Birch Hill we found that for the adolescents that accepted the rationale and made the model fit their own understanding of themselves and their life, the treatment seemed to work as intended and staff-patient encounters were without tensions and usually a cooperative and pleasant affair. However, when the adolescents’ storied performance of themselves and their illness did not fit in with the treatment model, this created conflict between them and the staff. The response of the listener very much affects the positions that are occupied by and made available to the narrator, and the form the illness narrative takes (Bauman, 1986; Iser, 1978, 1989). If the subject positions made available became troubled, this led to polemical positions and a deadlock in which the therapeutic alliance broke down. This finding is in accordance with previous studies in general practice that have demonstrated the problematic and sometimes “somatizing” effects of clinical communication (Epstein et al, 2006; Ring et al., 2005; Salmon et al., 2005). The therapeutic alliance is defined in psychology as the ability of patient and health professional to form an affective bond of mutual respect and collaboration (Bordin, 1979). According to Bordin, the therapeutic alliance consists of three essential elements: agreement on the goals of the treatment, agreement on the tasks, and the development of a personal bond made up of reciprocal positive feelings. In short, the optimal therapeutic alliance is achieved when patient and therapist share beliefs with regard to the goals of the treatment and view the methods used to achieve these as efficacious and relevant (Ardito & Rabellino, 2011). Psychological studies have consistently shown how this quality of the therapist-patient relationship is related to outcomes in therapy (Meadors & Murray, 2015), and common health care issues are strongly influenced by the nature of verbal and non-verbal communication in the encounter.

What the study at Birch Hill demonstrated was that when the therapeutic alliance broke down in interactions between staff and adolescents, a troubled subject position for the adolescents followed. Here, adolescents' behavior, personality, symptoms and patienthood were defined as the problem by health professionals, not the degree of accommodation to the explanatory model, the interaction in itself or the health professional's communicative approach. This tendency to explain lack of results in treatment by patient variables instead of shortcomings in the clinician's practice has also been demonstrated in psychotherapy research (Benum, Axelsen & Hartmann, 2017; Wampold, 2001), as well as in studies of doctor-patient communication in general practice (Groves, 2009; Steinmetz & Tabekin, 2001). A study by Mik-Meyer and Obling (2012) demonstrated that GPs constructed their own subjective criteria for judging the legitimacy of their patients' sickness. Drawing on a biopsychosocial discourse, the GPs' decisions to accept their patients' symptoms as grounds for sick leave seemed influenced by whether or not they identified social problems and problematic personality traits such as "personal shortcomings", "pre-morbid psyche", "low threshold for adversity", "whiners" and "inept at living". Likewise, in a study by Horton-Salway (2002), the author demonstrated through a discursive analysis of GPs case narratives how GPs used biopsychosocial reasoning to construct patient's identities and to define their illness as mental or physical. She argues that identity constructions function as a justification for defining an illness as psychosomatic, thereby shifting the blame for what might otherwise have been treated as medical failure or uncertainty. Several studies have found that clinicians develop heuristics and rely on categorical prototypes to develop their explanatory models and support them in their clinical decision making, for example by linking patients to fixed characteristics or types (Buchbinder, 2011; Desjarlais, 2000; Gremillion, 2003; Luhrmann, 2000). Such heuristics aid clinicians in managing time constraints and resource scarcity (Lester, 2009). However, they might also lead to communication barriers and difficulties in seeing the patient as an individual with a unique story and projects of being and becoming.

Historically, there are numerous examples of how patients with so-called psychosomatic illness have been understood as possessing a range of undesirable traits, such as overly sensitive, self-absorbed, nervous, dependent, self-defeating or malingering (Aronoff, 1985; Aronowitz, 1998; Beard, 1881; Fordyce, 1976; Groen, 1948; Harrington, 2008). In the medical anthropology literature, several authors have given rich descriptions of the process of diagnostic typecasting in different settings of clinical or social work. For example, Gremillion (2003) has demonstrated how patient categories of "true anorexia" and "borderline personality disorder" were construed among staff at a clinic for eating disorders, showing how embedded concepts of class, race and gender mediated a process of othering and exclusion. Gremillion describes how the internalizing behavior of depression or self-harm was marked as socially correct and connected to favorable personality characteristics like being hard-working, having will-power and a capacity for developing autonomy; by contrast, externalizing behavior of running away or actively opposing institutional rules was marked as indicative of negative personality traits such as being manipulative and lacking self-control.

In a similar fashion, Buchbinder (2011), in her study of adolescent patients at a pain clinic, demonstrated how clinicians linked the neurobiology of pain to certain desirable features of adolescent personhood, such as smartness, sensitivity and creativity, which revealed causal pathways and predictive claims about the likelihood of recovery. Desjarlais (2000) has described how people with mental illness are construed as fixed characters or types in a shelter for homeless people. An important message in all of these studies is the central role of language in illness experience and healing. However, the studies also demonstrate that the use of language and categories is not a one-way street, something the clinician or social worker impose on the patient or client. Rather, the categories in play can be thought of as "interactive kinds" (Hacking, 1986), taking on a life of their own as individuals put them to use; expanding, resisting, challenging and redefining them in their subjectivation processes. The process of categorization happens in a constantly negotiated interactive dialogue between the various positioned actors in the social field. These studies add to critical applied medical anthropology that through its investigation of cultural contradictions in the construction of medical and psychiatric knowledge challenges the assumption that the biomedical discourse is seamless and constitutes bodies and identities in a top-down fashion (Good, 1994; Good & Good, 1993; Rhodes, 1991).

All of these studies support the findings of the articles in this thesis, and illustrate the active negotiation processes in communicative practices, in which discourses reveal themselves as both constituting and constitutive of subjective experience.

6.3.2 Discourses of health and development: Ideals and realities in health care systems

The second and third articles seek to describe discourses of health, illness, adolescence and family life that inform normative ways of thinking among health professionals that affect their day-to-day clinical practices and their ways of understanding adolescents with illness of unknown etiology. In performing care, health professionals act as “moral entrepreneurs” (Becker, 1997), negotiating and adapting to available discourses. Individual interviews and a focus group interview with health professionals revealed the ideals that they wished to follow in their practice. Some of these ideals are to work within a phenomenological and interpretative framework, to aim at an attitude which makes patients experts on their own illness experience, to allow for creativity and alternative forms of expressivity, and to explore the issues involved through a relationship based on empathy, trust and emotional support of the individual young patient. These ideals can be said to be in accordance with the therapeutic ideal of patient-centered care. The second article, however, demonstrates that these ideals collide with certain realities in everyday clinical practice. These realities consisted of health professionals needing to adapt to diagnostic systems based on a biomedical understanding of disease, to balance the role of expert, gatekeeper and helper and to present solutions and answers based on limited information, resources and time. These realities could be understood as based on a biomedical understanding represented by the term evidence-based care. In the second article, these two opposing views and frameworks are described as epistemological and methodological paradoxes. These paradoxes describes a situation where, despite the apparent increasing focus on patient-centeredness and concepts such as participation, involvement and empowerment that inform various activities and technologies at different levels, there is still a tendency in health care systems to build decision making on biomedical paradigms. Programs based on a one-size-fits-all model in which narrow diagnostic categories form the basis for therapeutic and clinical interventions have been developed in several countries, exemplified by the recent development of health care delivery packages in several Scandinavian countries, a highly structured mode of health care delivery in which specific courses of health care interventions related to assessment and treatment are predefined in terms of both timing and content (Rossen, Buus, Stenager & Stenager, 2014).

The logic of rationalization and cost-effectiveness found in managed care models and the increased focus on manualized treatments standardized by diagnosis that we have seen in recent years in health care in Norway and worldwide does not necessarily allow for mutual exploration in egalitarian therapeutic relationships or customization of treatment to the individual’s unique life story. A study of clinical communication after the introduction of health care delivery packages in Denmark found that the framework of the health packages made it impossible to meet the needs of patients with more complex health concerns (Rossen et al., 2014). Some have claimed that this is an alarming development in health care policy, that managed care models pose a threat to the involvement of patients, especially young patients, in their own healing processes, and that an increased focus on predetermined goals and standardized tools limits rather than furthers growth and development (cf. Løkke, 2014).

Several previous studies have also described the many paradoxes in different health care systems and institutional contexts, and the incongruence between ideals and realities in clinical practice (cf. Johansen & Risør, 2017; Luhrmann, 2000; Løchen, 1970; May et al., 2004; olde Hartman, Hassink-Franke, Lucassen, van Spaendonck & van Weel, 2009; Woivalin, Krantz & Stone, 2014; Åsbring & Närvänen, 2003).

As argued by Greco (2017), evidence of disease in a biomedical model has traditionally offered a baseline discriminating criterion for access to the sick role and a barricade against moral ambiguity. In recent years, however, this criterion has become questionable and complicated due to the prevalence of chronic and "lifestyle" diseases, the redefinition of patients as "consumers", and the changing balance of power in medical consultations in line with patient-centeredness (Greco, 2017; Liberatore & Funtowicz, 2003). Despite these developments, doctors still make gatekeeping decisions that steer patients into the sick role. Classic work has shown how medicine has a normalizing function (Canguilhem, 1989; Foucault, 1977), not only restoring and repairing malfunctioning parts of the body, but also seeking to restore patients' abnormalities that go beyond pathological illness and to deal with norms that define 'normal' health in society and its institutions (Mik-Meyer & Obling, 2012). Health professionals can in this way be seen as "moral entrepreneurs" (Becker, 1997) because they legitimize and label illness, allowing patients to enter into the sick role, and thereby excusing them from performing the normal responsibilities of other social roles (Parsons, 1978). The process of how symptoms are classified and recognized by health professionals as grounds for entering the sick role is affected by medical discourse, as well as the different social contexts in which the negotiation of identity and dominating categories takes place. Several studies have demonstrated that this process has become less transparent and more difficult to account for in recent decades (Buchbinder, 2015; Mik-Meyer & Obling, 2012; Werner & Malterud, 2003). These studies have shown how patients and health professionals alike work hard to establish the symptoms as legitimate cause for entering the sick role by not only relying on a purely biomedical understanding, but by "making up" (Hacking, 1986) the patient as a credible and accountable person through a focus on social, personal and moral aspects.

In the absence of evidence of disease, as in the case of MUS, patients find themselves in clinical contexts in a dynamic in which they need to prove that their symptoms are "real" by fitting in with normative, often biomedical expectations to become a credible patient (Werner & Malterud, 2003: 1409). According to Greco (2017), this effort includes adopting an idiom of explanation that focuses on the physical etiology of symptoms at the expense of other and more nuanced idioms typically employed elsewhere. Patients are encouraged to present in this way by doctors who themselves tend to focus somatically and ignore psychosocial cues (Ring et al., 2005). A study by Seabrook (2017) analyzed interview data using a Foucauldian discourse analytical approach and found that practitioners constructed MUS in a way that made use of discourses of mind/body dualism and separation. They thus categorized patients as having either a mental problem or a medical one, but not both. Likewise, Greco (2012) has described a polemical polarization of the positions of doctor and patient as a situational and sociocultural embedded logic that sets up physical and psychological explanations as mutually exclusive alternatives. Kirkengen (2018), and Eriksen, Kirkengen and Vetlesen (2013) has argued that conventional medical formulations, being based on knowledge grounded in the episteme of the natural sciences, do not allow for understanding illness in all its complexity, and partly relate this to the way our health systems are organized. These structures locate physical and mental health specialists' work in different fields, resulting in a lack of integration of knowledge. Worldwide there has been an increasing focus on specialization, standardization and cost-effectiveness in the health care sector (Ahgren, 2014; Kirkpatrick, Dent & Jespersen, 2011; Rossen et al., 2017). This increased specialization might lead to difficulties in applying and incorporating integrative approaches into the reality of everyday clinical practice, which has been demonstrated in the research literature on epistemological incongruences in health care (Johansen & Risør, 2017). The findings in this thesis thus support a large body of research that suggests that conventional, biomedical discourses continue to dominate approaches to health care systems, health problems, services, diagnoses, treatment and practitioner-patient relationships (Orlans, 2013; Seabrook, 2017).

Some of the studies that describe incongruences between ideals and realities in clinical practices were conducted decades ago. However, as demonstrated in the three articles of this thesis, such an incongruence might still be governing health care systems and institutional practices today. It is in the intersection between ideals and realities, and thereby through the ensuing paradoxes, that one might gain insight into the discourses that govern our ways of thinking. Both health professionals and adolescents navigate within these discursive terrains. Often the discourses that rule our ways of thinking are not explicit; they may represent established and taken-for-granted understandings within any given cultural context. Making the paradoxes visible and thus the many competing paradigms of thought more explicit might lead to a more reflexive attitude in clinical practice, which is closer to the humanistic ideals of patient-centered practice.

6.4 Conclusions

This thesis offers a way of looking at illness and healing that might have consequences for clinical practice. By bringing attention to the different value systems and knowledge regimes that underpin clinical reasoning, the results might make for a more reflexive practice in line with principles from patient-centered care. By exploring how meaning is ascribed, how categories intersect and how experience is accounted for in everyday activities in specific contexts, the thesis demonstrates the complexity of meaning-making processes and offers a nuanced and contextualized understanding of the possibilities, challenges and limits among the subjects involved. Furthermore, by considering language as performative, and as constructing social realities, the results of this thesis suggest that the problem of explanation should be recast not in terms of its representational, objective "truth" leading to a particular treatment, but rather in terms of the pragmatic value and the quality of its clinical effects. Instead of thinking that one model offers more correct or "real" solutions and ways of understanding, it is suggested that we should explore the effects that certain ways of interpreting, describing or verbalizing might have on the individual's developmental efforts.

In this thesis, all explanations, biomedical as well as psychological or social, are understood as involving metaphorical and narrative work, which entails translating complex phenomena into something that can be grasped on a more concrete level, linking past, present and future into a coherent whole. From this perspective, explanations that can envisage new possibilities of becoming, by offering subject positions that cultivate the capacity of the individual to imagine him/herself differently, will have the potential of activating the individual's own capacity for self-healing and will thus be efficacious in a therapeutic sense.

In the studies presented in this thesis, efforts to resist or establish new subject positions are seen as a kind of developmental work. To support adolescents in these processes is therefore an important part of the therapeutic and clinical act. To find metaphors and modes of expression that give meaning to experiences is demonstrated to be a cooperative and negotiated project, one that requires the establishment of intersubjective relatedness (Benjamin, 2018). Effective clinical communication therefore acknowledges and validates the patient's sense of suffering and offers suggestions as to how concrete bodily processes may be visualized or imagined by indicating tangible and metaphorical mechanisms to explain the symptoms. Further, it allows patients to link physical symptoms to the psychosocial dimensions of their lives in a conversational framework and in response to their own cues (Dowrick, Ring, Humphris & Salmon, 2004; Salmon, Peters & Stanley, 1999). One important message in this conceptualization is that explanations that are co-constructed and developed between practitioner and patient rather than unilaterally imposed are more likely to have desirable outcomes. This approach foregrounds the importance of a collaborative process*,* and differs profoundly from the epistemological structure of biomedicine in which diagnosis and therapy are thought of as separate acts and in which the disease is seen as a biological reality that is simply waiting to be discovered and correctly labelled by the medical expert (Kirmayer, 1988). This approach resembles what Kirmayer (1993) has described as the symbolic healing of psychotherapy: it is the relational process of finding a common language and a shared metaphorical framework of meaning, one that is pointing towards new possibilities of being and becoming, that creates alleviation of suffering:

> "If every interpretation of distress is, at root, the invention of metaphors for experience, healing may occur not because a conflict is accurately represented, or even symbolically resolved, but because the metaphorization of distress gives the person room to maneuver, imaginative possibilities, behavioral options, and rhetorical supplies" (p. 165).

Establishing a foundation for mutual exploration and a practical care logic in close dialogue takes time, patience and careful fine-tuning to the young person's cues. In this study, the complexity involved in meaning making was revealed by the laborious process that the participants and researchers engaged in together in an effort to understand and put into words and images the thoughts, feelings and embodied experiences of illness and developmental interruptions. This process could be said to have some similarities to psychotherapeutic processes, in which therapist and client jointly attempt to give shape and background to the various experiences of the past, creating new storylines and narratives that make life more bearable. Conducting qualitative research interviews and exploring topics over film footage illuminated how the research context offered an alternative way of conversing, allowing for other stories to be told that constituted new possibilities for being for the young person involved. In this way, the research context could be used as a template for how professional helpers might stay engaged and supportive of adolescents with MUS in finding alternative developmental processes and sufficiently adapted everyday functioning. The opportunity for a slow exploration over time and for different forms of expressivity, where the professional engages in attentive listening and aims to reduce the clinician-patient divide, can open up new possibilities for young MUS sufferers to live with and cope with their illness.

References

Abbas, A., & Schubiner, H. (2018). *Hidden from view: A clinician's guide to psychophysiologic disorders.* Psychophysiologic Press.

Abebe, T. (2009). Multiple methods, complex dilemmas: negotiating socio-ethical spaces in participatory research with disadvantaged children. *Children's Geographies*, *7*(4), 451-465. https://doi.org/10.1080/14733280903234519

Ahgren, B. (2014). The path to integrated healthcare: Various Scandinavian strategies. *International Journal of Care Coordination, 17*(1-2), 52–58. https://doi.org/10.1177/2053435414540606

Alvesson, M., & Sköldberg, K. (2018). *Reflexive methodology. New vistas for qualitative research. Third edition.* Sage Publications.

Amundsen, I. H. (2014, September). Norske jenter stresser seg syke: - Vi stiller så høye krav til oss selv [Norwegian girls stress themselves sick. -We put too much pressure on ourselves]. *VG.* Retrieved from http://www.vg.no

Andenæs, A. (1995). Theories of development from the perspective of the children, their parents and the scientists. *European Early Childhood Education Research Journal, 3*(2), 15-28. https://doi.org/10.1080/13502939585207741

Andenæs, A. (1996). Fra undersøkelsesobjekt til medforsker: Livsformsintervju med 4-5-åringer. [From research object to co-researcher. Life mode interviews with 4-5 year olds]. In A. Andenæs (Ed.), *Foreldre og barn i forandring* [Parents and children in change]. Pedagogisk forum.

Andenæs, A. (2000). Generalisering: Om ringvirkninger og gjenbruk av resultater fra en kvalitativ undersøkelse [Generalization: On extended effects and recycling of results from a qualitative study] In H. Haavind (Ed.), *Kjønn og fortolkende metode: metodiske muligheter I kvalitativ forskning* [Gender and interpretive method: methodological possibilities in qualitative research] (pp. 289-320). Gyldendal Akademisk.

Ardito, R. B. & Rabellino, D. (2011). Therapeutic alliance and outcome of psychotherapy: historical excursus, measurements, and prospects for research. *Frontiers in Psychology,* 2, 270. https://doi.org/10.3389/fpsyg.2011.00270

Aronowitz, R. A. (1998). *Making sense of illness. Science, society, and disease.* Cambridge University Press.

Aronoff, G. (1985). *Evaluation and treatment of chronic pain*. Urban and Schwarzenberg.

Arnett, J. J. (1999). Adolescent storm and stress, reconsidered. *American Psychologist, 54*(5), 317-326. https://doi.org/10.1037/0003-066X.54.5.317

Åsbring, P., & Närvänen, A, L. (2003). Ideal versus reality: Physicians' perspectives on patients with chronic fatigue syndrom (CFS) and fibromyalgia, Social Science & Medicine, 57(4), 711-720. https://doi.org/10.1016/s0277-9536(02)00420-3

Ax, S., Gregg, V. H., & Jones, D. (2001). Coping and illness cognitions: chronic fatigue syndrome. *Clinical Psychology Review*, *21*(2), 161-182. https://doi.org/10.1016/s0272-7358(99)00031-8

Bakhtin, M. M. (1981). *The dialogic imagination: Four essays.* University of Texas Press.

Bakken, A. (2018). *Ungdata. Nasjonale resultater 2018. NOVA Rapport 8/18.* [Young data. National results 2018. NOVA Rapport 8/18]. NOVA.

Balint, E., Courtenay, M., Elder, A., Hull, S. & Julian, P. (1993). *The doctor, the patient and the group: Balint revisited*. Routledge.

Bamberg, M. (2004). Form and functions of 'slut bashing' in male identity constructions in 15-year-olds. *Human Development, 47*(6), 331-353. https://doi.org/10.1159/000081036

Banks, J., & Prior, L. (2001). Doing things with illness. The micro politics of the CFS clinic. *Social Science & Medicine, 52*(1), 11-23. https://doi.org/ 10.1016/s0277-9536(00)00117-9

Barbour, R. S. (2010). Focus groups. In I. Bourgeault, R. Dingwall & R. de Vries (Eds.). The Sage handbook of wualitative methods in health research. (pp. 327-352). Sage Publications.

Barnhart, M. (2017). Oppsoitional defiant disorder: The psy apparatuses and youth resistance, Journal of Progressive Human Services, 29(1), 6-27. https://doi.org.ezproxy.uio.no/10.1080/10428232.2017.1394788

Barth, F. (1969). *Ethnic groups and boundaries: The social organization of culture difference*. Universitetsforlaget.

Bauman, R. (1986). *Story, performance, and event: Contextual studies of oral narrative.* Cambridge University Press.

Beard, G. (1881). *American nervousness, its causes and consequences: A supplement to nervous exhaustion.* Putnam.

Becker, H. S. (1997). *Outsiders: Studies in the sociology of deviance*. Free Press.

Bekken, W. (2014). *Children's participation in paediatric rehabilitation. An exploration of consultation practices.* [Doctoral dissertation, Faculty of medicine, University of Oslo].

Bell, S. E. (2000). Experiencing illness in/and narrative. In Bird, C. E., Conrad, P., & Fremons, A. M. (Eds.) *Handbook of medical sociology, 5th Edition*. (pp. 184-199). Prentice Hall.

Benjamin, J. (2018). *Beyond doer and done to. Recognition theory, intersubjectivity and the third.* Routledge.

Benum, K., Axelsen, E. D., & Hartmann, E. (Eds.) (2017). *God psykoterapi. Et intergrativt perspektiv* [Good psychotherapy. An integrative perspective]. Pax Forlag.

Berger, P. L. & Luckman, T. (1966). *Den samfundsskabte virkelighed: en videnssociologisk afhandling* [The social construction of reality]. Lindhardt og Ringhof.

Berntsson, L. T., Kohler, L., & Gustafsson, J. E. (2001). Psychosomatic complaints in schoolchildren: a Nordic comparison. *Scandinavian Journal of Public Health*, *29*(1), 44–54. https://doi.org/10.1177/14034948010290011001

Blakely, A. A., Howard, R. C., Sosich, R., Murdoch, J. C., Menkes, D. B., & Spears, G. F. S. (1991). Psychiatric symptoms, personality and ways of coping in chronic fatigue syndrome. *Psychological Medicine, 21*(2), 347-362. https://doi-org.ezproxy.uio.no/10.1017/S0033291700020456

Bloor, M., Frankland, J., Thomas, M., & Robson, K. (2001). *Focus groups in social research.* Sage Publications.

Bordin, E. S. (1979). The generalizability of the psychoanalytic concept of the working alliance. *Psychotherapy: Theory, Research & Practice*, *16*(3), 252-260. https://doi.org/10.1037/h0085885

Bourdieu, P. (1977). *Outline of a theory of practice.* Cambridge University Press.

Bourdieu, P, Accardo, A., Balazs, G., Beaud, S., Bonvin, F., Bourdieu, E. … & Wacquant, L. J. D. (1993). *The weight of the world: Social suffering in contemporary society.* Stanford University Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Brown, R. J. (2007). Introduction to the special issue on medically unexplained symptoms: Background and future directions. *Clinical Psychology Review, 27*(7), 769-780. https://doi.org/10.1016/j.cpr.2007.07.003

Bruner, J. (1990). *Acts of meaning.* Harvard University Press.

Buchbinder, M. (2011). Personhood diagnostics: Personal attributes and clinical explanations of pain. *Medical Anthropology Quarterly, 25*(4), 457-478. https://doi.org/10.1111/j.1548-1387.2011.01180.x

Buchbinder, M. (2015). *All in your head: Making sense of pediatric pain.* University of California Press.

Burman, E. (1994). *Deconstructing developmental psychology*. Routledge.

Burr, V. (2003). *Social constructionism*. Routledge.

Burr, V. (1995). *An introduction to social constructionism.* Taylor & Frances/Routledge.

Bury, M. (2001). Illness narratives: fact or fiction? *Sociology of Health & Illness, 23*(3), 263-285. https://doi.org/10.1111/1467-9566.00252

Butler, J. (1990). *Gender trouble.* Routledge.

Butler, J. (1993). *Bodies that matter.* Routledge.

Butler, J. (1995). For a careful reading. In S. Benhabib (Ed.), *Feminist contentions: A philosophical exchange.* Routledge.

Butler, C. C., Evans, M., Greaves, D., & Simpson, S. (2004). Medically unexplained symptoms: The biopsychososial model found wanting. *Journal of the Royal Society of Medicine, 97*(5)*,* 219-222. https://doi.org/10.1258/jrsm.97.5.219

Campo, J. V., Bridge, J., Ehman, M., Altman, S., Lucas, A., Birmaher, B. … & Brent, D. A. (2004). Recurrent abdominal pain, anxiety and depression in primary care. *Pediatrics, 113*(4), 817-824. https://doi.org/10.1542/peds.113.4.817

Campo, J. V., DiLorenzo, C., Chiappetta, L., Bridge, J., Colborn, D. K., Gartner, J. C. …& Brent, D. (2001). Adult outcomes of pediatric recurrent abdominal pain: Do they just grow out of it? *Pediatrics,* 108(1), E1. https://doi.org/10.1542/peds.108.1.e1

Canguilhem, G. (1989). *The normal and the pathological*. Zone Boos.

Carlson, E. D., Engebretson, J., & Chamberlain, R. M. (2006). Photovoice as a social process of critical consciousness. *Qualitative Health Research, 16*(6), 836–852. https://doi.org/10.1177/1049732306287525

Carpenter-Song, E. (2009). Children's sense of self in relation to clinical processes: Portraits of pharmaceutical transformation. *Ethos, 37*(3), 257-281. https://doi.org/10.1111/j.1548-1352.2009.01053.x

Chalfen, R., & Rich, M. (2007). Combining the applied, the visual and the medical. Patients teaching physicians with visual narratives. In S. Pink (Ed.) *Visual interventions* (pp. 53–70). Berghahn.

Cegala, D. J. (1997). A study of doctors' and patients' communication during a primary care consultation: implications for communication training. *Journal of Health Communication*, *2*(3), 169-194. https://doi.org/10.1080/108107397127743

Christensen, P. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children & Society, 18*(2)*,* 165-176. https://doi.org/10.1002/chi.823

Cohen, S. (1972). *Folk devils and moral panics*. MacGibbon and Kee.

Cole, M. (1995). Culture and cognitive development: From cross-cultural research to creating systems of cultural mediation, *Culture & Psychology, 1*(1), 25-54. https://doi.org/10.1177/1354067X9511003

Cooper, L. (1997). Myalgic encephalomyelitis and the medical encounter. *Sociology of Health and Illness, 19*(2), 186-207. https://doi.org/10.1111/1467-9566.ep10934404

Conrad, P., & Barker, K. K. (2010). The social construction of illness: key insights and policy implications, *Journal of Health and Social Behavior,* 51, S, S67-S79. https://doi.org/10.1177/0022146510383495

Creed, F., Guthrie, E., Fink, P., Henningsen, P., Rief, W., Sharpe, M., & White, P. (2010). Is there a better term than "medically unexplained symptoms? *Journal of Psychosomatic Research, 68*(1), 5-8. https://doi.org/ 10.1016/j.jpsychores.2009.09.004

Crossley, M. M. L (2000). *Introducing narrative psychology: Self, trauma and the construction of meaning.* Open University Press.

Dalsgaard, T. (2005). *'If only I had been in a wheelchair': An anthropological analysis of narratives of sufferers with medically unexplained symptoms.* Doctoral dissertation, Department of Anthropology and Ethnography, Aarhus University.

Damasio, A. (1994). *Descartes error.* G. P. Putnam's Sons.

Davidson, L., & Chan, K. K. S. (2014). Common factors: Evidence-based practice and recovery, *Psychiatric Services, 65*(5), 675-677. https://doi.org/10.1176/appi.ps.201300274

Davies, B. (2000). *A body of writing 1990-1999.* AltaMira Press.

Davies, B. (2006). Subjectification: the relevance of Butler's analysis for education. *British Journal of Sociology of Education, 27*(4), 425-438. https://doi.org/10.1080/01425690600802907

Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves, *Journal for the Theory of Social Behavior, 20*(1), 43-63. https://doi.org/10.1111/j.1468-5914.1990.tb00174.x

Deary, V. (2005). Explaining the unexplained? Overcoming the distortions of a dualist understanding of medically unexplained illness, *Journal of Mental Health, 14*(3), 213-221. https://doi.org/10.1080/09638230500136605

Derrida, J. (1976). *Of grammatology.* John Hopkins University Press.

Derrida, J. (1978). *Speech and phenomena.* Northwestern University Press.

Desjarlais, R. (2000). The makings of personhood in a shelter for people considered Homeless and mentally ill, *Ethos, 27*(4), 466-489. https://doi.org/10.1525/eth.1999.27.4.466

Dinos, S., Ascoli, M., Owiti, J. A., & Bhui, K. (2017). Assessing explanatory models and health beliefs: An essential but overlooked competency for clinicians. *British Journal of Psychiatry (Advances), 23*(2), 106–114. https://doi.org/10.1192/apt.bp.114.013680

Donmoyer, R. (1990). Generalizability and the single case study. In E. Eisner, & A. Peshkin (Eds.), *Qualitative inquiry in education: The continuing debate* (pp. 175-199). Teachers College Press.

Dowrick, C., Gask, L., Hughes, J.G., Charles-Jones, H., Hogg, J. A., Peters, S., … & Morriss, R. K. (2008). General practitioners' views on reattribution for patients with medically unexplained symptoms: A questionnaire and qualitative study. *BMC Family Practice, 9*(46). https://doi.org/10.1186/1471-2296-9-46

Dowrick,C., Ring, A., Humphris, G. M., & Salmon, P. (2004). Normalization of unexplained symptoms by general practitioners: A functional typology. *British Journal of General Practice, 54*(500), 165-170.

Drotner, K. (1991). *At skabe sig selv: ungdom, æstetik, pædagogik* [To create one's self: youth, esthetics and pedagogy]. Gyldendal.

Drotner, K., & Bay, J. (1986). *Ungdom, en stil, et liv: en bog om ungdomskulturer* [Youth, style and life: a book on youth cultures]. Tiderne skifter.

Dumit, J. (2006). Illnesses you have to fight to get: Facts and forces in uncertain, emergent illnesses. *Social Science & Medicine, 62*(3), 577-590. https://doi.org/10.1016/j.socscimed.2005.06.018

Edwards, C. R., Thompson, A. R., & Blair, A. (2007). An 'overwhelming illness'. Women's experiences of learning to live with chronic fatigue syndrome/myalgic encephalomyelitis. *Journal of Health Psychology*, *12*(2), 203–214. https://doi.org/10.1177/1359105307071747

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). *Writing ethnographic fieldnotes. 2nd edition.* University of Chicago Press.

Eminson, D. M. (2007). Medically unexplained symptoms in children and adolescents. *Clinical Psychology Review 27*(7), 855–871. https://doi.org/10.1016/j.cpr.2007.07.007

Engel, G (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129-136. https://doi.org/10.1126/science.847460

Epstein, R. M., Shields, C. G., Meldrum, S. C., Fiscella, K., Carroll, J., Carney, P. A. et al. (2006). Physicians' responses to patients' medically unexplained symptoms. *Psychosomatic Medicine, 68*(2), 269-276. https://doi.org/10.1097/01.psy.0000204652.27246.5b

Eriksen, T. E., Kerry, R., Mumford, S., Lie, S. A., & Anjum, R. L. (2013). At the borders of medical reasoning: aetiological and ontological challenges of medically unexplained symptoms, *Philosophy, Ethics, and Humanities in Medicine*, *8*(1), 354-363. https://doi.org/10.1186/1747-5341-8-11

Eriksen, T. E., Kirkengen, A. L., & Vetlesen, A. J. (2013). The medically unexplained revisited. *Medicine, Health Care and Philosophy, 16*(1), 587-600. https://doi.org/10.1007/s11019-012-9436-2

Erikson, E. H. (1950). *Childhood and society.* Imago.

Ertesvåg, F., Wallenius, H., & Huuse, C. (2016, October 23). Stadig flere unge legges inn med stress-sykdommer [More and more young people are admitted to hospital because of stress-related illnesses]. *VG*, Retrieved from: http://www.vg.no/nyheter/innenriks/oppvekst/

Falzon, M. A. (2009) (Ed.). *Multi-sited ethnography. Theory, praxis and locality in contemporary research.* Ashgate.

Fangen, K. (2010). *Deltagende observasjon. 2. utgave* [Participant observation. 2nd edition]. Fagbokforlaget.

Fine, M. (2002). *Disruptive voices: The possibilities for feminist research.* University of Michigan Press.

Fink, P. (1992). The use of hospitalizations by persistent somatizing patients. *Psychological Medicine*, *22*(1), 173-180. https://doi.org/10.1017/S0033291700032827

Fink, P., Rosendal, M., & Olesen, F. (2004). Classification of somatization and functional somatic symptoms in primary care. *Australian and New Zealand Journal of Psychiatry*, *39*(9), 772-781. https://doi.org/10.1080/j.1440-1614.2005.01682.x

Fink, P., & Schrøder, A. (2010). One single diagnosis, bodily distress syndrome, succeeded to capture ten diagnostic categories of functional somatic syndromes and somatoform disorders. *Journal of Psychosomatic Research, 68*(5), 415-426. https:/doi.org/10.1016/j.jpsychores.2010.02.004

Finlay, L. (2003). Through the looking glass: Intersubjectivity and hermeneutic reflection. In L. Finlay, & B. Gough (Eds.), *Reflexivity. A practical guide for researchers in health and social sciences* (pp. 105-119). Blackwell.

Finlay, L., & Evans, K. (2009). *Relational-centred research for psychotherapists. Exploring meanings and experience.* Wiley-Blackwell

Fisher, H., & Crawley, E. (2013). Why do young people with CFS/ME feel anxious? A qualitative study. *Clinical Child Psychology and Psychiatry, 18*(4), 556–573. https://doi.org/10.1177/1359104512460862

Flor, J. A. & Kennair, L. E. O. (2019). *Skadelige samtaler – myten om bivirkningsfri terapi.* [Disruptive conversations – the myth of non-existing adverse effects in psychotherapy]. Tiden.

Fordyce, W. (1976). *Behavioral methods for chronic pain and illness.* C. V. Mosby.

Foucault, M. (1973). *The birth of the clinic: An archeology of medical perception.* Tavistock.

Foucault M. (1976). *The history of sexuality: An introduction.* Penguin.

Foucault, M. (1977). *Discipline and punish: the birth of the prison.* Pantheon Books.

Foucault, M. (1988). *Madness and Civilization. A History of Insanity in the Age of Reason.* Vintage Books.

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics.* University of Chicago Press.

Frank, A. W. (2005). What is dialogical research, and why should we do it? *Qualitative Health Research, 15*(7) 964-974. https://doi.org/10.1177/1049732305279078

Frank, A. (2010). *Letting stories breathe. A socio-narratology.* University of Chicago Press.

Frank, A. W. (2016). From sick role to narrative subject: An analytic memoir, *Health, 20*(1), 9-21. https://doi.org/10.1177/1363459315615395

Freidson, E. (1988). *Profession of medicine: A study of the sociology of applied knowledge.* University of Chicago Press.

Frønes, I. (1995). *Among peers: On the meaning of peers in the process of socialization.* Scandinavian University Press.

Garro, L. C. (1994). Narrative representations of chronic illness experience: Cultural models of illness, mind, and body in stories concerning the Temporomandibular Joint (TMJ). *Social Science & Medicine, 38*(6), 775-788. https://doi.org/10.1016/0277-9536(94)90150-3

Geertz, C. (1973). *The interpretation of cultures: Selected essays.* Basic Books

Geist, R., Weinstein, M., Walker, L., & Campo, J. V. (2008). Medically unexplained symptoms in young people: The doctor's dilemma, *Paediatrics & Child Health, 13*(6), 487-91. http://dx.doi.org/10.1093/pch/13.6.487

Gergen, K. J. (1992). Toward a postmodern psychology. In S. Kvale (Ed.), *Psychology and postmodernism* (pp. 17-30). Sage Publications.

Gergen, K. J., & Gergen, M. M. (1986). Narrative form and the construction of psychological science. In: T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 22-44). Praeger.

Goffman, E. (1971). *The presentation of self in everyday life.* Penguin.

Goffman, E. (1981). *Forms of talk.* Blackwell.

Good, B. J. (1994). *Medicine, rationality, and experience: An anthropological perspective.* Cambridge University Press.

Good, B. J., Fischer, M. M. J., Willen, S. S., & Good, M. J. D. (Eds.) (2010). *A reader in medical anthropology: Theoretical trajectories, emergent realities.* Wiley-Blackwell.

Good, B., & Good, M. J. D. (1993). Learning medicine: The constructing of medical knowledge at Harvard Medical School. In S. Lindenbaum, & M. Lock (Eds.) *Knowledge, power and practice. The anthropology of medicine and everyday life* (pp. 81-107). University of California Press.

Goodman, N. (1978). *Ways of worldmaking.* Hackett.

Greco, M. (1993). Psychosomatic subjects and the ‘duty to be well’: personal agency within medical rationality, *Economy and Society*, *22*(3), 357-372. https://doi.org/10.1080/03085149300000024

Greco, M. (2012). The classification and nomenclature of “medically unexplained symtoms”: Conflict, collusion and critique, *Social Science & Medicine, 75*(12), 2362-2369. https://doi.org/10.1016/j.socscimed.2012.09.010

Greco, M. (2017). Pragmatics of explanation: Creative accountability in the care of ‘medically unexplained symptoms’, *The Sociological Review Monographs, 65*(2), 110-129. https://doi.org/10.1177/0081176917710425

Greenberg, J. R. & Mitchell, S. A. (1983). *Object relations in psychoanalytic theory.* Harvard University Press.

Gremillion, H. (2003). *Feeding anorexia. Gender and power at a treatment center.* Duke University Press.

Griffin, C. (2010). Youth research, the ‘new Europe’ and the global youth culture. *Children & Society, 24*(3), 147-166. https://doi.org/10.1177/0907568201008002002

Groen, J. (1948). Psychogenesis and psychotherapy of ulcerative colitis. *Psychosomatic Medicine, 9*(3), 151-174. https://doi.org/10.1097/00006842-194705000-00001

Groves, J. (2009). *Taking care of the hatefulpPatient. Personality disorder the definitive reader.* In G. Adshead, & C. Jacob (Eds.) (pp. 52-63). Jessica Kingsley Publishers.

Grue, J. (2016). Illness is work: Revisiting the concept of illness careers and recognizing the identity work of patients with ME/CFS, *Health, 20*(4), 401-412. https://doi.org/10.1177/1363459315628044

Grzybowski, S. C., Stewart, M. A., & Weston, W. W. (1992). Nonverbal communication and the therapeutic relationship: Leading to a better understanding of healing, *Canadian Family Physician Medecin de Famille Canadien*, *38*(1), 1994–1998.

Gudmundsson, G. (2006). *Wrestling with(in) the welfare state. An overview of Nordic youth research.* Universitat Autonoma de Barcelona.

Gulbrandsen, L. M. (1998). *I barns dagligliv* [In children's everyday lives]. Universitetsforlaget.

Gulbrandsen, L. M. (2000). Samspill mellom barn som kjønnsskapte og kjønnskapende prosesser. Et analytisk perspektiv. [Children's interactions as created by gender and as creating gender. An analytical perspective]. In H. Haavind (Ed.), *Kjønn og fortolkende metode* [Gender and interpretational research]. Gyldendal Akademisk.

Gulbrandsen, L. M. (2003). Peer relations as arenas for gender constructions among young teenagers, *Pedagogy, Culture & Society, 11*(1), 113-132. https://doi.org/10.1080/14681360300200163

Gulbrandsen, L. M. (2006). Fra små jenter til ungjenter: Heteroseksualitet som normativ utviklingsretning. [From small girls to young girls: Heterosexuality as normative developmental direction]. *Tidsskrift for kjønnsforskning*, 4, 5-20.

Gulbrandsen, L. M. (Ed.) (2014). *Barns deltagelse i hverdagsliv og profesjonell praksis – en utforskende tilnærming* [Children's participation in everyday life and professional practice – an exploratory approach]. Universitetsforlaget.

Haavind, H. (1987). *Liten og stor: mødres omsorg og barns utviklingsmuligheter* [The big and the little one: Maternal care and the developmental possibilities for children]. Universitetsforlaget.

Haavind, H. (2000). Analytiske retningslinjer ved empiriske studier av kjønnede betydninger [Analytical guidelines in empirical studies of gendered meanings] In H. Haavind (Ed.), *Kjønn og fortolkende metode: Metodiske muligheter i kvalitativ forskning* [Gender and interpretive method: methodological possibilities in qualitative research] (pp. 155-219). Gyldendal akademisk.

Haavind, H. (2003). Masculinity by rule-breaking: cultural contestations in the transitional move from being a child to being a young male, *NORA: Nordic Journal of Women's Studies, 11*(2), 89-100. https://doi.org/10.1080/08038740310002941

Haavind, H. (2007). Accountability in persons. What is in the telling to others about yourself? In D. Staunæs, & J. Kofoed (Eds.), *Magtballader* [Plays in power] (pp. 159-178). Danmarks Pædagogiske Universitets Forlag.

Haavind, H. (2014). 'Who does he think he is?': making new friends and leaving others behind – on the path from childhood to youth. In R. M. Schott, & D. M. Søndergaard (Eds.), *School bullying. New theories in context* (pp. 129-158). Cambridge University Press.

Hacking, I. (1986). Making up people. In T. L. Heller, M. Sosna, & D. E. Wellbery (Eds.), *Reconstructing individualism: Autonomy, individuality, and the self in Western thought* (pp. 222-236). Stanford University Press.

Hacking, I. (1999). *The social construction of what?* Harvard University Press.

Habermas, J. (1987). *Knowledge and human interests.* Polity Press.

Hahn, S. R. (2001). Physical symptoms and the physician-experienced difficulty in the physician-patient relationship, *Annals of Internal Medicine, 134*(9), 894-904. https://doi.org/10.7326/0003-4819-134-9_Part_2-200105011-00014

Hahn, S. R., Thomson, K. S., Wills, T. A., Stern, V., & Budner, N. S. (1994). The difficult doctor-patient relationship: somatization, personality and psychopathology, *Journal of Clinical Epidemiology, 47*(6), 647-657. https://doi.org/10.1016/0895-4356(94)90212-7

Hahn, S. R., Kroenke, K., Spitzer, R. L., Brody, D., Williams, J. B., & Linzer, M. (1996). The difficult patient, *Journal of General Internal Medicine, 11*(1), 1-8. https://doi.org/10.1007/bf02603477

Halldén, G., Änggård, E., Markström, A. M., & Simonsson, M. (2007). *Den moderna barndomen och barns vardagliv* [Modern childhood and children's everyday life]. Carlssons bokförlag.

Hall, G. S. (1904). *Adolescence, its psychology and its relations to physiology, anthropology, sociology, sex, crime, religion and education (Vol. 2.).* Appleton & Company.

Hamer, S. (2005). Evidence-based practice. In S. Hamer, & G. Collinson (Eds.). *Achieving evidence-based practice. A handbook for practitioners (2nd ed.).* Elsevier.

Hammersley, M., & Atkinson, P. (1995). *Ethnography: principles in practice.* Routledge.

Haraway, D. (1992). The promises of monsters: a regenerative politics of inappropriate/d others. In L. Grossberg, C. Nelson, & P. A. Treichler (Eds.), *Cultural studies* (pp. 295-337). Routledge.

Harrington, A. (2008). *The cure within: A history of mind-body medicine.* W. W. Norton.

Hareide, L., Finset, A., & Wyller, V. B. (2011). Chronic fatigue syndrome: a qualitative investigation of young patient's beliefs and coping strategies, *Disability and Rehabilitation,* 33(23-24), 2255-2263. https://doi.org/10.3109/09638288.2011.568663

Hauge, M. I. (2009). *Doing, being and becoming. Young people's processes of subjectivation between categories of age.* [Doctoral dissertation, Department of Psychology, Faculty of Social Sciences, University of Oslo].

Hellhammer, D. H., & Hellhammer, J. (2008) (Eds.), *Stress: The brain-body connection.* Karger.

Hoffart, C. M., & Sherry, D. D. (2016). Fibromyalgia - toward a definition in children, *Journal of Pediatrics*, 169, 9-10. https://doi.org/10.1016/j.jpeds.2015.11.034

Holland, S. (2009). Listening to children in care: A review of methodological and theoretical approaches to understanding looked after children's perspectives, *Children & Society*, *23*(3), 226-235. https://doi.org/10.1111/j.1099-0860.2008.00213.x

Hollway, W., & Jefferson, T. (2000). *Doing qualitative research differently: Free association, narrative and the interview method.* Sage Publications.

Holstein, J. A., & Gubrium, J. F. (1995). *The active interview.* Sage Publications.

Holquist, M. (2002). *Dialogism: Bakhtin and his world. (2nd ed.).* Routledge.

Horowitz, L. M., & Malle, B. (1993). Fuzzy concepts in psychotherapy research, *Psychotherapy Research*, *3*(2), 131-148. https://doi.org/10.1080/10503309312331333739

Horst, C. (2009). Expanding sites: The question of 'depth' explored. In M. A. Falzon (Ed.), *Multi-sited ethnography. Theory, praxis and locality in contemporary research* (pp. 119-133). Ashgate.

Horton-Salway, M. (2001). Narrative identities and the management of personal accountability in talk about ME: A discursive psychology approach to illness narrative, *Journal of Health Psychology, 6*(2), 247-259. https://doi.org/10.1177/135910530100600210

Horton-Salway, M. (2002). Bio-psycho-social reasoning in GP's case narratives: the discursive construction of ME patients' identities, *Health: An interdisciplinary Journal for the study of Health, Illness and Medicine, 6*(4), 401-421. https://doi.org/10.1177/136345930200600401

Horton-Salway, M. (2007). The "ME-bandwagon" and other labels: Constructing the genuine case in talk about a controversial illness, *British Journal of Social Psychology*, *46*(4), 895-914. https://doi.org/10.1348/014466607X173456

Hotvedt, S. K., & Aardal, E. B. (2014, August 11). De skulker ikke, de drikker ikke – men de stresser [They don't ditch school, they don't drink – but they stress]. *NRK*, Retrieved from https://www.nrk.no/norge/unge_-prektige-_og-stressa-1.11873587

Huuse, C. F. & Ertesvåg, F. (2016, October 30). Barn stresser seg syke: - Konflikter hjemme øker presset. [Children stress themselves sick – conflicts at home make the pressure worse]. *VG,* Retrieved from http://www.vg.no

Hydén, L. C. (1997). Illness and narrative. *Sociology of Health & Illness, 19*(1), 48-69. https://doi.org/10.1111/j.1467-9566.1997.tb00015.x

Iser W. (1978). *The act of reading: A theoretical aestethic response.* John Hopkins University Press.

Iser, W. (1989). *Prospecting: From reader response to literary anthropology*. John Hopkins University Press.

Jackson, M. (2002). *The politics of storytelling: Violence, transgression and intersubjectivity.* Museum Tusculanum Press, University of Copenhagen.

James, A. (2009). Agency. In J. Qvotrup, W. A. Corsaro, & M. S. Honig (Eds.), *The Palgrave handbook of childhood studies.* Palgrave-Macmillan.

James, A., & James, A. L. (2001). Childhood: Toward a theory of continuity and change. *The ANNALS of the American Academy of Political and Social Science, 575*(1), 25-37. https://doi.org/10.1177/000271620157500102

James, A., & Prout, A. (1997). *Constructing and reconstructing childhood* (2nd ed.). Falmer.

Jansen, A. (2010). Victim or troublemaker: Young people in residential care, *Journal of Youth Studies, 13*(4), 423-437. https://doi.org/10.1080/13676261003801770

Jansen, A. (2011). *Young people in residential care. Narrative engagement and processes of subjectivation.* [Doctoral dissertation, Department of Psychology, Faculty of Social Sciences, University of Oslo].

Jansen, A. (2013). *Narrative kraftfelt. Psykologisk utvikling hos barn og unge i et narrativt psykologisk perspektiv* [Narrative power fields. Psychological development in children and young people in a narrative psychological perspective]. Universitetsforlaget.

Jansen, A., & Andenæs, A. (2013). 'Heading for Japan' – Prospective narratives among youth living in residential care, *Qualitative Social Work, 12*(2), 119-134. https://doi.org/10.1177/1473325011423588

Jansen, A., & Haavind, H. (2011). 'If only' and 'Despite all'. Narrative configuration among youths living in residential care, *Narrative Inquiry, 21*(1), 68-87. https://doi.org/10.1075/ni.21.1.04jan

Jelbert, R., Stedmon, J., & Stephens, A. (2010). A qualitative exploration of adolescents' experiences of chronic fatigue syndrome, *Clinical Child Psychology and Psychiatry, 15*(2), 267-283. https://doi.org/10.1177/1359104509340940

Jenks, C. (1996). *Childhood.* Routledge.

Johannessen, C. R., & Kreutz-Hansen, H. (2014, September 16). Debatt i kveld: Tre av ti jenter stresser seg syke. [Debate: three of ten girls stress themselves sick]. *VG,* Retrieved from http://www.vg.no

Johansen, M. L., & Risør, M. B. (2017). What is the problem with medically unexplained symptoms for GPs? A meta-synthesis of qualitative studies. *Patient Education and Counseling, 100*(4), 647-654. https://doi.org/0.1016/j.pec.2016.11.015

Johnson, J. L., & Alderson, K. G. (2008). Therapeutic filmmaking: An exploratory pilot study, *The Arts in Psychotherapy*, *35*(1), 11–19. https://doi.org/10.1016/j.aip.2007.08.004

Jutel, A. (2009). Sociology of diagnosis: a preliminary review, *Sociology of Health & Illness*, *31*(2), 278-299. https://doi.org/10.1111/j.1467-9566.2008.01152.x

Jørgensen, M., & Phillips, L. (2002). *Discourse analysis as theory and method.* Sage Publications.

Karterud, H. N., Haavet, O. R., & Risør, M. B. (2016). Social participation in young people with nonepileptic seizures (NES): A qualitative study of managing legitimacy in everyday life, *Epilepsy & Behavior,* 57(A), 23-28. https://doi.org/10.1016/j.yebeh.2016.01.009

Karterud, H. N., Risør, M. B., & Haavet, O. R. (2015). The impact of conveying the diagnosis when using a biopsychosocial approach: A qualitative study among adolescents and young adults with NES (non-epileptic seizures), *Seizure: European Journal of Epilepsy*, *24*, 107-113. https://doi.org/10.1016/j.seizure.2014.09.006

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of dsm-iv disorders in the national comorbidity survey replication, *Archives of General Psychiatry,* 62(6), 593-602. https://doi.org/10.1001/archpsyc.62.6.593

Kirkengen, A.L. (2018). From wholes to fragments to wholes-what gets lost in translation? Journal of Evaluation In Clinical Practice, 24(5), 1145-1149. https://doi.org/10.1111/jep.12957

Kirkpatrick, I., Dent, M., & Jespersen, P. K. (2011). The contested terrain of hospital management: Professional projects and healthcare reforms in Denmark, *Current Sociology, 59*(4), 489–506. https://doi.org/10.1177/0011392111402718

Kirmayer, L. J. (1988). Mind and body as metaphors: Hidden values in biomedicine. In M. Lock, & D. R. Gordon (Eds.), *Biomedicine Examined* (pp. 57-93). Kluwer Academic Publishers.

Kirmayer, L. J. (1993). Healing and the invention of metaphor: The effectiveness of symbols revisited, *Culture, Medicine and Psychiatry, 17*(2), 165-195. https://doi.org/10.1007/bf01379325

Kirmayer, L. J. (2000). Broken narratives. Clinical encounters and the poetics of illness experience. In C. Mattingly, & L. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp. 153-180). University of California Press.

Kirmayer, L. J., Lemelson, R., & Cummings, C. (Eds.) (2015). *Re-visioning psychiatry: Cultural phenomenology, critical neuroscience and global mental health.* Cambridge University Press.

Kirmayer, L. J., Groleau, D., Looper, K. J., & Dao, M. D. (2004). Explaining medically unexplained symptoms, *The Canadian Journal of Psychiatry, 49*(10), 663-672. https://doi.org/10.1177/070674370404901003

Kleinman, A. (1980). *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry.* University of California Press.

Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition.* Basic Books.

Kleinman, A. (1994). Pain & resistance: The delegitimation and releitimation of local worlds. In M. J. D. Good, P. E Brodwin, B. J. Good, & A. Kleinman (Eds.). *Pain as human experience. An anthropological perspective* (pp. 169-197). University of California Press.

Kofoed, J. (2008). Appropriate pupilness: Social categories intersecting in school, *Childhood*, *15*(3), 415-430. https://doi.org/10.1177/0907568208091671

Konijnenberg, A. Y., Uiterwaal, C. S., Kimpen, J. L., van der Hoeven, J., Buitelaar, J. K., & de Graeff-Meeder, E. R. (2005). Children with unexplained chronic pain: Substantial impairment in everyday life, *Archives of Disease in Childhood, 90*(7), 680-686. https://doi.org/10.1136/adc.2004.056820

Kornelsen, J.,Atkins, C., Brownell, K., & Woollard, R. (2016). The meaning of patient experiences of medically unexplained physical symptoms, *Qualitative Health Research*, *26*(3), 367-376. https://doi.org/10.1177/1049732314566326

Knapstad, M- L. (2013, August). De sykt flinke. [The insanely clever]. *Aftenposten.* Retrieved from http://www.aftenposten.no

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Sage Publications.

Lather, P. (2007). *Getting lost. Feminist efforts toward a double(d) science.* State University of New York Press.

Lesko, N. (2001). *Act your age! A cultural construction of adolescence.* Routledge.

Lester, R. (2009). Brokering authenticity: Borderline personality disorder and the ethics of care in an American eating disorder clinic, *Current Anthropology, 50*(3), 281-302. https://doi.org/10.1086/598782

Lian, O. S., & Hansen, A. H. (2016). Factors facilitating satisfaction among women with medically unexplained long-term fatigue: A relational perspective, *Health, 20*(3), 308-326. https://doi.org/10.1177/1363459315583158

Lian, O. S., & Robson, C. (2017). “It’s incredible how much I’ve had to fight.” Negotiating medical uncertainty in clinical encounters, *International Journal of Qualitative Studies on Health and Well-Being, 12*(2), 1392219. https://doi.org/10.1080/17482631.2017.1392219

Liberatore, A., & Funtowicz, S. (2003). ‘Democratizing’ expertise, ‘expertizing’ democracy: What does it mean, and why bother? *Science and Public Policy*, *30*(3), 146–150. https://doi.org/10.3152/147154303781780551

Luhrmann, T. M. (2000). *Of two minds: The growing disorder in American psychiatry.* Knopf.

Løchen, Y. (1970). *Idealer og realiteter i et psykiatrisk sykehus* [Ideals and realities in a psychiatric hospital]. Universitetsforlaget.

Løkke, P. A. (2014). Jenters stumme raseri – i diagnosenes tidsalder [The silent rage of girls – in the time of diagnoses]. *Tidsskrift for Norsk Psykologforening, 51*(9), 767-772.

Madsen, O. J. (2018). *Generasjon prestasjon: hva er det som feiler oss?* [The performance generation: what is the matter with us?]. Universitetsforlaget.

Malterud, K. (2011). *Kvalitative metoder i medisinsk forskning: en innføring* [Qualitative methods in medical research: an introduction]. Universitetsforlaget.

Malterud, K. (2016). Theory and interpretation in qualitative studies from general practice: Why and how? *Scandinavian Journal of Public Health, 44*(2), 120-129. https://doi.org/10.1177/1403494815621181

Marcus, G. E. (1995). Ethnography in/of the world system: The emergence of multi-sited ethnography, *Annual Review of Anthropology*, *24*(1), 95-117. https://doi.org/10.1146/annurev.an.24.100195.000523

Markus, H., & Nurius, P. (1986). Possible selves, *American Psychologist, 41*(9), 954-969. https://doi.org/10.1037/0003-066X.41.9.954

Mattingly, C. (1994). The concept of therapeutic ’emplotment’, *Social Science & Medicine*, *38*(6), 811-822. https://doi.org/10.1016/0277-9536(94)90153-8

Mattingly, C. (2013). Moral selves and moral scenes: Narrative experiments in everyday life, *Ethnos, 78*(3), 301-327. https://doi.org/10.1080/00141844.2012.691523

Mattingly, C. (2014). *Moral laboratories: family peril and the struggle for a good life.* University of California Press.

MacDougall, D. (2006). *The corporeal image: Film, ethnography and the senses*. Princeton University Press.

May, C., Allison, G., Chapple, C., Chew-Graham, C., Dixon, C., Gask, L., …, & Roland, M. (2004). Framing the doctor-patient relationship in chronic illness: a comparative study of general practitioners' accounts, *Sociology of Health & Illness, 26*(2), 135-158. https://doi.org/10.1111/j.1467-9566.2004.00384.x

McAdams, D. P. (2003). Identity and the life story. In R. Fivush, & C. Hayden (Eds.), *Autobiographical memory and the construction of a narrative self: developmental and cultural perspectives.* Lawrence Erlbaum.

McDermott, R. P. (1993). The acquisition of a child by a learning diability. In S. Chaiulin, & J. Lave (Eds.), *Understanding practice: Perspectives on activity and context.* Cambridge University Press.

McFarlane, A., Ellis, N., Barton, C., Browne, D., & van Hoeff, M. (2008). The conundrum of medically unexplained symptoms: Questions to consider. *Psychosomatics, 49*(5), 369-377. https://doi.org/10.1176/appi.psy.49.5.369

McNaughton, G. (2005). *Doing Foucault in early childhood studies. Applying poststructuralist ideas.* Routledge.

Mead, N., & Bower, P. (2000). Patient-centredness: A conceptual framework and review of the empirical literature, *Social Science & Medicine, 51*(7), 1087-1110. https://doi.org/10.1016/s0277-9536(00)00098-8

Meadors, J. D., & Murray, C. B. (2015). Doctor-patient interaction in the West: Psychosocial aspects, *International Encyclopedia of the Social & Behavioral Sciences*, *2*(6), 613-619. https://doi.org/10.1016/B978-0-08-097086-8.14017-6

Mik-Meyer, N., & Obling, A. R. (2012). The negotiation of the sick role: General practitioners' classification of patients with medically unexplained symptoms, *Sociology of Health & Illness*, *34*(7), 1025-1038. https://doi.org/10.1111/j.1467-9566.2011.01448.x

Miller, P. J. (1994). Narrative practices: Their role in socialization and self-construction. In U. Neisser, & R. Fivush (Eds), *The remembering self. Construction and accuracy in the self-narrative* (pp. 158-179). Cambridge university press.

Mishler, E. G. (1984). *The discourse of medicine. The dialectics of medical interviews.* Ablex.

Mischler, E. G. (1995). Models of narrative analysis: A typology, *Journal of Narrative & Life History, 5*(2), 77–123. https://doi.org/10.1075/jnlh.5.2.01mod

Mitchell, S. A. (1988). Relational concepts in psychoanalysis. An integration. Harvard University Press.

Mitchell, C. & Sommer, M. (2017) (Eds.). *Participatory visual methodologies in global public health.* Routledge.

Mol, A. (2008). *The logic of care: Health and the problem of patient choice.* Routledge.

Morss, J. (1990). *Growing critical: Alternatives to developmental psychology.* Routledge.

Moss-Morris, R. (2005). Symptom perceptions, illness beliefs and coping in chronic fatigue syndrome, *Journal of Mental Health, 14*(3), 223-235. https://doi.org/10.1080/09638230500136548

Moulin, V., Akre, C., Rodondi, P. Y., Ambresin, A. E.., & Suris, J. C. (2015a). A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 1: Experiences and impact on daily life, *Journal of Adolescence, 45*(1), 307-316. https://doi.org/10.1016/j.adolescence.2015.10.010

Moulin, V., Akre, C., Rodondi, P. Y., Ambresin, A. E.., Suris, J. C. (2015b). A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 2: How is healthcare perceived? *Journal of Adolescence, 45*(1), 317-326. https://doi.org/10.1016/j.adolescence.2015.10.003

Mørch, S. (2010). Ungdomsforskningen som perspektiv og mulighet [Youth research as perspective and opportunity], *Psyke & Logos, 31*(1), 11-44. https://tidsskrift.dk/psyke/article/view/8447

Nater, U. M., Wagner, D., Solomon, L., Jones, J., Unger, E. Papanicolaou, D., ..., & Heim, C. (2006). Coping styles in people with chronic fatigue syndrome identified from the general population in Wichita, KS, *Journal of Psychosomatic Research, 60*(6), 567-573. https://doi.org/10.1016/j.jpsychores.2006.04.001

Neinstein, L. S. (2002). *Adolescent health care: a practical guide.* (*4th ed.)* Lippincott, Williams & Wilkins.

Nettleton, S. (2006). 'I just want permission to be ill': Towards a sociology of medically unexplained symptoms, *Social Science and Medicine, 62*(5), 1167–1178. https://doi.org/10.1016/j.socscimed.2005.07.030

Nettleton, S., O'Malley, L. Watt, I., & Duffey, P. (2004). Enigmatic Illness: Narratives of patients who live with medically unexplained symptoms, *Social Theory & Health, 2*(1), 47-66. https://doi.org/10.1057/palgrave.sth.8700013

Nettleton, S., Watt, I, O'Malley, U., & Duffey, P. (2005). Understanding the narratives of people who live with medically unexplained illness, *Patient Education and Counseling*, *56*(2), 205-210. https://doi.org/10.1016/j.pec.2004.02.010

Neville, K. (2003). Uncertainty in illness: An integrative review, *Orthopaedic Nursing*, *22*(3), 206–214. https://doi.org/10.1097/00006416-200305000-00009

Nimnuan, C., Hotopf, M., & Wessely, S. (2001). Medically unexplained symptoms: An epidemiological study in seven specialties, *Journal of Psychosomatic Research, 51*(1), 361-367. https://doi.org/10.1016/s0022-3999(01)00223-9

Norregaard, J., Bulow, P., Prescott, E., Jacobsen, S., & Danneskiold-Samsoe, B. (1993). A four-year follow-up study in fibromyalgia: Relationship to chronic fatigue, *Scandinavian Journal of Rheumatology, 22*(1), 35-38. https://doi.org/10.3109/03009749309095109

O'Dowd, T. (1988). Five years of heartsink patients in general practice, *BMJ, 297*(6647), 528-530. https://doi.org/10.1136/bmj.297.6647.528

Øiestad, G. (2011). Selvfølelsen hos barn og unge. [Sense of self in children and young people]. Gyldendal.

Olde Hartman, T. C., Hassink-Franke, L. J., Lucassen, P. L., van Spaendonck, K. P., & van Weel, C. (2009). Explanation and relations. How do general practitioners deal with patients with persistent medically unexplained symptoms: a focus group study, *BMC Family Practice, 10*(1), 68. https://doi.org/10.1186/1471-2296-10-68

Olde Hartman, T., Woutersen-Koch, H., & van der Horst, H. E. (2013). Medically unexplained symptoms: Evidence, guidelines, and beyond, *The British journal of general practice: the journal of the Royal College of General Practitioners, 63*(617), 625-626. https://doi.org/10.3399/bjgp13X675241

Orlans, V. (2013). The nature and scope of counselling psychology. In G. Davey (Ed.), *Applied Psychology.* The British Psychological Society and Blackwell Publishing Ltd.

Østbye, S. V. (2009). *En sang om smerte og styrke: bearbeiding og reparasjon av ekstreme traumer i et narrativt psykologisk perspektiv* [A song of suffering and strength: a narrative psychological perspective on reconciliation and reconstruction after extreme trauma]. (Master thesis). University of Oslo, Oslo, Norway.

Øverlien, C. (2011). Narrating the good life – children in shelters for abused women talk about the future, Qualitative Social Work, 11(5), 470-485. https://doi.org/10.1177/1473325011401469

Øverlien, C. & Hydén, M. (2009). Children's actions when experiencing domestic violence, Childhood, 16(4), 479-496. https://doi.org/10.1177/0907568209343757

Page, L. A., & Wessely, S. (2003). Medically unexplained symptoms: Exacerbating factors in the doctor-patient encounter, *Journal of the Royal Society of Medic*ine, *96*(5), 223-7. https://doi.org/10.1177/014107680309600505

Parsons, T. (1978). *Action theory and the human condition*. Free Press.

Patton, M.Q. (2007). *Qualitative research & evaluation methods.* Sage Publications.

Peveler, R., Kilkenny, L., & Kinmonth, A.L. (1997). Medically unexplained physical symptoms in primary care: A comparison of self-report screening questionnaires and clinical opinion, *Journal of Psychosomatic Research, 42*(3), 245-52. https://doi.org/10.1016/S0022-3999(96)00292-9

Pink, S. (2006). *The Future of Visual Anthropology – engaging the senses.* Routledge.

Pink S. (2007). *Doing Visual Ethnography.* Sage Publications.

Potter, J. & Wetherell, M. (1987). *Discourse and Social Psychology.* Sage Publications.

Powney, J. (1988). Structured eavesdropping, *Research Intelligence (Journal of the British Educational Research Foundation)*, *28*(1), 10-12.

Prescott, E., Kjøller, M., Jacobsen, S., Bülow, P. M., Danneskiold-Samsøe, B., & Kamper-Jørgensen, F. (1993). Fibromyalgia in the adult Danish population: A prevalence study, *Scandinavian Journal of Rheumatology, 22*(5), 233-237. https://doi.org/10.3109/03009749309095129

Price, J. R., & Okai, D. (2016). Functional disorders and 'medically unexplained physical symptoms', *Medicine*, *44*(12), 706-710. https://doi.org/10.1016/j.mpmed.2016.09.012

Prout, A. & James, A. (1997). A new paradigm for the sociology of childhood? Provenance, promise and problems. In A. James, & A. Prout (Eds.), *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood.* Falmer Press.

Qvotrup, J. (2009). Childhood as a structural form. In J. Qvotrup, W. A. Corsaro, & M. S. Honig (Eds.), *The Palgrave handbook of childhood studies.* Palgrave-Macmillan.

Radley, A. (1997). The triumph of narrative? A reply to Arthur Frank, *Body & Society*, *3*(3), 93-101. https://doi.org/10.1177/1357034X97003003005

Radnitzky, G. (1970). *Contemporary schools of metascience.* Akedemiførlaget.

Rask, C. U., Olsen, E. M., Elberling, H., Christensen, M. F., Ørnbøl, E., Fink, P., ..., & Skovgaard, A. M. (2009). Functional somatic symptoms and associated impairment in 5-7-year-old children: The Copenhagen Child Cohort 2000, *European Journal of Epidemiology, 24*(10), 625-634. https://doi.org/10.1007/s10654-009-9366-3

Reid, S., Whooley, D., Crayford, T., & Hotopf, M. (2001). Medically unexplained symptoms - GPs' attitudes towards their cause and management, *Family Practice, 18*(5), 519-523. https://doi.org/10.1093/fampra/18.5.519

Reiners, G. (2012). Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research, *Journal of Nursing and Care*, *1*(5), 119. https://doi.org/10.4172/2167-1168.1000119

Rich, M. (2004). Health literacy via media literacy. Video intervention/prevention assessment, *American Behavioral Scientist, 48*(2), 165-188. https://doi.org/10.1177/0002764204267261

Richards, J., Chaplin, R., Starkey, C., & Turk, J. (2006). Illness beliefs in chronic fatigue syndrome: A study involving affected adolescents and their parents, *Child and Adolescent Mental Health, 11*(4), 198-203. https://doi.org/10.1111/j.1475-3588.2006.00409.x

Riessman, C. K. (2003). Performing identities in illness narrative: Masculinity and multiple sclerosis, *Qualitative Research, 3*(1), 5-33. https://doi.org/10.1177/146879410300300101

Riessman, C. K. (2008). *Narrative methods for the human sciences.* Sage Publications.

Riessman, C. K., & Quinney, L. (2005). Narrative in social work: A critical review, *Qualitative Social Work, 4*(4), 391-412. https://doi.org/10.1177/1473325005058643

Ring, A., Dowrick, C. F., Humphris, G. M., Davies, J., & Salmon, P. (2005). The somatising effect of clinical consultation: What patients and doctors say and do not say when patients present medically unexplained physical symptoms, *Social Science & Medicine, 61*(7), 1505-1515. https://doi.org/10.1016/j.socscimed.2005.03.014

Risør, M. B. (2009). Illness explanations and medically unexplained symptoms – different idioms for different contexts, *Health, 13*(5), 505-521. https://doi.org/10.1177/1363459308336794

Rhodes, L. (1991). *Emptying beds: The work of an emergency psychiatric unit.* University of California Press.

Rosendal, M., olde Hartman, T. C., Aamland, A., van der Horst, H., Lucassen, P., Budtz-Lilly, A., & Burton, C. (2017). "Medically unexplained" symptoms and symptom disorders in primary care: Prognosis-based recognition and classification, *BMC Family Practice, 18*(1), 18. https://doi.org/10.1186/s12875-017-0592-6

Rosendal, Olesen & Fink (2004). Management of medically unexplained symptoms, *BMJ, 330*(7481), 4-5. https://doi.org/10.1136/bmj.330.7481.4

Rossen, C. B., Buus, N., Stenager, E., & Stenager, E. (2014). The role of assessment packages for diagnostic consultations: A conversation analytic perspective, *Health, 19*(3), 294-317. https://doi.org/10.1177/1363459314545698

Rossen, C. B., Buus, N., Stenager, E., & Stenager, E. (2019). Identity work and illness careers of patients with medically unexplained symptoms, *Health, 23*(5), 551-567. https://doi.org/10.1177/1363459317739440

Roth, S. (2017). *Educational trajectories in cultural worlds: An ethnographic study of multiethnic girls across different levels of schooling.* [Doctoral dissertation, Faculty of Educational Sciences, University of Oslo].

Rouch, J. (1967). *Jaguar* [Motion picture]. France.

Rouch, J. & Morin, E. (1961). *Chronique d'un été.* [Motion picture]. Paris/ Saint Tropez, France.

Salmon, P. (2007). Conflict, collusion or collaboration in consultations about medically unexplained symptoms: The need for a curriculum of medical explanation, *Patient Education and Counseling, 67*(3), 246-254. https://doi.org/10.1016/j.pec.2007.03.008

Salmon, P., Ring, A., Dowrick, C. F., & Humphris, G. M. (2005). What do general practice patients want when they present medically unexplained symptoms, and why do their doctors feel pressurized? *Journal of Psychosomatic Research, 59*(4), 255-260. https://doi.org/10.1016/j.jpsychores.2005.03.004

Salmon, P. Dowrick, C., Ring, A., & Humphris, G. M. (2004). Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners, *British Journal of General Practice, 54*(500), 171-176.

Salmon, P., Peters, S., & Stanley, I. (1999). Patients' perceptions of medical explanations for somatization disorders: *Qualitative analysis. British Medical Journal, 318*(7180), 372–376. https://doi.org/10.1136/bmj.318.7180.372

Schulte, I. E., & Petermann, F. (2011). Somatoform disorders: 30 years of debate about criteria! What about children and adolescents? *Journal of Psychosomatic Research, 70*(3), 218-228. https://doi.org/10.1016/j.jpsychores.2010.08.005

Seabrook, M. (2017). *Exploring "medically unexplained symptoms" with GPs and counselling psychologists: A Foucauldian Discourse Analysis.* [Doctoral dissertation, London Metropolitan University].

Sharpe, M., Mayou, R., & Walker, J. (2006). Bodily symptoms: New approaches to classification, *Journal of Psychosomatic Research, 60*(4), 353-356. https://doi.org/10.1016/j.jpsychores.2006.01.020

Shotter, J. (1993). *Conversational realities: The construction of life through language.* Sage Publications.

Shotter, J., & Billig, M. A. (1998). Bakhtinian psychology: From out of the heads of individuals and into the dialogues between them. In M. M. Bell, & M. Gardiner (Eds.), *Bakhtin and the human sciences: No last words* (pp. 13-29). Sage Publications.

Sletten, M. A. (2011). *Å ha, å delta, å være en av gjengen. Velferd og fattigdom i et ungdomsperspektiv* [To have, to participate and to be one in the group. Welfare and poverty in a youth perspective] [Doctoral dissertation, Institutt for sosiologi og samfunnsgeografi, det samfunnsvitenskapelige fakultet. Universitetet i Oslo.]

Smith, R. C. & Dwamena, F. C. (2007). Classification and diagnosis of patients with medically unexplained symptoms, *Society of General Internal Medicine, 22*(5), 685-691. https://doi.org/10.1007/s11606-006-0067-2

Soler, J. K., & Okkes, I. (2012). Reasons for encounter and symptom diagnoses: a superior description of patients' problems in contrast to medically unexplained symptoms (MUS), *Family Practice*, *29*(3), 272-282. https://doi.org/10.1093/fampra/cmr101

Sommer, D., Samuelsson, I. O., & Hundeide, K. (2010). In search of child perspectives and children's perspectives in contextual-relational developmental psychology. In D. Sommer, I. P. Samuelsson, & K. Hundeide (Eds.), *Child Perspectives and Children's Perspectives in Theory and Practice. International Perspectives on early childhood education and development* (pp. 29-55). Dordrecht.

Sowinska, A. (2018). "I didn't want to be psycho no. 1": Identity struggles in narratives of patients presenting medically unexplained symptoms, *Discourse Studies, 20*(4), 506-522. https://doi.org/10.1177/1461445618754433

Staunæs, D. (2003). Where have all the subjects gone? Bringing together the concepts of intersectionality and subjectification, *Nora: Nordic Journal of Women's Studies, 11*(2), 101-110. https://doi.org/10.1080/08038740310002950

Staunæs, D. (2004). *Køn, etnicitet og skoleliv* [Gender, Ethnicity and Life at School]. Samfundsliteratur.

Staunæs, D. (2005). From culturally avant-garde to sexually promiscuous: Troubling subjectivities and intersections in the social transition from childhood into youth, *Feminism and Psychology, 15*(2), 149-167. https://doi.org/10.1177/0959353505051719

Steinmetz, D., & Tabenkin, H. (2001). The 'difficult patient' as perceived by family physicians, *Family Practice*, *18*(5), 495-500. https://doi.org/10.1093/fampra/18.5.495

Stevens, L. P., Hunter, L., Pendergast, D., Carrington, V., Bahr, N., Kaptizke, C., & Mitchell, J. (2007). Reconceptualizing the possible narratives of adolescence, *The Australian Educational Researcher, 34*(1), 107-127. https://doi.org/10.1007/BF03216860

Stoller, P. (1997). Globalizing method: The problems of doing ethnography in transnational spaces. *Anthropology & Humanism, 22*(2), 181-200. https://doi.org/10.1525/ahu.1997.22.1.81

Stone, L. (2014a). Managing the consultation with patients with medically unexplained symptoms: a grounded theory study of supervisors and registrars in general practice, *BMC Family Practice,* 5(15), 192. https://doi.org/10.1186/s12875-014-0192-7

Stone, L. (2014b). Blame, shame and hopelessness: medically unexplained symptoms and the ‘heartsink’ experience, *Australian Family Physician, 43*(4), 191-196.

Søndergaard, D. M. (1996). *Tegnet på kroppen. Køn: Koder og konstruksjoner blandt unge voksne i akademia*. [The mark on the body. Gender: Codes and constructions among young adults in academia]. Museum Tusculanums forlag, Københavns Universitet.

Søndergaard, D. M. (2002). Poststructural approaches to empirical analysis, *Qualitative Studies in Education, 15*(2), 187-204. https://doi.org/10.1080/09518390110111910

Sønderggard, D. M. (2005). Making sense of gender, age, power and sisciplinary position: Intersecting siscourses in the academy, *Feminism & Psychology, 15*(2), 189-208. https://doi.org/10.1177/0959353505051728

Tavory, I., & Timmermans, S. (2014). *Abductive analysis: Theorizing qualitative research.* University of Chicago Press.

Terrence, J. L-S.,Walsh, M. E., Raczek, A. E., Vuilleumier, C. E., Foley, C., Heberlse, A., … & Dearing, E. (2018). The long-term impact of systemic student support in elementary school: Reducing high school dropout, *AERA Open*, *4*(4). https://doi.org/10.1177/2332858418799085

Thomas, W. I., & Thomas, D. S. (1928). *The child in America.* Knopf.

Thomson, P. (2008). Children and young people: Voices in visual research. In P. Thomson (Ed.) *Doing visual research with children and young people* (pp. 1-19). Routledge.

Thompson, R., Isaac, C. L., & Rowse, G. (2009). What is it like to receive a diagnosis of nonepileptic seizures? *Epilepsy & Behavior, 14*(3), 508–515. https://doi.org/10.1016/j.yebeh.2008.12.014

Thorne, B. (1993). *Gender play: Girls and boys in school.* Rutgers University Press.

Thorstenson-Ed, T. (2007). Children's life paths through preschool and school: Letting youths talk about their own childhood- theoretical and methodological conclusions, *Childhood, 14*(1), 47-66. https://doi.org/10.1177/0907568207072527

Tickle, S. (2017). Ethnographic research with young people: methods and rapport, *Qualitative Research Journal*, *17*(2), 66-76. http://dx.doi.org/10.1108/QRJ-10-2016-0059

Trigwell, P., Hatcher, S., Johnson, M., Stanley, P., & House, A. (1995). "Abnormal" illness behaviour in chronic fatigue syndrome and multiple sclerosis, *BMJ, 311*(6996), 15– https://doi.org/10.1136/bmj.311.6996.15

Tucker, I. (2004). 'Stories' of chronic fatigue syndrome: an exploratory discourse psychological analysis, *Qualitative Research in Psychology, 1*(2), 153-167. https://doi.org/10.1191/1478088704qp008oa

Ulvestad, E. (2008). Chronic fatigue syndrome defies the mind-body-schism of medicine: New perspectives on a multiple realisable developmental systems disorder, *Medicine, Health Care and Philosophy, 11*(3), 285-292. https://doi.org/10.1007/s11019-008-9126-2

Uprichard, E. (2008). Children as 'beings and becomings': Children, childhood and temporality, *Children & Society, 22*(4), 303-313. https://doi.org/10.1111/j.1099-0860.2007.00110.x

Visweswaren, K. (1994). *Fictions of feminist ethnography.* University of Minnesota Press.

Waage, T. (2013). Seeing together: Towards a shared anthropology with visual tools. In T. Kristensen, A. Michelsen, & F. Wiegand, (Eds.), *Transvisuality: The cultural dimension of visuality* (pp. 157-173). Liverpool University Press.

Waage, T. (2016). Confronting realities through reflexive visual storytelling. Ethnographic film courses for teenage girls. In L. Purchez (Ed.), *Quand les professionels de la santé et des sciences sociales se rencontrent.* (pp. 105-115). Éditions des Archives Contemporaines.

Wampold, B. E. (2001). Contextualizing psychotherapy as a healing practice: Culture, history, and methods, *Applied & Preventive Psychology, 10*(2), 69-86. https://doi.org/10.1017/S0962-1849(02)01001-6

Ware, N. C. (1992). Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome, *Medical Anthropology Quarterly, 6*(4), 347-361. https://doi.org/10.1525/maq.1992.6.4.02a00030

Weiler, K. (2001) (Ed.). *Feminist engagements: Reading, resisting and revisioning male theorists in education and cultural studies.* Routledge.

Wetherell, M. (1998). Positioning and interpretative repertories: Conversations analysis and poststructuralism in dialogue, *Discourse and Society, 9*(3), 387-412. https://doi.org/10.1177/0957926598009003005

Werner, A., & Malterud, K. (2003). It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors, *Social Science & Medicine, 57*(8), 1409-1419. https://doi.org/10.1016/s0277-9536(02)00520-8

Werner, A., Isaksen, L. W., & Malterud, K. (2004). 'I am not the kind of woman who complains of everything': Illness stories on self and shame in women with chronic pain, *Social Science & Medicine*, *59*(5), 1035–1045. https://doi.org/10.1016/j.socscimed.2003.12.001

Wessely, S., Nimnuan, C., & Sharpe, M. (1999). Functional somatic syndromes: One or many? *The Lancet, 354*(9182), 936–939. https://doi.org/10.1016/S0140-6736(98)08320-2

Whitehead, L. (2006). Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study, *International Journal of Nursing Studies, 43*(8), 1023–31. https://doi.org/10.1016/j.ijnurstu.2006.01.003

Williams, G. (1984). The genesis of chronic illness: narrative-reconstruction, *Sociology of Health & Illness*, *6*(2), 175-200. https://doi.org/10.1111/1467-9566.ep10778250

William, G. (1993). Chronic illness and the pursuit of virtue in everyday life, in A. Radley (Ed.), *Worlds of illness: Biographical and cultural perspectives on health and disease* (pp. 92-108). Routledge.

Willig, C. (2001). *Introducing qualitative research in psychology. Adventures in theory and method.* Open University Press.

Willis, P. E. (1977). *Learning to labor: How working class kids get working class jobs.* Colombia University Press.

Wilson, A. C., Moss, A., Palermo, T. M., & Fales, J. L. (2014). Parent pain and catastrophizing are associated with pain, somatic symptoms, and pain-related disability among early adolescents, *Journal of Pediatric Psychology, 39*(4), 418–426. https://doi.org/10.1093/jpepsy/jst094

Wileman, L., May, C., & Chew-Graham, C, A. (2002). Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study, *Family Practice*, *19*(2), 178-182. https://doi.org/10.1093/fampra/19.2.178

Winger, A. (2015). *Pain and health related quality of life in adolescents with chronic fatigue syndrome: a mixed method study* [Doctoral dissertation, Institute of Clinical Medicine, Faculty of Medicine, University of Oslo].

Winger, A., Ekseth, M., Wyller, V. B., & Helseth, S. (2013). ‘Sometimes it feels as if the world goes on without me’: adolescents' experiences of living with chronic fatigue syndrome, *Journal of Clinical Nursing, 23*(17-18), 2649-2657. https://doi.org/10.1111/jocn.12522

Wittgenstein, L. (1953). *Philosophical Investigations.* Blackwell.

Woivalin, T., Krantz, G., Mantyranta, T., & Ringsberg, K. C. (2004). Medically unexplained symptoms: perceptions of physicians in primary health care, *Family Practice, 21*(2), 199-203. https://doi.org/10.1093/fampra/cmh217

Wolcott, H. F. (1999). *Ethnography: A way of seeing.* AltaMira Press.

Wortman, M. S. H., Lokkerbol, J., van der Wouden, J. C., Visser, B., van der Horst, H. E., & olde Hartman, T. C. (2018). Cost-effectiveness of interventions for medically unexplained symptoms: A systematic review, *PLoS ONE, 13*(10): e0205278. https://doi.org/10.1371/journal.pone.0205278

Wright, L. J., Afari, N., & Zautra, A. (2009). The illness uncertainty concept: A review, *Psychiatric Management of Pain*, *13*(2), 133–138. https://doi.org/10.1007/s11916-009-0023-z

Wyn, J. & White, R. (1997). *Rethinking youth.* Sage Publications.

Wysenbeek, A.J., Shapira, Y., & Leibovici, L. (1991). Primary fibromyalgia and the chronic fatigue syndrome, *Rheumatology International, 10*(1), 227–229. https://doi.org/10.1007/BF02274883

Youdell, D. (2005). Sex – gender – sexuality: How sex, gender and sexuality constellations are constituted in secondary schools, *Gender and Education, 17*(3), 249-270. https://doi.org/10.1080/09540250500145148

Youdell, D. (2006a). Diversity, inequality, and a post-structural politics for education, *Discourse: Studies in the Cultural Politics of Education, 27*(1), 33-42. https://doi.org/10.1080/01596300500510252

Youdell, D. (2006b). Subjectivation and performative politics. Butler thinking Althusser and Foucault: Intelligibility, agency and the race-nationed-religioned subjects of education, *British Journal of Sociology and Education, 27*(4), 511-528. www.jstor.org/stable/30036159

Zuckerman, B., Stevenson, J. & Bailey, V. (1987). Stomachaches and headaches in a community sample of preschool children, *Pediatrics, 79*(5), 677-682. https://doi.org/10.1111/j.1469-7610.1988.tb00761.x

Paper I

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‘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 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 medically

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unexplained symptoms, 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, that is, 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, medically unexplained symptoms, 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) 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' (pp. 12–13). 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 (Biehl et al., 2007).

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 (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 (Risør, 2010).

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 has, however, 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 dialogic–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' (Mishler, 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 consist 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 (Haavind, 2007, 2014).

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, for example, 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 researchers 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

Derailment I

We start our co-constructed narrative by presenting Peter's 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 emplotment 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.

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).

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).

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 him 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).

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).

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 emplotment by positioned subjects (Frank, 2016; Mattingly, 1994, 2013, 2014)

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.

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 a 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).

Making sense of embodied experience 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 reinterpreted 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.

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 a duration of two hours 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 reinterpreted 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.

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 judgements and interpretations of the challenges he was experiencing.

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 (Arendt, 1958:311). 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 reinterpretation 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. First, 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 emphatic response in his audience. Second, 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, to belong and to 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 reconstruction (Williams, 1984), both outside and within our encounters, Peter's disruption was reinterpreted 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 emplotment, 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, that is, 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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References

Arendt H (1958) *The Human Condition*. Chicago, IL: The University of Chicago Press.

Bakhtin MM (1981) *The Dialogic Imagination: Four Essays*. Austin, TX: University of Texas Press.

Bell SE (2000) Experiencing illness in/and narrative. In: Bird CE, Conrad P and Fremons AM (eds) *Handbook of Medical Sociology*. 5th ed. Upper Saddle River, NJ: Prentice Hall, pp. 184–199.

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

Binder PE, Holgersen H and Nielsen GH (2008) Establishing a bond that works: A qualitative study of how psychotherapists make contact with adolescent patients. *European Journal of Psychotherapy and Counselling* 10: 55–69.

Bourdieu P (1977) *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.

Bruner J (1991) The narrative construction of reality. *Critical Inquiry* 18: 1–20.

Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health & Illness* 4: 168–182.

Bury M (2001) Illness narratives: Fact or fiction? *Sociology of Health & Illness* 23(3): 263–285.

Carlson ED, Engebretson J and Chamberlain RM (2006) Photovoice as a social process of critical consciousness. *Qualitative Health Research* 16: 836–852.

Chalfen R and Rich M (2007) Combining the applied, the visual and the medical. Patients teaching physicians with visual narratives. In: Pink S (ed.) *Visual Interventions*. Oxford: Berghahn, pp. 53–70.

Chenhall R, Davison B, Fitz J, et al. (2013) Engaging youth in sexual health research: Refining a ‘youth friendly’ method in the Northern Territory, Australia. *Visual Anthropology Review* 29(2): 123–132.

Conrad P and Barker KK (2010) The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior* 51: S67–S79.

Cousins M (2011) *The Story of Film: An Odyssey* (TV Mini-Series documentary, 15 episodes). England: Hopscotch films.

Crossley ML (2000) Narrative psychology, trauma and the study of self/identity. *Theory & Psychology* 10(4): 527–546.

Csordas TJ (1990) Embodiment as a paradigm for anthropology. *Ethos* 18(1): 5–47.

Csordas TJ (ed.) (1994) *Embodiment and Experience: The Existential Ground of Culture and Self (Cambridge studies in medical anthropology)*. Cambridge: Cambridge University Press.

Davidson L and Chan KKS (2014) Common factors: Evidence-based practice and recovery. *Psychiatric Services* 65(5): 675–677.

Davies B and Harré R (1990) Positioning: The discursive production of selves. *Journal for the Theory of Social Behavior* 20(1): 43–63.

Desjarlais R and Throop J (2011) Phenomenological approaches in anthropology. *Annual Review of Anthropology* 40: 87–102.

Eminson DM (2007) Medically unexplained symptoms in children and adolescents. *Clinical Psychology Review* 27(7): 855–871.

Farmer A, Fowler T, Scourfield J, et al. (2004) Prevalence of chronic disabling fatigue in children and adolescents. *British Journal of Psychiatry* 184: 477–481.

Frank AW (1995) *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, IL: The University of Chicago Press.

Frank AW (2005) What is dialogical research, and why should we do it? *Qualitative Health Research* 15(7): 964–974.

Frank AW (2010) *Letting Stories Breathe: A Socio-Narratology*. Chicago, IL: The University of Chicago Press.

Frank AW (2016) From sick role to narrative subject: An analytic memoir. *Health* 20(1): 9–21.

Furnman L (1990) Video therapy: An alternative for the treatment of adolescents. *Arts in Psychotherapy* 17: 165–169.

Gamlin JB (2011) My eyes are red from looking and looking: Mexican working children’s perspectives of how tobacco labour affects their bodies. *Vulnerable Children and Youth Studies* 6(4): 339–345.

Good BJ (1994) *Medicine, Rationality and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.

Greco M (1993) Psychosomatic subjects and the 'duty to be well': Personal agency within medical rationality. *Economy and Society* 22(3): 357–372.

Guillemin M and Drew D (2010) Questions of process in participant-generated visual methodologies. *Visual Studies* 25(2): 175–188.

Haavind H (2007) Accountability in persons: What is in the telling to others about yourself? In: Staunæs D and Kofoed J (eds) *Magtballader* [Plays in Power]. Copenhagen: Danmarks Pædagogiske Universitets Forlag, pp. 159–178.

Haavind H (2014) 'Who does he think he is?' Making new friends and leaving others behind – On the path from childhood to youth. In: Schott RM and Søndergaard DM (eds) *School Bullying: New Theories in Context*. Cambridge: Cambridge University Press, pp. 129–158.

Hareide L, Finset A and Wyller VB (2011) Chronic fatigue syndrome: A qualitative investigation of young patient's beliefs and coping strategies. *Disability and Rehabilitation* 33: 22–23.

Holquist M (2002) *Dialogism: Bakhtin and His World* (New Accents). 2nd ed. London: Routledge.

Hydén LC (1997) Illness and narrative. *Sociology of Health & Illness* 19(1): 48–69.

Jackson M (2002) *The Politics of Storytelling: Violence, Transgression and Intersubjectivity*. Copenhagen: Museum Tusculanum Press, University of Copenhagen.

Johnson JL and Alderson KG (2008) Therapeutic filmmaking: An exploratory pilot study. *The Arts in Psychotherapy* 35: 11–19.

Jutel A and Nettleton S (2011) Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine* 73: 793–800.

Karterud HN, Haavet OR and Risør MB (2016) Social participation in young people with nonepileptic seizures (NES): A qualitative study of managing legitimacy in everyday life. *Epilepsy & Behavior* 57: 23–28.

Kirmayer LJ (2000) Broken narratives: Clinical encounters and the poetics of illness experience. In: Mattingly C and Garro L (eds) *Narrative and the Cultural Construction of Illness and Healing*. Berkeley, CA: University of California Press, pp. 153–180.

Kirmayer LJ (2008) Empathy and alterity in cultural psychiatry. *Ethos* 364: 457–474.

Kleinman A (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books.

Kornelsen J, Atkins C, Brownell K, et al. (2016) The meaning of patient experiences of medically unexplained physical symptoms. *Qualitative Health Research* 26(3): 367–376.

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

McWilliams A, Reilly C, McFarlane FA, et al. (2016) Nonepileptic seizures in the pediatric population: A qualitative study of patient and family experiences. *Epilepsy & Behavior* 59: 128–136.

Mattingly C (1994) The concept of therapeutic 'emplotment'. *Social Science & Medicine* 38(6): 811–822.

Mattingly C (2013) Moral selves and moral scenes: Narrative experiments in everyday life. *Ethnos* 78: 301–327.

Mattingly C (2014) *Moral Laboratories: Family Peril and the Struggle for a Good Life*. Oakland, CA: University of California Press.

Merleau-Ponty M (1962) *Phenomenology of Perception*. London: Routledge.

Mishler EG (1995) Models of narrative analysis: A typology. *Journal of Narrative & Life History* 5(2): 77–123.

Moulin V, Akre C, Rodondi PY, et al. (2015a) 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.

Moulin V, Akre C, Rodondi PY, et al. (2015b) A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 2: How is healthcare perceived? *Journal of Adolescence* 45: 317–326.

Nettleton S (2005) ‘I just want permission to be ill’: Towards a sociology of medically unexplained symptoms. *Social Science & Medicine* 62(5): 1167–1178.

Nettleton S, Watt I, O’Malley L, et al. (2005) Understanding the narratives of people who live with medically unexplained illness. *Patient Education and Counselling* 56: 205–210.

Ogden J, Branson R, Bryett A, et al. (2003) What’s in a name? An experimental study of patients’ views of the impact and function of a diagnosis. *Family Practice* 20: 248–253.

Pink S (2006) *The Future of Visual Anthropology – Engaging the Senses*. London; New York: Routledge.

Pink S (2007) *Doing Visual Ethnography*. London: SAGE.

Riessman CK (2003) Performing identities in illness narrative: Masculinity and multiple sclerosis. *Qualitative Research* 3(1): 5–33.

Riessman CK (2008) *Narrative Methods for the Human Sciences*. Los Angeles, CA: SAGE.

Risør MB (2009) Illness explanations and medically unexplained symptoms – Different idioms for different contexts. *Health* 13(5): 505–521.

Risør MB (2010) Healing and recovery as a social process among patients with medically unexplained symptoms (MUS). In: Fainzang S, Hem HE and Risør MB (eds) *The Taste for Knowledge: Medical Anthropology Facing Medical Realities*. Aarhus: Aarhus University Press, pp. 133–149.

Rosendal M, Olesen F and Fink P (eds) (2005) Management of medically unexplained symptoms. *British Medical Journal* 330: 4–5.

Salmon P, Dowrick C, Ring A, et al. (2004) Voiced but unheard agendas: Qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. *British Journal of General Practice* 54: 171–176.

Shotter J and Billig MA (1998) Bakhtinian psychology: From out of the heads of individuals and into the dialogues between them. In: Bell MM and Gardiner M (eds) *Bakhtin and the Human Sciences: No Last Words*. Thousand Oaks, CA: SAGE, pp. 13–29.

Stoller P (1997) *Sensuous Scholarship*. Philadelphia, PA: University of Pennsylvania Press.

Undeland M and Malterud K (2007) The fibromyalgia diagnosis – Hardly helpful for the patients? *Scandinavian Journal of Primary Health Care* 25(4): 250–255.

Waage T (2013) Seeing together: Towards a shared anthropology with visual tools. In: Kristensen T, Michelsen A and Wiegand F (eds) *Transvisuality: The Cultural Dimension of Visuality*. Liverpool: Liverpool University Press, pp. 157–173.

Waage T (2016) Confronting realities through reflexive visual storytelling: Ethnographic film courses for teenage girls. In: Purchez L (ed.) *Quand les professionels de la santé et des sciences sociales se rencontrent*. Paris: Éditions des archives contemporaines, pp. 105–115.

Wampold BE (2001) Contextualizing psychotherapy as a healing practice: Culture, history, and methods. *Applied and Preventive Psychology* 10: 69–86.

Whyte SR (2005) Uncertain undertakings: Practicing health care in the subjunctive mood. In: Steffen V, Jenkins J and Jessen H (eds) *Managing Uncertainty, Ethnographic Studies of Illness, Risk and the Struggle for Control*. Copenhagen: Museum Tusculanum Press, pp. 245–264.

Williams G (1984) The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness* 6(2): 175–200.

Woodward RC, Broom DH and Legge DG (1995) Diagnosis in chronic illness: Disabling or enabling – The case of chronic fatigue syndrome. *Journal of the Royal Society of Medicine* 88: 325–329.

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RESEARCH **Open Access**

Epistemological and methodological paradoxes: secondary care specialists and their challenges working with adolescents with medically unexplained symptoms

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Abstract

Background: Early adolescence is considered a critical period for the development of chronic and recurrent medically unexplained symptoms (MUS), and referrals and system-initiated patient trajectories often lead to an excess of examinations and hospitalizations in the cross-section between mental and somatic specialist care for this group of patients. Dimensions of the relationship and communication between clinician and patient are shown in primary care studies to be decisive for subsequent illness pathways, often creating adverse effects, but knowledge on clinical communication in specialist care is still scarce.

Methods: This study explores communicative challenges specific to clinical encounters between health professionals and adolescent patients in specialist care, as presented through interviews and focus group data with highly experienced specialists working in adolescent and child services at a Norwegian university hospital.

Results: The results are presented in a conceptual model describing the epistemological and methodological paradoxes inherent in the clinical uncertainty of MUS. Within these paradoxes, the professionals try to solve the dilemmas by being creative in their communication strategies; applying metaphors and other rhetorical devices to explain complex ideas; creating clinical prototypes as a way to explain symptoms and guide them in clinical action; relying on principles from patient-centered care involving empathy; and trying to balance expertise and humility.

Conclusion: The challenges in communication arise as a result of opposing discourses on biomedicine, family, health and adolescence that create dilemmas in everyday clinical work. By moving away from a positivist and biomedical framework towards an interpretive paradigm, where culturally derived and historically situated interpretations are used to understand the social life-world of the patient, one can create a more humane health service in accordance with ideals of patient-centered care.

Keywords: Adolescents, Medically unexplained symptoms, Communication, Clinical encounters, Specialist care

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Background

Medically unexplained symptoms (MUS) are those for which a treating physician or other healthcare providers have found no medical cause, or whose cause remains contested below [1]. Symptoms that have no definite medical diagnosis are common in all areas of primary care as well as in specialty medicine [2]. Surveys in primary care have reported prevalence rates of medically unexplained symptoms varying from 15 to 30% of consultations [3–6], and in specialist care the estimate has been as high as 52% [7]. In children and adolescents 10% to 30% report chronic somatic complaints [8–10], and these symptoms have been found to cause substantial impairment on multiple domains in everyday life, often leading to huge personal and socioeconomic costs [7, 11]. Common symptoms include fatigue, musculoskeletal pain, abdominal pain, gastrointestinal symptoms and dizziness, and typical diagnoses that are included in the category of MUS are chronic fatigue syndrome [8], fibromyalgia [12] and irritable bowel syndrome [9]. The symptoms are seen in all age groups, but early adolescence is considered a critical period for the development of chronic and recurrent somatic symptoms [13]. Most research on MUS and its inherent problems has concentrated on adults, but because symptoms often start in childhood and later develop into chronic somatization, there is growing attention to adolescents and children [14–17]. In studies on adults, it has been shown that the encounter between patients and health professionals is decisive for subsequent illness aspects, often creating adverse, somatizing effects [18–20]. Somatic symptoms and syndromes are not limited to individual bodily sensations, but are processed and developed in relational clinical contacts and health encounters, e.g. by the physician's inclination to pursue somatic explanations and interventions [20, 21] or the patient's need for an acknowledged diagnosis [22, 23]. Various dimensions of the relationship between health care provider and patient increase the risk of 'dysfunctional encounters' and iatrogenic harm. For example, studies have found that patients often have difficulties explaining the complexity of their complaints and being heard [3, 24–26], and that physicians experience difficulties in the communication and the relation with these patients and lack clear and consistent management strategies and clinical approaches [27–30]. Diagnostics have been shown to be dependent upon the medical specialty that is consulted [31], and referrals and system-initiated patient trajectories often lead to an excess of examinations and hospitalizations [32]. The health care provider's attitudes to patients with MUS have been demonstrated to play an important role [20, 33, 34], and communication problems and challenges seem to arise when patient expectations and explanatory models of disease are incompatible [3, 24, 35]. Hence, a series of challenges and negative prospects have been shown to follow from encounters with patients with MUS in primary care, but knowledge on clinical communication in specialist care is still scarce.

Sociocultural dimensions in the understanding of MUS

From a positivist viewpoint, diseases are considered as observable, steady and true entities, with epistemological assumptions of universal, objective facts to be identified and predicted by standardized, deductive approaches and research methods where controlled observations yield objective certainty [36]. In line with this way of thinking, the paradigm of evidence-based medicine is widely accepted as a way to support practitioners in their decision-making in order to eliminate the use of ineffective, inappropriate, too expensive and potentially dangerous practices by finding, appraising and applying scientific evidence to the management of healthcare [37].

Within a social constructionist framework, by contrast, medicine is understood as a cultural system: a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions [38]. Clinical explanatory models provide a conceptual framework that allows clinician and patient to make sense of suffering and point towards possible solutions; the clinician therefore aims not only to convey objective knowledge of truth and objective certainty, but also to emotionally engage, support, motivate, change and empower the patient [39]. The language of medicine is thus not a mirror of the empirical world, but rather shaped by cultural values and different modes of knowledge, including empathetic, emotional and contextual knowledge [40]. The biopsychosocial model is one explanatory model where illness is understood as consisting of a dynamically intertwined and hierarchical system of sociocultural, mental and physiological components [41]. This model is often foregrounded as useful for the management of MUS, and is suggested as a key to *patient-centered care,* a framework that puts an emphasis on the therapeutic alliance, the personal experience of the patient and egalitarian doctor-patient relationships [42]. Within this framework, the aim is to reorient clinical practice around the understanding of and engagement with the patient as a person, from which follows systematic attention to the social and cultural world in which the patient lives [43]. By extension, this represents a movement away from *"one-person medicine"*, where the application and therapeutic techniques are a fundamentally objective issue, to *"two-person medicine"*, in which both the doctor's and the patient's subjectivity are an integral aspect of any satisfactory clinical descriptions [44]. This way of thinking has been influential in parts of specialist health care in Norway, mental health and physical medicine being typical examples.

MUS can be said to challenge the evidence-based approaches of biomedicine. In this study, our point of departure is that medical science is not only a natural science, but that it also, in its social and moral concerns, integrates elements of the human sciences [45]. Based on challenges in the intersection of evidence-based medicine and socio-cultural dimensions of clinical practice, we will explore communicative challenges specific to health encounters with adolescents with MUS, by taking a closer look at the explanatory models and rationales for clinical action that highly experienced and engaged professionals construct in order to overcome clinical uncertainty.

Methods

Design

The data consists of one focus group discussion with six participants, and ten individual interviews. The focus group discussion was held before the individual interviews, with the aim of familiarization with the field. The individual interviews were conducted later to obtain richer and more experience-near descriptions, and to make sure different views were represented in the data. Both individual interviews and the focus group discussion represented an interactional context for storytelling [46]. Stories are socially situated actions that are identity-giving [47], drawing on overarching cultural frameworks that include notions about ontology (what the world is made up of), epistemology (how knowledge can be acquired and verified) and morality (what is the right way to live one's life). Drawing on strands from narrative theory, we look at the narratives constructed in the context of the interview setting as performative events, focusing on stories as collective or collaborative productions that not only take place under particular social conditions, but are social actions that construct, legitimate and maintain social realities [48].

Recruitment and sample

We recruited highly experienced and engaged professionals to explore their experiences with and views on communicative challenges in clinical encounters with adolescents with MUS. To obtain sufficient variation of descriptions, professionals with different occupational backgrounds were purposefully selected. Participants were recruited from different departments in the adolescent and child services at a Norwegian university hospital, i.e. units specializing in child psychiatry or mental health, pediatric pain, chronic fatigue, pediatric rheumatology and adolescent medicine. Initial contact was established with leaders of the different departments, followed by several scheduled meetings to give information about the study to possible participants. Those interested in participating wrote down their names and contact information, and further arrangements were made through e-mail correspondence and by phone. All participants encountered patients with MUS in their practices, and had +5 years (average 13 years) of experience of treatment and/or assessment of patients between the ages of 12–23. The sample consisted of three men and 13 women; six physicians, six psychologists, one nurse, two physiotherapists, and one occupational therapist. Authors IPHG and KEK conducted the individual interviews, while authors SVØ and MBR led the focus group discussion.

Data collection

The focus group discussion lasted for 90 min and took place in a scheduled meeting at the research leader's workplace. Prior to the meeting, the participants were given information on the study and encouraged to recall memories of particular clinical encounters with young MUS patients that they had perceived as challenging or illuminating. Constructed clinical cases were used as an elicitation technique to spark the discussion and aid the recollection of events and experiences by the participants, and a discussion guide was utilized for follow-up questions and clarifications. Questions were concentrated on thoughts and perspectives on challenges in communication, difficulties regarding cooperation between clinicians at different levels of organizations, and barriers in individual clinical encounters between practitioner and patient. Solutions and future possibilities were also discussed. An observer took notes, summarized the overall impression at the end of the interview, and sought clarity to correct potential misunderstandings.

The individual interviews lasted between 45 and 90 min, and took place at the participants' workplaces to fit into their schedules. Interviews followed an interview guide where questions were formulated according to four research questions: (1) What is the general understanding of adolescents with MUS among health professionals working in specialist care? (2) How do they describe their experiences of working with these patients? (3) What are the main challenges that they encounter in their work? (4) How do they try to overcome these challenges?

All data were audio-recorded, anonymized and transcribed verbatim.

Analysis

Our research team has a background from clinical psychology and medical anthropology, and had previous experience of the ambiguity and uncertainty inherent in the process of diagnostics and treatment of adolescent patients presenting with MUS, both in the capacity as researchers and as clinicians. We were therefore interested in how highly experienced professionals try to solve the dilemma of clinical uncertainty and how they describe and try to overcome communication challenges.

Initial analysis was informed by general principles for thematic analysis, following the six-phased process of coding as formulated by Braun and Clarke [49]. The analysis was influenced by both inductive and deductive reasoning, being for example based on both primary material (i.e. interview transcripts) and secondary sources (i.e. a review of the literature). The process started with intense familiarization with the transcripts, followed by initial code generation, categorization of data into tentative themes, continuous reviewing of the themes before theme definition, and finally a narrative reporting of themes across cases (see Table 1 for an illustration of the analytical process and the generation of themes, subthemes, categories and subcategories).

The analysis was conducted with an explorative approach, moving back and forth between the different stages. Regular meetings between the first author and the other members of the research team provided a forum to discuss and explore data collection procedures, analytical approaches, and to develop emergent ideas and interpretations.

During this process, we became interested in performative actions as well as structural elements, and explored in greater detail how the accounts were produced interactively and dialogically and hence performed narratively [46]. In this process, we also started to look for less obvious voices, hidden or taken-for-granted discourses, paradoxes, gaps and indeterminate sections that related to shared discursive practices in social, cultural and theoretical contexts [48]. By engaging in this type of re-contextualization with the research material, a larger narrative emerged about clinical uncertainty in the context of health systems trying to integrate ideals from a biomedical and positivist framework of professional certainty and evidence-based medicine with more recent ideals from patient-centered care.

Results

In the following presentation of the results, we will provide a conceptual model of how the professionals responded to dilemmas in their everyday clinical practice, and how this translated to communicative challenges in individual encounters with the patients. The model consists of two different but connected themes: the epistemological paradox and the methodological paradox. The epistemological paradox describes two interrelated problems that both concern meaning making and interpretation: (1) finding a common language in trying to explain the unexplained, and (2) the creation of clinical prototypes and explanatory models. The methodological paradox describes the problem of combining expertise and uncertainty, and explores the devices that the professionals applied to resolve the crisis and uncertainty surrounding MUS, as represented through the two subthemes: (1) empathy and the dilemma of clinical uncertainty, and (2) the dilemma of the uncertain expert.

The epistemological paradox: Explaining the unexplained

Language and the dilemma of explaining the unexplained

> *"What we're supposed to do is examine the patients, then diagnose, and then give treatment based on the diagnosis to make sure they receive the best treatment. And here you have patients that you can't put in any category or boxes, and you don't understand it yourself, and the patient most certainly doesn't understand it."*

As illustrated by the quotation above, the translation of lived experience into clusters of potentially applicable symptoms and diagnostic categories as a basis for clinical action was not a straightforward process for patients with MUS. The problem of MUS was to find a common language that could help explain and frame the puzzling symptoms. As one of the professionals explained:

> *"The challenge in our work together is the language. Do we understand each other?"*

Without a shared language and understanding of the problems, the professionals' tasks became unclear and ambiguous, creating obstacles in the clinical encounter. Creating order in the disordered by naming the problems, finding explanations and agreeing on tasks and goals was an important requisite for the patient-professional dyad to function, e.g. by creating explanatory models, guidelines and frameworks that despite ambiguities could ascribe some sort of meaning to the symptoms, and rationalize a particular course of clinical action.

Many of the professionals distanced themselves from the biomedical model of disease as an explanatory model. They perceived it as too narrow in its approach and incapable of responding to the many challenges that they were facing in their everyday clinical practice. As one of the physiotherapists explained:

> *"The biomedical dualistic approach is in stark contrast to the more holistic view that my discipline is based on. I mean phenomenology... Seeing connections... Understanding the human being in its bodily expressions, as something more than just a machine that comes in with a problem."*

Table 1 Illustration of the analytical process with examples of themes and categories developed during analysis

Themes	Subthemes	Categories	Subcategories	Quotes
A First topic: the epistemological paradox: explaining the unexplained				
A1 Language and the dilemma of explaining the unexplained	The inherent problem in communicating inner and embodied states	Alternative approaches to communication	Using metaphors Using visual tools Connecting to the senses Play Sharing experiences	*"We have tried to close in on the problems by using visual methods. (…) For example, they have taken with them a picture they have drawn or a photo, and we have looked at it together. Or we have watched film clips that sort of captures some of the things they struggle with."*
	The problem of diagnosis	Nomenclature Taxonomy Typification	Pragmatics Interpretation as negotiation	*"It's not so easy to create a sense of coherence and understanding that maybe I have, and make it meaningful to them."(…) "A big challenge is to create that basic mutual understanding of what this is about"*
A2 Creating explanatory models and clinical prototypes	Clinical prototypes	The "good girl"	Personality Lack of assertiveness Perfectionism Performance-oriented Pressure to achieve Workload	*"Some of them are very focused on performance and accomplishments, trying to be perfect and live up to some sort of ideal."*
		The "trauma victim"	Negative life events Bullying Abuse Divorce Poverty Neglect	*"A lot of these patients have traumatic experiences."*
	Explanatory models	(Bio)psychosocial model Vulnerability-stress model	Psychological factors Societal factors Acute or chronic stress	*"I've been wondering about the school system that we have today, that there is more pressure on young people… maybe in general in our society… that we have so much to do and are so busy. I think that I have seen an increase in tired and exhausted kids the last few years."*

Table 1 (continued)

Themes	Subthemes	Categories	Subcategories	Quotes
B Second topic: The methodological paradox: the uncertain expert				
B1 Empathy and the dilemma of clinical uncertainty	Focusing on emotions and relational aspects	Creating a good working alliance Building on principles from patient-centred care	Believing in the patient´s story Building trust and acceptance in clinical encounters Working towards a common goal	*"You have to believe that this is a person who really is in pain. They are really suffering. You have to believe that to create an alliance and really help them."*
	Creating an in-group identity of engaged professionalism	Identity markers Performative aspects	Advocating patient interests Distancing themselves from biomedical parts of the health system Connecting to like-minded colleagues	*"It's very frustrating when your referrals are declined because the person doesn't fit the diagnostic criteria, when you know that this is a person that is suffering and could have been helped if they had been given the opportunity. That is one of our biggest frustrations. Diagnostics and the systems that we are forced into."*
B2 The dilemma of the uncertain expert	Balancing opposing roles and tasks	Opposing roles Opposing tasks	The gate-keeper The expert The caring and nurturing helper The humble servant	*"Sometimes you feel you have some sort of diamond, that they so desperately want. And then it's sort of up to the clinician to give an approximate evaluation of whether they should have it or not. Some of them can get very disappointed, cry or make a scene if they don't receive the diagnosis they had expected."*
	Relying on knowledge and experience	Tacit knowledge Years of experience Clinical intuition	Knowing their own limitations Tried techniques for themselves Having a "tool-box" of interventions and techniques Having seen several patients with similar problems Being able to seek support from experienced colleagues Being able to share responsibility with patients when appropriate	*"I'm old in the game; I have a lot of experience to keep me floated. I don't think you should start in this job as a young psychologist or doctor. That wouldn't work."*

The professionals distanced themselves from the biomedical metaphor of the body-as-machine, and used instead other metaphors to explain the patients' symptoms and their work. Their work was described as *"a journey"*, *"detective work"* or *"investigative journalism"*. A psychologist described how symptoms could be traced back to difficult life experiences, the body being a container for memories, leaving marks on the body:

> *"I think that burdens in life, difficult experiences, trauma, everything... The body remembers and everything is contained in the body. (...) Life experiences and the life you have led leave their marks on the body, as a pain, a stiffness, as something indefinable, as a discomfort."*

The professionals' understanding of symptoms was that they were metaphors for something else, the meaning of which could be uncovered in the clinical encounter. In this way, they did not see the symptoms as inexplicable, despite being medically unexplained.

To communicate their interpretations and explanations, however, was not an easy process, and several of them pointed out the limitations in the use of language for understanding and explaining the illness experience of their patients. They described how they had to be creative in the clinical encounters and in their communication strategies, for example by using visual tools like video or photographs. Many used drawings or figures to symbolize complex ideas, and others relied on metaphors as a rhetorical device.

A physiotherapist told a story about a patient with pelvic pain that she had worked with for several years; together they had created a metaphor for the patient's body as *"a dead city"*. As their work progressed and the pain decreased, the city gradually became populated and full of life. Another professional told a story about a young boy with intense, debilitating headaches; here, they together came up with the metaphor for the symptoms as *"a wild party"*. This had enabled them to talk about what a wild party meant for the boy, and eventually his father's alcohol problems, his difficult relationship with his father's new girlfriend, and his parents' divorce.

The professionals thus described being concerned with meaning making and interpretation: understanding symptoms as signs that needed to be interpreted with their patients, not as objective facts. Despite this, they also presented the process of interpretation as a negotiation process, in which they had to convince the patients to agree to their explanations so that consensus could be reached. In the focus group, two of the professionals discussed difficulties in the negotiation of meaning and understanding of symptoms:

> *Professional 1:"You see it up front when you read the referrals... You know, you see at once what this is about. We sort of recognize the patients, we've seen it before." (...) Professional 2: "You can sometimes anticipate that it will get difficult to create mutual understanding, it will be almost impossible to get that far."*

In the example above, the two professionals seemed to posit the view that there existed an objective truth of causality behind their patients' symptoms which they, based on their experience and expertise, could know up-front. In this lies the epistemological stance that one conception of reality is more real than another, and that one can uncover the objective meaning behind any given symptom independent of context. The biopsychosocial model has been criticized for precisely this paradox, i.e. that it is still caught in the separate systems view of Cartesian dualism that places different value on different types of explanations, concerning itself with finding the "right" or the "wrong" causes of patients' suffering, and thereby excluding the patient's illness experience [50].

Clinical prototypes and explanatory models

Many of the professionals claimed they were working within a holistic framework, and that they relied on the biopsychosocial model in their understanding of illness. However, despite their intentions, the analysis revealed that the professionals' accounts mostly consisted of psychological and social explanations. They saw the symptoms as physical, but explained their causes in terms of psychological trauma, stress or personality variables, such as perfectionism or lack of assertiveness. One psychologist explained how she interpreted the symptoms:

> *"I'm thinking about 'good girls', hard-working, living up to others' expectations. I actually detest that expression 'good girls', but still my impression of these patients is that they're often very concerned with achievement, want to succeed at everything, doing everything perfectly and trying to live up to some sort of ideal."*

The quotation above illustrates how the professionals on the one hand were often wary of psychologizing patients' problems, disliking terms like *"good girls"*, referring to the frustrations many patients experienced in the health system with assumptions of problems being *"all in their head"* when no direct physical cause could be found. Several of the professionals pointed out how mental health problems had potential stigmatizing effects, and how psychological explanations seemed to have lower status in the health system. On the other hand, they too relied on psychosocial explanations when describing clinical cases.

Two prototypical patients were presented in which the causal explanations for illness, and with them ideas of responsibility and morality, were very different. In the first prototypical category, as demonstrated in the quotation above, the patients were presented as *"good girls"*, typically excelling academically and/or in after-school activities and placing high value on personal achievement and success. The explanations for their symptoms were based on a vulnerability-stress model, one in which the patients had put too much pressure on themselves over time, failing to find ways to relax. Here the professionals' tasks were to make the patient aware of her perfectionist tendencies, and teach her strategies for self-care. By placing the patients within an identity-bearing diagnostic category where personal characteristics were interwoven with the symptoms, the responsibility both for the symptoms development and for the treatment was transferred to the patient. By appealing to the patients' identity as a *"good girl"*, the professional drew their attention to their moral responsibility for taking care of one's health and making an effort to get better [cf. 45]. This placing of responsibility on the patient can be said to be in line with patient-centered care, in which the ideal is to share power and responsibility with the patients, but at the same time, it can be interpreted as serving to legitimize the professional role by lifting the burden of prognostic uncertainty.

By contrast, the other prototypical patient was presented as the *"trauma victim"*. Here the explanation for the symptoms was external factors, e.g. traumatic experiences outside of the patients' control. The responsibility for the symptoms was placed, not on the patients, but on some unknown external factor, and typically, the family became a suspect in the explanatory model. One of the psychologists expressed it like this:

> *"It's hard to ignore the idea that their family background plays an important part. What kind of relationship they have with their parents, how much support they've experienced. (...)"*

There were two ways that the family could be assigned responsibility for the patients' problems: either the primary cause as the scene in which traumatic relational events had occurred, or as a secondary cause, where the family's responses to the symptoms or the family dynamics aggravated the adolescents' condition. One of the physicians described her frustrations at working with families like this:

> *"One period we talked a lot about pathological mothers [laughing]. Where the parents have a negative influence. They become very protective like: 'We cannot expect her to walk outside for five minutes if she's tired.' They contradict you when you provide some explanations, like: 'No, we haven't experienced that.' They interrupt and... Yeah, kind of take over so that you aren't able to communicate with the kid."*

As the quotations above illustrate, in their explanatory models, the professionals presented normative ideas about the roles of the mother and father, about the nature of adolescence and relations between kin. There were several traps that the family, especially the mother, could walk into when dealing with her adolescent child: being overprotective, pushing too hard or being neglectful. Thus, the adolescent was presented as either a person that needed to develop autonomy without too much interference from the parents, or as vulnerable and in need of parental support. The mother was particularly highlighted as having responsibility for balancing and attending to these opposing needs of the child.

As this theme of the epistemological paradox has shown, the professionals work within a complex multilayered field with several tensions and contrasting discourses on biomedicine, health, family, and adolescence. The professionals have to navigate within this field, trying to overcome communication challenges and create meaning for themselves in their work and for their patients, and attempting to create explanatory models that work as mediators to understand the symptoms and legitimize a particular course of clinical action. These explanatory models are, as we have shown, not value-free, but infused with normative ideals and morals.

The methodological paradox: the uncertain expert

Empathy and the dilemma of clinical uncertainty

> *"We are trained to do our examinations and to find a diagnosis, because if you don't have a diagnosis you don't know what to treat. And here we have a group of patients where we have to tolerate the uncertainty on the same level as them. They don't know what's wrong with them, and we actually don't know either."*

This quotation from one of the psychologists in the focus group illustrates the immense uncertainty that professionals have to endure in clinical work with medically unexplained symptoms. Professionals have to handle different levels of uncertainty: epistemic (our limited understanding of the world around us, including the lifeworld of another), ontological (our descriptions and theorizing, e.g. diagnostic categorization, can never fully capture the essence of lived experience), and prognostic (we cannot predict the future). In an attempt to deal with these many layers of uncertainty, the professionals emphasized the need to come as close to the patients' experience as possible and believe in their suffering. These can be said to be values inherent in the concept of empathy [39]. By cultivating their empathic abilities, they could overcome some of the uncertainty of never being fully able to understand their patients' experiences, and overcome some of the limitations they had in trying to explain and relieve their burden.

In their goal of coming close to the patients' experiences, it also became important for them to represent another way of meeting the patient, as opposed to the typical procedure in other parts of the health system. They built their professional identity around the goal of making right the wrong that other health professionals had done by acknowledging the experiences and believing in the suffering of the patient. Many of them said that the health system was not suited to the needs of these patients, and felt the frustrations of limitations in the diagnostic language, rigid systems, and financial and bureaucratic constraints:

> *"It's very frustrating when your referrals are declined because the person doesn't fit the diagnostic criteria, when you know that this is a person that's suffering and could have been helped if they'd been given the opportunity. That is one of our biggest frustrations... Diagnostics and the systems we're forced into."*

The professionals' descriptions suggested that they felt that their values were endangered in the current health care system, and they emphasized the need to stand together, creating a collective in-group identity of being professionals:

> *"We're the professionals, we can override decisions. And we must. (...) I think it's our responsibility to. I mean of course we should be compliant, but not blindly so."*

In the examples from the focus group given above, the performative role of language became evident as the participants presented themselves as professionals, deeply invested in caring for this group of patients. The pressure to handle patient interactions with great care and sensitivity was based on their knowledge that these patients often had previous experiences of referrals to numerous specialist physicians, a seemingly endless stream of diagnostic testing, the burden of medical uncertainty, and insinuations that their symptoms were only "psychological". As one of the professionals phrased it in an interview:

> *"We're very conscious of the importance of them feeling understood and never distrusted. Because there are so many others that have distrusted them."*

One of the most essential tasks that they faced as health professionals was thus to create an atmosphere of empathy, trust and acceptance in the clinical encounters. Their ability to do so reflected back on them as professionals, strengthening their role as capable health care providers and distinguishing them from other professionals who had failed to meet the patients' needs. These values can be said to be in accordance with a patient-centered practice, but at the same time, they functioned to strengthen the identity and legitimacy of their professional role, thereby serving to counteract the many layers of uncertainty in the reality of their everyday clinical practice.

The dilemma of the uncertain expert

In dealing with patients with MUS, it was expected of the professionals that they should find a diagnosis that satisfactorily explained the symptoms of the patients and prevented further searching for answers. Going through exclusion criteria, meaning that various underlying causes needed to be checked and ruled out, was a key aspect of the diagnostic process. Many of the diagnostic labels were similar and had overlaps, but only some legitimized the patient's sick role, providing access to publicly funded treatments or social benefits. Thus, the professionals took on the role of a gatekeeper, deciding who deserved to enter the sick role. How patients' symptoms were explained was thus of great importance in the diagnostic process, involving different ideas of morality and responsibility. The systems within which the professionals worked were often seen as the end of the road for the patients, and an important task for the professionals was therefore to reassure them that no more examinations and testing were needed, putting a stop to further referrals and system-initiated patient trajectories. One of the physicians described the diagnostic process as follows:

> *"Sometimes you feel you have some sort of diamond, that they so desperately want. And then it's sort of up to the clinician to give an approximate evaluation of whether they should have it or not. Some of them can get very disappointed, cry or make a scene if they don't receive the diagnosis they had expected."*

In this description, the professional role is that of an expert or gatekeeper with a firm grip on the answer, the diagnosis, or the *"diamond"*, legitimizing the symptoms for some patients and not for others. In this role, the professionals presented an attitude of suspicion and distrust, aiming at exposing malingerers. Implicit in this lay the biomedical assumptions that they as experts could provide value-free certainty and context-independent truth. This role stood in stark contrast to the caregiving role they had in the context of treatment, where they described the importance of believing in patients' suffering, listening empathetically to their story and supporting them in their process towards recovery.

Many of the professionals emphasized that an important part of being able to perform their job was that they had several years of experience. It was of value to have experience that could aid them in their interpretations and give a sense of certainty. The years of experience gave them a form of tacit knowledge and clinical intuition, providing them with the necessary tools for being able to stand firm in difficult situations and balancing the different roles they had in relation to the patients. It also gave them legitimacy when talking to their patients, helping them in their work of reassurance and trust building.

> *"Clinical experience and clinical intuition, that's really important for being able to handle this job. It actually helps to have a few grey hairs. They [the patients] can tell that I've been around the block, so they can't just… I look at them and ask 'Do you think I've seen this before?' and they say to me 'Yeah, I bet you have.'"*

As the above quotation from a physician shows, clinical experience not only built a sense of certainty in an uncertain and ambiguous field, but it also created legitimacy for them in their professional role, as someone who could be trusted and whose opinions were of value and should be respected. Despite this, many of the professionals said that they did not conceive of themselves as experts, pointing out that it is the patients that do the work in the healing process, by listening to their own bodies and making changes in their lives. As one of the physicians said in an interview:

> *"I always say, you're the expert, I'm only the doctor. I have to learn from you."*

This sharing of power and responsibility can be said to be in line with patient-centered care. However, the previous examples also show the contrasting roles the physicians assumed, sometimes placing emphasis on themselves as *"professionals"* with knowledge and experience that could provide them with certainty and guide them in their attempts to give advice or present solutions, while at other times they presented themselves as humble servants without clear answers and merely supporters of the patients' own processes.

Discussion

We have presented a conceptual model for communication challenges in the context of clinical uncertainty consisting of two interrelated paradoxes: the epistemological paradox of explaining the unexplained, and the methodological paradox of the uncertain expert. We have demonstrated the many dilemmas inherent in the uncertainty of MUS that professionals face in their everyday clinical practice, and have shown how they try to solve these dilemmas and navigate within the many complex and disparate discourses on biomedicine, health, adolescence and family.

The epistemological paradox concerns the problem of meaning making and interpretation, and the translation process of experiences and phenomena in the world into concepts that we can understand. Our language not only represents the world, but also creates the world through the interpersonal process of interpretation and meaning making [47]. The problem of MUS can be said to result from the difficulties in conceptualizing and framing symptoms within the theoretical models and taxonomies represented by the biomedical framework [3], and the translation of complex theoretical ideas into the understanding of individual cases [51].

The explanatory models created by the professionals provided them with a conceptual framework that allowed clinician and patient to make sense of the puzzling and disturbing phenomena that MUS represents, making the suffering tolerable by creating meaning and pointing towards possible solutions. As such, the explanatory models not only aimed at conveying objective knowledge of truth and certainty, but were also created to emotionally engage, support, motivate, change and empower the patient [43].

The professionals claimed to be working in accordance with a biopsychosocial model. However, the professionals' accounts clearly revealed that to work within this framework may have been an impossible ideal to live up to in the everyday reality of their practice [cf. 30]. Instead, the explanatory models that the professionals used relied on clinical prototypes that were based on the knowledge provided by their many years of experience, describing how illness could result either from personality traits or from dimensions within the family [cf. 45]. The prototypes served as mental shortcuts that could guide them in their everyday practice, lifting the burden of medical uncertainty. In this way, their approach can be said to be pragmatic, trying to capture both the unique in each patient's story, but at the same time giving them a general understanding that could be applied in their clinical decisions. Studies from general practice have also demonstrated that the epistemological incongruence between disease models and the reality of clinical practice is managed in a more flexible and pragmatic way with more experience [52].

However, as we have shown, the professionals' explanatory models were not value-free, but were infused with normative and moral imperatives on what constitutes a good life, a good family and a good adolescence. These moral imperatives shifted the responsibility for the symptoms and for the treatment over to the patients in some cases, and to the family (and especially the mother) in others. This tendency to place responsibility on the patients and their families has also been pointed out in previous research, and the concept of "blaming the mother" has been amply demonstrated in studies on family welfare, adolescent health and child protection work [45, 53, 54].

The professionals tried to overcome the challenges of interpretation and meaning making by relying on alternative forms of communication. They showed a high level of creativity in their application of rhetorical devices and visual tools, like the use of metaphors or reliance on photos or video. The reliance on metaphors to explain symptoms and break down complex ideas into something that can be grasped on a more concrete level has also been demonstrated in other studies as a valuable strategy for handling uncertainty and overcoming communication challenges in clinical encounters [55], especially relevant to adolescents with MUS [56].

The professional ideals of our participants were grounded in a phenomenological and interpretive framework, placing value on subjectivity and trying to capture the patient's own experience of his/her lifeworld. However, at the same time the participants emphasized their professional expertise and abilities in revealing the objective truth behind the presented symptoms. In this way, the professionals' accounts demonstrated the multilayered and complex nature of meaning making in clinical work, in that they seemed to create narrative threads from competing paradigms and knowledge regimes at the same time. Studies from general practice have proposed that the problem with MUS for physicians is the epistemological incongruence between learnt ideal disease models, and the reality of meeting patients suffering from persistent illness and distress [52]. This incongruence also seems to exist in specialist health systems, perhaps as a result of the different paradigms and epistemological realities that frame the health system [39]. Much of the somatic health system is founded on a biomedical positivist paradigm where clinicians are seen as experts who should find the cure for the diseased part of the body-machine and replace it. In psychotherapy and mental health domains, however, the ideal is an interpretivist paradigm where patients' symptoms are understood as signs to be interpreted and where healing is a complex interpersonal process of meaning making. Consequently, adolescent patients with MUS are confronted with a health system that is divided in its understanding of their illness.

The methodological paradox concerns the fact that the theoretical underpinnings for understanding the most suitable methods, or best practices, for specific cases, were not compatible in a coherent methodology. This is illustrated by the many opposing and incompatible tasks that the professionals were expected to perform, and the opposing and conflicting roles in the clinical encounters. The professionals tried to overcome the challenges in combining the role of the expert and the uncertainty inherent in the phenomenon of MUS by relying on empathy in the clinical encounters, acknowledging their patients' suffering and aspiring to make the patient an expert on his/her own illness experience. The importance of relational factors like trust, empathy and emotional support in clinical encounters with MUS patients has also been demonstrated in studies from general practice [34, 52, 55]. These ideals can be said to be in accordance with patient-centered practice, and at the same time, they functioned to strengthen professional identity and lift the burden of prognostic uncertainty.

Despite the challenges they experienced and the many paradoxes and dilemmas they were confronted with in their practice, the professionals all claimed that they enjoyed working with this group of patients, presenting themselves as high in expertise and having the necessary capacities to do their job in a satisfactory way. This finding stands in contrast to research from general practice, where the overall picture is that physicians find encounters with MUS patients strenuous and troublesome, the patients often being described as difficult and demanding [18, 27, 29, 30]. The professionals in our study also described challenges in their work, but at the same time they felt that their work was meaningful and fulfilling. Their accounts demonstrated that they were highly invested, building their professional identity around their ability to help and support their patients and offering them something that other health professionals had failed to provide. Being the last resource in a long line of medical encounters for the patients, and also having made a deliberate choice of this line of work through their specializations in pediatric medicine or mental health care, they perhaps felt greater pressure and demands than GPs for finding strategies and solutions to solve the clinical dilemmas and cope with the uncertainty. As we have shown, the professionals assumed a pragmatic and creative attitude in handling their demanding work, both in their communication strategies, their explanations and creation of clinical prototypes, and in their use of empathy and the balancing of expertise and humility in relation to their patients.

Strengths and limitations

Most studies on communication challenges in clinical encounters are from primary care with adult patients [see 52]. Adolescents are a patient group which in terms of health behavior is 'in the making', where lifelong patterns of self-management of and adjustment to chronic health conditions are established [57]. Research contributing to the understanding of specific challenges in clinical work with adolescents presenting with MUS is therefore of great value.

A limitation of the study is that the findings reveal the professionals' perceptions and interpretations, and do not necessarily reflect what is actually happening in encounters with patients. Such issues should be the subject of observational studies. In the literature on MUS, there is a clear gender difference [2, 5, 58]. It is a limitation of our study that this issue was not included in the interview guide and research questions. To investigate gendered issues should be a topic in future research. Moreover, norms and conventions may influence interview responses and there might have been a certain discrepancy between what the professionals actually thought and what they said. Further, the relatively small sample of professionals from different areas in the health system makes it difficult to draw general conclusions. Accordingly, the findings should not be regarded as a reproduction of reality, but rather a reflection and an interpretation of a reality described by these professionals at a given time and place.

Conclusion

The study illustrates the many dilemmas that professionals working with adolescents with MUS face in clinical encounters, and shows how they try to solve these dilemmas pragmatically to meet their patients' needs. The use of alternative and creative methods of communication seems especially productive for overcoming communicative challenges in clinical encounters with adolescent patients with MUS, and should be studied further. The study also demonstrates the limitations of the biomedical systems of classification on which the paradigm of evidence-based medicine is based, when managing patients with MUS. The idea of medicine being context-independent and able to provide value-free certainty, even with well-known somatic diagnoses, can be said to be an illusion presented by "the voice of medicine" that creates difficulties and communication challenges in clinical encounters and across health systems [59, 60]. The application of the generalized truths of biomedical science to the unique context of an individual patient's life and circumstances will always be uncertain [51]. By moving away from a positivist and biomedical framework towards an interpretive paradigm, where culturally derived and historically situated interpretations are used to understand the social life-world of the patient, placing value on subjectivity, reflexivity and contextuality in the process of clinical understanding, one can create a more humane health service in accordance with ideals of patient-centered care [43].

Authors' contributions

SVØ moderated and MBR co-moderated the focus group. KEK and IPG conducted 5 interviews each. KEK and IPG transcribed the interviews. SVØ, CEAW and MBR had several meetings to discuss analytic strategies and structuring of preliminary findings. SVØ wrote the article, but all authors provided comments on drafts of the manuscript. All authors read and approved the final manuscript.

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Competing interests

The authors declare that they have no competing interests.

Availability of data and materials

The data for this study has not been translated from the original language, and are therefore not made publicly available. The data may be made available from the corresponding author upon reasonable request.

Consent for publication

Not applicable.

Ethics approval and consent to participate

The Norwegian Centre for Research Data (NSD) approved this study in August 2014 (ID 39362). We have adhered to ethical scientific conduct and secured informed consent from each participant.

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References

1. Fink P, Rosendal M, Olesen F. Classification of somatization and functional somatic symptoms in primary care. Aust N Z J Psychiatry. 2005;39(9):772–81.
2. Nimnuan C, Hotopf M, Wessely S. Medically unexplained symptoms. An epidemiological study in seven specialties. J Psychosom Res. 2001;51:361–7.
3. Kirmayer LJ, Groleau D, Looper KJ, Dao MD. Explaining medically unexplained symptoms. Can J Psychiatry. 2004;49(10):663–72.
4. Peveler R, Kilkenny L, Kinmonth A. Medically unexplained physical symptoms in primary care: a comparison of self-report screening questionnaires and clinical opinion. J Psychosom Res. 1997;42:245–52.
5. Kirmayer LJ, Robbins JM. Three forms of somatization in primary care: prevalence, co-occurrence and sociodemographic characteristics. J Nerv Ment Dis. 1991;179:647–80.
6. Fink R, Sorensen L, Engberg M, Holm M, Munk-Jorgensen P. Somatization in primary care: prevalence, health care utilization, and general practitioner recognition. Psychosomatics. 1999;40:330–8.
7. Creed F, Henningsen P, Fink P, editors. Medically unexplained symptoms, somatisation and bodily distress: developing better clinical services. Cambridge: Cambridge University Press; 2011.
8. Viner R, Christie D. Fatigue and somatic symptoms. BMJ. 2005;330:1012–5.
9. Hyams JS, Burke G, Davis PM, Rzepski B, Andrulonis PA. Abdominal pain and irritable bowel syndrome in adolescents: a community-based study. J Pediatr. 1996;129:220–6.
10. Zuckerman B, Stevenson J, Bailey V. Stomachaches and headaches in a community sample of preschool children. Pediatrics. 1987;79:677–82.
11. Konijnenberg AY, Uiterwaal CSPM, Kimpen JLL, van der Hoeven J, Buitelaar JK, de Graeff-Meeder ER. Children with unexplained chronic pain: substantia impairmen in everyday life. Arch Dis Child. 2005;90:680–6.
12. Hoffart CM, Sherry DD. Fibromyalgia—toward a definition in children. Pediatrics. 2016;169:9–10.
13. Wilson AC, Moss A, Palermo TM, Fales JL. Parent pain and catastrophizing are associated with pain, somatic symptoms and pain-related disability among early adolescents. J Pediatr Psychol. 2014;39(4):418–26.
14. Schulte IE, Petermann F. Somatoform disorders: 30 years of debate about criteria! What about children and adolescents? J Psychosom Res. 2011;70(3):218–28.
15. Rask C, Olsen EM, Elberling H, Christensen MF, Ornbøl E, Fink P, Thomsen PH, Skovgaard AM. Functional somatic symptoms and associated impairment in 5–7-year-old children: the openhagen Child Cohort 2000. Eur J Epidem. 2009;24(10):625–34.
16. Berntsson LT, Kohler L. Long-term illness and psychosomatic complaints in children aged 2–17 years in the five Nordic countries. Comparison between 1984 and 1996. Eur J Public Health. 2001;11(1):35–42.
17. Eminson DM. Medically unexplained symptoms in children and adolescents. Clin Psycol Rev. 2007;27(7):855–71.
18. Ring A, Dowrick CF, Humphris GM, Davies J, Salmon P. The somatising effect of clinical consultation: what patients and doctors say and do not say when patients present medically unexplained physical symptoms. Soc Sci Med. 2005;61(7):1505–15.
19. Weiland A, Van de Kraats RE, Blankenstein AH, Van Saase JLCM, Van der Molen HT, Bramer WM, Van Dulmen AM, Arends LR. Encounters between medical specialists and patients with medically unexplained physical symptoms; influences of communication on patient outcomes and use of health care: a literature overview. Perspect Med Educ. 2012;1:192–206.
20. Page LA, Wessely S. Medically unexplained symptoms: exacerbating factors in the doctor–patient encounter. J Roy Soc Med. 2003;96(5):223–7.
21. Salmon P, Phil D, Wissow L, Carroll J, Ring A, Humphris GM, Davies JC, Dowrick CF. Doctors' attachment style and their inclination to propose somatic interventions for medically unexplained symptoms. Gen Hosp Psychiatry. 2008;30(2):104–11.
22. Undeland M, Malterud K. The fibromyalgia diagnosis—hardly helpful for the patients? A qualitative focus group study. Scand J Prim Health Care. 2007;25(4):250–5.
23. Robson C, Lian OS. "Are you saying she is mentally ill then?" Explaining medically unexplained seizures in clinical encounters. For Qual Soc Res. 2016;17(1):2.
24. Peters S, Rogers A, Salmon P, Gask L, Dowrick C, Towey M, Clifford R, Morriss R. What do patients choose to tell their doctors? Qualitative analysis of potential barriers to reattributing medically unexplained symptoms. J Gen Intern Med. 2009;24(4):443–9.
25. Risør MB. Illness explanations among patients with medically unexplained symptoms—different idioms for different contexts. Health. 2009;13(5):505–21.
26. Salmon P, Dowrick CF, Ring A, Humphris GM. Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. Br J Gen Pract. 2004;54(500):171–6.
27. Walker EA, Unutzer J, Katon WJ. Understanding and caring for the distressed patient with multiple medically unexplained symptoms. Jam Board Fam Pract. 1998;11:347–56.
28. Malterud K. Symptoms as a source of medical knowledge: understanding medically unexplained disorders in women. Fam Med. 2000;32:603–11.
29. Hahn SR, Thompson KS, Wills TA, Stern V, Budner NS. The difficult doctor-patient relationship: somatization, personality and pychopathology. J Clin Epidemiol. 1994;47:647–57.
30. Asbring P, Närvänen AL. Ideal versus reality: physicians' perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. Soc Sci Med. 2003;57(4):711–20.
31. Nimnuan C, Rabe-Hesketh S, Wessely S, Hotopf M. How many functional somatic syndromes? J Psychosom Res. 2001;51(4):549–57.
32. Henningsen P, Zipfel S, Herzog W. Management of functional somatic syndromes. Lancet. 2007;369(9565):946–55.
33. Furness P, Glazebrook C, Tay J, Abbas K, Slaveska-Hollis K. Medically unexplained physical symptoms in children: exploring hospital staff perceptions. Clin Child Psychol Psychiatry. 2009;14(4):575–87.
34. Salmon P, Ring F, Humphris GM. What do general practice patients want when they present medically unexplained symptoms, and why do their doctors feel pressurized? J Psychosom Re. 2005;59(4):255–62.
35. Casiday RE, Hungin APS, Cornford CS, de Wit NJ, Blell MT. GPs' explanatory models for irritable bowel syndrome: a mismatch with patient models? Fam Pract. 2009;26:34–9.
36. Malterud K. Theory and interpretation in qualitative studies from general practice: why and how? Scand J Public Health. 2016;44:120–9.
37. Hamer S. Evidence-based practice. Achieving evidence-based practice. In: Hamer S, Collinson G, editors. A handbook for practitioners. 2nd ed. Oxford: Elsevier; 2005. p. 3–12.
38. Kleinman A. Patients and healers in the context of culture: an exploration of the borderland between anthropology, medicine, and psychiatry. Berkeley: University of California Press; 1980.
39. Kirmayer LJ, Lemelson R, Cummings C, editors. Re-visioning psychiatry: cultural phenomenology, critical neuroscience and global mental health. New York: Cambridge University Press; 2015.
40. Good B. Medicine, rationality and experience: an anthropological perspective. Cambridge: Cambridge University Press; 1994.
41. Engel G. The need for a new medical model: a challenge for biomedicine. Science. 1977;196(4286):129–36.
42. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med. 2000;51(7):1087–110.
43. Kirmayer LJ, Bennegadi R, Kastrup M. Cultural awareness and responsiveness in person-centered psychiatry. In: Mezzich JE, Botbol M, Christodoulou G, Cloninger CR, Salloum I, editors. Person centered psychiatry. Heidelberg: Springer; 2016. p. 77–95.
44. Balint M, Courtenay M, Elder A, Hull S, Paul J. The doctor, the patient and the group: balint revisited. London: Routledge; 1993.
45. Buchbinder M. All in your head. Making sense of pediatric pain. Oakland: University of California Press; 2015.
46. Riessman CK. Narrative methods for the human sciences. Los Angeles: Sage Publications; 2008.
47. Bakhtin MM. The dialogic imagination: Four essays. Austin: University of Texas Press; 1981.
48. Davies B, Harré R. Positioning: the discursive production of selves. J Theor Soc Behav. 1990;20(1):43–63.
49. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psy. 2006;3(2):77–101.
50. Butler CC, Evans M, Greaves P, Simpson S. Medically unexplained symptoms: the biopsychosocial model found wanting. J R Soc Med. 2004;97(5):219–22.
51. Mol A. The logic of care: health and the problem of patient choice. New York: Routledge; 2008.

52. Johansen ML, Risør MB. What is the problem with medically unexplained symptoms for GPs? A meta-synthesis of qualitative studies. Patient Educ Couns. 2007;100(4):647–54.
53. Mulkeen M. Gendered processes in child protection: mother-blaming and the erosion of men's accountability. Ir J Appl Soc Stud. 2012;12(1):74–88.
54. Vagli Å. Behind closed doors: exploring the institutional logic of child protection work, doctoral dissertation. Bergen: University of Bergen; 2009.
55. Olde Hartman TC, Hassink-Franke LJ, Lucassen PL, van Spaendonck KP, van Weel C. Explanations and relations. How do general practitioners deal with persistent medically unexplained symptoms: a focus group study. BMC Fam Pract. 2009;10:68.
56. Karterud HN, Risør MB, Haavet OR. The impact of conveying the diagnosis when using a biopsychosocial approach: a qualitative study among adolescents and young adults with NES (non-epileptic seizures). Seizure. 2015;24:107–13.
57. Grabowski D, Rasmussen KK. Adolescents' health identities: a qualitative and theoretical study of health education courses. Soc Sci Med. 2014;120:67–75.
58. Lian OS, Bondevik H. Medical constructions of long-term exhaustion, past and present. Soc Health Illness. 2015;37(6):920–35.
59. Barry CA, Stevenson FA, Britten N, Barber N, Bradley CP. Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor–patient communication in general practice. Soc Sci Med. 2001;53:487–505.
60. Mischler EG. The discourse of medicine. The dialectics of medical interviews. Norwood: Ablex; 1984.

Paper III

The makings of ‘classic’ and ‘complex’ patients: An ethnographic study of clinical rehabilitation for adolescents with medically unexplained long-term fatigue

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Keywords: *Medically unexplained symptoms, clinical interaction, categorization processes, adolescents, ethnography*

Abstract

Medically unexplained symptoms represent clinical challenges in terms of communication, treatment and understanding. This article examines communicative challenges between health professionals and adolescents diagnosed with medically unexplained long-term fatigue. Using ethnographic fieldwork with a focus on talk-in-interaction in four cases, the aim was to bring forward an analysis of the process of negotiated and co-constructed meaning during the treatment process. Based on discursive and critical approaches within psychology, we explore how the category of appropriate patienthood is construed in a multidisciplinary rehabilitation facility. We have paid attention to the ways in which established sociocultural categories such as age, gender and class interweave with local perceptions of “classic” and “complex” versions of illness, showing how institutional ideologies and discourses produce norms of patienthood that might be hidden within generalizing terms of health and illness. In closing, we discuss the implications of such categorization for adolescents’ illness paths and subjectification processes.

The makings of ‘classic’ and ‘complex’ patients: An ethnographic study of clinical rehabilitation for adolescents with medically unexplained long-term fatigue

Introduction

Chronic fatigue syndrome or myalgic encephalomyelitis (CFS/ME) is an illness surrounded by medical uncertainty, and is characterized by being difficult to diagnose, having an elusive etiology and no clear-cut treatment strategy (Helsedirektoratet, 2015). It is therefore often included in the category of medically unexplained symptoms (MUS). Patients with MUS have been argued to be important ‘case studies’ for examining sociocultural dimensions of medical knowledge production, and how societal and personal processes for understanding illness and treatment are intertwined (Kleinman, 1994). The term “medically unexplained symptoms” describes a social and clinical predicament, not a specific disorder, and the concept draws attention to a situation in which the meaning of distress is contested (Kirmayer, Groleau, Looper & Dao, 2004).

Medically unexplained symptoms are seen in all age groups, but early adolescence is considered a critical period for the development of chronic and returning somatic symptoms (Wilson, Moss, Palermo & Fales, 2014). MUS in adolescence may have profound existential, developmental and social consequences, as adolescents have to find new ways to organize developmental aims and domains for social participation (Østbye et al., 2018a). Clinical encounters have been demonstrated to be decisive for subsequent illness aspects, either assisting patients in their process of healing, or creating somatizing effects (Ring, Dowrick, Humphris, Davies & Salmon, 2005). It is during adolescence that lifelong patterns of self-management of and adjustment to chronic health conditions are established (Williams, Hombeck & Greenley, 2002). As adolescents are often vulnerable and in a process of establishing norms, beliefs and practices under the influence of social networks (Jones, 2009), even more is at stake in the communication in clinical encounters with this patient group (Grabowski & Rasmussen, 2014).

Much of medical anthropological and sociological literature on MUS and clinical encounters has focused on the initial diagnostic process that takes place in primary care, often with adult patients. Some of these studies have focused on the illness experience from the patient’s perspective (Boulton, 2018; Kornelsen, Atkins, Bronwell & Woollard, 2016; Lian & Lorem, 2016; Lian & Robson, 2018; Nettleton, O'Malley, Watt & Duffey, 2004; Rebman et al., 2015; Sowinska, 2018; Sowinska & Czachowski, 2018; Werner, Steihaug & Malterud, 2003), while others have dealt with the perspective of the treating physician (Furness, Glazebrook, Tay, Abbas & Slaveska-Hollis, 2009; Harsh, Hodgson, White, Lamson & Irons, 2015; Østbye, Wang, Granheim, Kristensen & Risør, 2018; Åsbring & Närvänen, 2002). This demonstrates the conflictual and incompatible epistemological realities of patients and health professionals (Kirmayer, Groleau, Looper & Dao, 2004; Mischler, 1984; Salmon, Ring, Dowrick & Humphris, 2005).

By contrast, this article examines communicative challenges between health professionals and adolescents already diagnosed with CFS/ME. The aim was to bring forward an analysis of the process of negotiated and co-constructed meaning during the treatment process. Based on discursive and critical approaches within psychology, we explore how the category of appropriate patienthood is construed in the local context of a multidisciplinary rehabilitation facility that we have called Birch Hill. Birch Hill provided an institutional context where groups of young patients with CFS/ME were included in social and activity-based recovery processes. This arrangement enabled us to conduct ethnographic fieldwork and collect data from talk-in-interaction (Goffman, 1971, 1981). The analysis directed research attention to the 'microlandscapes' of interaction, showing how institutional ideologies and discourses produce norms of patienthood that might be hidden within generalizing terms of health and illness. We paid attention to the ways in which established sociocultural categories such as age, gender and class interweave with local perceptions and ideas of "real", and thus "classic", versions of illness, or "factitious", and thus "complex", versions. These efforts to explore converging and diverging understandings in patients and health professionals led us to discussions of the implications of such categorization for adolescents' illness paths and subjectification processes.

Discourse and social categories

In general, both health professionals and adolescent patients are actively engaged in processes of subjectification, encountering and working upon discursive sets of meanings that are tied to social categories (Burman & Parker, 1993; Potter & Wetherell, 1987). These discourses regulate possible legitimate, appropriate and normative ways of being an adolescent girl or boy with an illness of unknown etiology, and work to open up or constrain future possibilities.

Based on data from the fieldwork, we explored ongoing interactions in talk and text as discursive work with particular attention to the ways in which subjectivities and experiences are constituted within and regulated by these discourses. We thereby see language "as a culturally-located, social practice in which 'versions of reality' (Potter & Wetherell, 1987) – objects, events, identities, experiences – are actively brought into being, asserted, negotiated and contested" (Malson, 2010: 199).

Language is a historically generated collective tool that mediates the world as people use it in their everyday practices. It is essential for providing perspectives on reality, but it is also the principal mechanism through which our knowledge of the world comes into existence. Patients and medical personnel alike cannot simply report on what they see; inevitably they will produce different versions of persons, actions, events and things (Hacking, 1999; Goodman, 1978; Shotter, 1993). Meaning does not exist out in the world waiting to be discovered or accurately conveyed; rather, it is created within language. The term discourse refers to "a set of meanings, metaphors, representations, images, stories (…) that in some way together produce a particular version of events" (Burr, 1995: 48). An instance of discourse articulates one possible version of things, but there are always other possible versions (Potter & Wetherell, 1987). To assert one version rather than another has specific effects: articulating, maintaining or opposing particular power relations or "regimes of truth" (Foucault, 1977). For Foucault, a central aspect was that discourses had the effect of producing truths about what is considered 'normal' and 'common', 'unnatural' or 'deviant'. In line with this, discourses such as those of adolescence, health and illness or families can be understood as producing 'normalizing truths', i.e. expectations regarding what is 'common' or even 'moral' in the behavior of a specific group of people.

In addition to efforts to categorize illness into a system of diagnoses, gender and age are classical categories around which meaning is clustered. However, as Søndergaard (2002) points out, social categories can also imply local perceptions such as "patienthood" (how to be a proper patient), "treatment personnel" (how to be a proper helper) or "illness/disease" (what are considered legitimate symptoms). For these categories there are associated signs, as well as values and norms, and in this way social categories are tools for inclusion, exclusion, positioning and creating hierarchies. In postmodern and critical research traditions, categories are understood as being "done" (Kitzinger & Wilkinson, 1996), as dynamic and embedded in power relations. They are never completely fixed but come into being as they are made in daily interactions between actors *in situ* and in relation to normative conceptions of in/appropriateness (Staunæs, 2003). Categories are not forced upon the individual but take on a life of their own as individuals actively put them to use for self-understanding and self-definition. People can populate social categories, and social categories can acquire people and make certain traits visible (Hacking, 1986, 1995).

Subjectification processes in clinical contexts

Subjectivity is the post-structural concept for a person's effort to create and sustain a sense of self. In contrast to the concept of identity, subjectivity is built upon a certain understanding of the relation between a sense of self and the social context, where it is seen as an ongoing process of becoming (Hauge, 2009; Søndergaard, 2002). The process of subjectification is in Foucauldian terms described as a process in which the human actor is both acting upon contextual conditions and being subject to, in a way determined by, those conditions (Foucault, 1977, 1988). Researchers within post-structuralist and critical traditions have further developed this concept to include descriptions of how people take up, ignore or resist accessible discourses, being actively engaged in their own process of becoming (Haavind, 2007, 2014; Staunæs, 2003; Søndergaard, 2002; Wetherell, 1998).

The notion that persons are subject to discourse and at the same time are discourse users makes it possible to study how young people as social agents are constructed by a variety of discourses. The way in which subjects position themselves within discourses, as well as which subject positions (Davies & Harré, 1990) are available, must be understood as highly context-driven. In a clinical context such as that of Birch Hill, there is a limited number of subject positions that the adolescents can occupy, take up and make their own. Whether subject positions become troubled or untroubled (Wetherell, 1998) is an ongoing process that depends on actual and comprehensible discourses, practices and distributions of power, as well as the compositions of actors.

The concept of troubled subject positions covers interactions and negotiations where subject positions become inappropriate, destabilized and difficult, i.e. positions that challenge the normativities at stake in certain contexts of lived experience (Wetherell, 1998).

Diagnostic typecasting refers to a classification process in which patients are linked to an array of fixed types (Buchbinder, 2011), creating either troubled or untroubled subject positions. Historically there are numerous examples of how patients with so-called psychosomatic illness have been understood as possessing a range of undesirable traits, such as overly sensitive, self-absorbed, nervous, dependent, self-defeating or malingering (Aronoff, 1985; Aronowitz, 1998; Beard, 1881; Fordyce, 1976; Harrington, 2008; Kotarba, 1983). In the medical anthropological and critical psychological literature, several authors have provided rich descriptions of the process of diagnostic typecasting in different settings of clinical or social work.

Gremillion (2003) has for example demonstrated how local perceptions of patient categories such as ‘true anorexia’ and ‘borderline personality disorder’ were construed among staff at a treatment facility for eating disorders, showing how descriptions of symptoms and personality characteristics interwove with embedded concepts of class, race and gender, mediating a process of othering and exclusion. In a similar fashion, Buchbinder (2011), in her study of adolescent patients at a pain clinic, demonstrated how clinicians in their reasoning linked the neurobiology of pain to certain desirable features of adolescent personhood, such as smartness, sensitivity and creativity, which gave way to theories of causal pathways and predictive claims about the likelihood of recovery. Desjarlais (2000) described how people with mental illness were constructed as fixed characters or personality types in a shelter for homeless people, and Horton-Salway (2002) demonstrated how patients’ identities were discursively construed in GPs’ biopsychosocial case narratives, “talking up” patients as having an illness of either mental or physical origin.

An important message in all of these studies is that the experience of symptoms, the language and metaphors used for describing symptoms and their causes, and the process of recovery are inextricably linked in complex ways, and that social categories like gender, class, personality characteristics, medical or psychiatric diagnoses, and age intersect (Crenshaw, 1994; Staunæs, 2003, 2004, 2005; Søndergaard, 2005) and mediate this process. These studies add to critical and post-structural approaches within psychology and medical anthropology that challenge the biomedical ontological “truths” about bodies and subjectivities (Good & Good, 1993; Good, 1994; Rhodes, 1991). All of these studies illustrate the active negotiation processes in communicative practices, demonstrating the cultural contradictions inherent in medical and psychiatric knowledge production in which discourses reveal themselves as both constituting and constitutive of subjective experience (Foucault, 1977, 1988).

Fieldwork site and methods

Conducting fieldwork over two months, we were allowed to follow a group of eight adolescents aged 12-18 diagnosed with CFS/ME. The adolescents were patients participating in a closed four-week short-term group rehabilitation program in Birch Hill. One month before the group program started, the adolescents' families were also invited to a three-day pre-screening in which they were given information about the program and were interviewed by staff about their current situation and treatment goals.

During fieldwork, the first author conducted intensive participant observation across a range of activities during both the pre-screening and the four-week group program, such as therapy sessions, client meals and outings, group activities, staff meetings, conversations between staff and individual patients, treatment team meetings and informal talk amongst staff and patients in between organized activities. Semi-structured formal and unstructured informal interviews with clinical and administrative staff, patients and family members were also conducted. When observing encounters between staff and patients and in therapy sessions, full note-taking was possible. When full note-taking was difficult, field notes were written up from memory as soon as possible. Interviews and staff meetings, as well as some of the encounters between patients and staff, were audio-recorded and transcribed verbatim.

The adolescents

Most of the patients in our study had been ill for at least two years, typically with mild to moderate symptoms, and most were already experiencing some level of recovery. Core symptoms were severe tiredness that was not relieved by sleep or rest, muscle and joint pain, digestive issues and headaches. Additional symptoms were difficulties with concentration, sleep disturbances and dizziness. Some also had seizures and paralysis. The staff described the group as heterogeneous in terms of symptomatic expressions and degree of impairment, but they were all diagnosed with CFS/ME. Most of the patients had at some point dropped out of school or leisure activities due to their illness. The group consisted of seven girls and one boy, aged 12 to 18. For those under 16, the parents were required to stay at Birch Hill with their child, participating in the activities and treatment program. Parents of those over 16 could decide for themselves whether they wanted to stay at the center, but the staff often considered it a good sign that parents did not interfere too much with the adolescents' treatment process. The majority of the patients had been through several rounds of differential diagnostic testing in specialist health care before receiving a diagnosis, and a prerequisite for being offered a place at the center was that this process had been finalized. Treatment at Birch Hill involved agreeing to follow a preset schedule of activities, open to some individual adjustments.

The site: Birch Hill

Birch Hill offered intensive rehabilitation programs for both children and adults for different symptoms and diagnoses, such as cancer, chronic fatigue, chronic pain, neurological disorders or chronic injuries. The facility had a wide range of activities for its patients: fitness classes, personal training in a fitness studio, yoga and meditation/relaxation, climbing, group therapy sessions, physiotherapy, evening and afternoon activities, trips and all-day activities like sleighing with horses, boat trips, riding or archery. They had a hot water therapy pool, solarium, cafeteria that offered four meals a day, lounges for the patients to relax, a games room and patient rooms with space for visitors. The center was located with a view over the sea, surrounded by a garden. It also had its own school on site. The treatment approach for CFS/ME at Birch Hill was in line with the national treatment guidelines for this condition in Norway (Helsedirektoratet, 2015). These guidelines are based on a biopsychosocial model describing how all symptoms are caused by a complex interplay between physical, social and psychological factors (Engel, 1977). The national guidelines recommend that patients should make an effort to find the right balance between activity and rest: regulating sleep, learning relaxation techniques, and exercising in appropriate amounts. In addition, cognitive behavioral therapy to target negative thought patterns and emotions that often follow from living with chronic illness is recommended. From a cognitive behavioral perspective, the underlying causes and ongoing functions of the illness are not a focus of concern. Rather, unlearning the illness of CFS/ME rests on e.g. interventions targeting specific behaviors (avoidance of activity) and challenging unhelpful thoughts and beliefs ("activity can harm me"). The treatment program at Birch Hill thus focused on day-to-day activities, social experiences, physical exercise, regular meals, time for rest and sleep, mastery and positive thinking, and had less of a focus on etiology and causes behind symptoms.

The staff

The staff of Birch Hill was divided into treatment teams depending on the type of problems they worked on, and within each team, there were so-called ‘close contact teams’ consisting of three health professionals assigned to work with one patient. Seven staff members with more responsibility for individual patients and more day-to-day contact with them were followed more closely. They supervised the adolescents’ treatment processes and were in charge of activities, the organizing of daily schedules, individual follow-up, group or individual therapy sessions, the organizing of meetings between family members, patients and cooperative partners in the treatment, and discharge planning.

Some staff members were qualified physiotherapists with various specialties in physical activity or rehabilitation, while others were social educators, social workers or had nursing degrees. In addition to these, there were two mental health nurses at the center, one psychologist, one speech therapist and two physicians, and several teachers at the school. These were less involved in daily interaction with the CFS/ME patients, but played a part in designing and discussing the treatment and clinical interventions. Most of these professionals were present during treatment meetings in which patients were discussed in terms of progress, causational theories, interventions and potential difficulties in treatment.

Birch Hill was proud of being a workplace with low turnover, and most of the staff we interviewed had been working there for several years, had extensive experience in the field of physical rehabilitation and was engaged in and enthusiastic about their work. In addition to the staff involved in clinical work, those involved in research and administration were also interviewed, as this provided insight into treatment philosophies and general workings at the center.

Access and ethical considerations

Access to the fieldwork site was obtained through contact with the leaders and the head of research and development at Birch Hill. The first contact with the adolescents and their families was established through collaboration with the staff. Information about the study was provided and written and oral consent from patients and family members was obtained at a pre-screening and information meeting some weeks before the study took place.

The adolescents could decide whether they wanted to participate in interviews, and they were informed of their right to refuse to be mentioned in descriptions based on participant observation. Both legal guardians and adolescents had to give their consent. The staff was given information on the study in a separate meeting, and they too were informed of their right to refuse to be mentioned in the data gathered from participant observation and to abstain from taking part in interviews. Oral consent for recording was given in each instance. All names and other identifiable characteristics have been altered in order to ensure the anonymity of the informants. The Norwegian Centre for Research Data (NSD) approved the study in August 2014 (ID 39362), and we also received ethical approval from the regional ethics committee.

Findings

Over the course of the fieldwork, we observed how treatment approaches and guidelines were managed and applied in the everyday work at Birch Hill. The analysis of the talk-in-interaction (Goffman, 1971, 1981) at Birch Hill demonstrated how the category of appropriate patienthood was discursively construed in the clinical encounters. Staff and patients used biopsychosocial reasoning to construct patients' subjectivities and to emphasize either physiological or psychosocial explanations, represented through local perceptions of *"classic"* or "*complex"* illness. Both the complex and the classic categories were emic concepts in which illness attributions and understandings of social categories were interwoven in a way that established the patient as a certain kind of person, creating either troubled or untroubled subject positions (Wetherell, 1998). To explore in more depth how the categories of classic and complex patienthood were discursively construed, we will now present four cases representing the variation in communication between the young person with CFS/ME and the professional staff. In two of these cases, which we have named Madeleine and Zach, the staff and the adolescent draw on discourses and use categories in a way that creates a mutual understanding of the illness path and the possible process of recovery. However, in the two other cases, which we have named Alicia and Grace, the staff and adolescents draw on discourses and use categories in a way that makes such a mutual understanding difficult.

Madeleine was seen as "supermotivated"

When Madeleine arrived at Birch Hill at the age of 18, it was one year since she had been diagnosed with CFS/ME. She was the youngest of four siblings, living with her mother, father and sister in a small rural town. Her mother worked as a secretary but had been at home for most of Madeleine's childhood. Her father worked as an electrician in his own firm. In Madeleine's own description of her illness, she stated that her first symptoms started two years previously, after having caught some kind of infection, without ever quite recovering. She was rarely sick before this. Her blood tests showed signs of infection, but the exact cause was never discovered.

In Madeleine's illness presentation, her narrative was linear and non-problematizing, with a clear starting point to the illness experience and with descriptions of how it affected her body. She also emphasized how she used to be active before turning ill; she was involved in dancing and horse riding, working part-time after school in a beauty salon, giving dance lessons to children and hanging out with other girls most days of the week. After becoming ill, she had to quit most of her after-school activities, struggling a great deal with fatigue and pain. Despite this, she had continued to attend all her classes at school, eager to become a qualified cosmetologist.

In this way of describing herself and the way illness affected her life, she could be seen as scripting herself as being a particular kind of person, one who would not normally choose to live a restricted existence. The appropriate balance of activity and rest is made an accountable issue in Madeleine's presentation. This effectively manages the dilemma where "illness talk carries with it the threat that one might be seen as a potential malingerer or even a habitual complainer" (Radley & Billig, 1996: 225-226). However, it also carries with it a potential risk because if one gets the balance wrong, one's illness might be interpreted as self-inflicted and a result of an overactive lifestyle or perfectionist tendencies. In Madeleine's case, however, she seemed to be able to account for herself in a way that complied with the values and norms of appropriate patienthood relating to CFS/ME, finding the right balance between actively fighting the illness and resting appropriately. In the first treatment meeting, Madeleine's narrative was confirmed by the staff in their presentation:

Staff 1: *"She is 18 years old, comes from x. She wrote us an e-mail stating that she wants to learn how to live with the illness and is very positive towards the prospect of being here. She is here alone. She had influenza-like symptoms and never quite recovered from it. So she's struggled a lot with joint pain, been sensitive to light and sound, been dizzy and... eh... temperature regulation problems and such. She... Eating and sleeping seem to be in order, don't they, staff 2?"*
Staff 2: *"Yes."*
Staff 1: *"She goes to school. Eh. Cosmetology. She is very school... school oriented. Works part-time as a dance instructor. Working with children... so she has... she is active as well. But less active than*

she used to be. (...) But she is supermotivated. Seems very positive and is the type of person that wakes up early in the morning and is... it seems like she is in a good phase."

Here the staff member offers a description of Madeleine's personality that is interwoven with a biomedical narrative about an influenza infection that she never recovered from. The staff member's explanations are supported by the construction of a particular kind of identity for the patient. The inclusion of scene-setting evidence (see Horton-Salway, 2001, 2002) in the second sentence effectively instructs the listeners as to what is relevant in order to understand this particular patient; through her e-mail she demonstrates that she has a positive attitude and that she is a coper. Beginning a story at one point in time rather than another sets the parameters for what is to be made relevant, and this has profound consequences for the kind of causal account that the speaker goes on to construct (Horton-Salway, 2001; Riessman, 1993). The patient's physical symptoms are in this narrative contrasted with an identity of positivity and perseverance, constructing the patient as a type of person that does not easily give way to illness and has a positive coping style.

The fact that she is alone at the center, is school oriented, wakes up early in the mornings, and manages to remain active despite her illness, further underlines her identity as a resilient coper. This has the unintended effect of countering psychosocial explanations, for example that her illness might be a result of psychological vulnerability, like sensitivity to stress, or dysfunctional illness behavior and coping skills, like avoidance of activity. These kinds of explanations are often the building blocks in a psychosocial theory for triggering and maintaining factors in CFS/ME, and are the rationale for prescribing cognitive-behavioral therapy as a treatment for CFS/ME sufferers (Fink & Rosendal, 2015; Halligan & Mansel, 2006; Wessely, 1997). The description of her being less active now than before the infection and of how the illness has affected her body in terms of pain, dizziness and temperature regulation problems further corroborates with Madeleine's own narrative, and supports the notion that there is something genuinely physically wrong. The contrast between her activity level before and after her illness is also supported and elaborated on by Madeleine's mother, who in a different meeting gives a description of how Madeleine used to be before turning ill:

"We have been so spoilt having Madeleine. She used to be such a perfect homemaker, often surprising us by cleaning the whole house or by baking or making a three-course meal."

Madeleine's actions when arriving at Birch Hill further established her as a patient that in the staff's words would be *"plain sailing"*. She soon started to equip her room with cushions, blankets, candles and photos from home, perhaps to mark her presence and willingness to be there. During her stay she did not ask critical questions and never expressed any resistance. She carefully and smilingly followed the prescribed program of activity, rest and meals. In the social activities and therapy sessions, she was polite and participated in everything she was asked to, but never took center stage in the group. She also seemed to get on well with the other adolescents in the group, and even made some new friends.

In Madeleine's case, the process of co-constructed meaning between staff, family members and patient was without complications, as their narratives were perfectly aligned. At team meetings when cases were discussed, her case was only briefly mentioned and then only to make reassurances that she was making good progress, or to quickly establish that although she might be seen as *"a typical good girl"*, or her mother possibly *"a little overinvolved"*, this did not represent a major problem. Madeleine was generally well liked among the staff and was described in backstage talk as a *"dream client"* – *"just lovely, always so positive and smiling"*. Madeleine was given hope and reassurance in her early encounters with the staff, being told that she could expect a quick and complete recovery. During her stay she also seemed to gradually get better from her symptoms, and staff commented on how she seemed to be flourishing in the activities day by day.

Alicia was seen as failed recovery

When Alicia arrived at Birch Hill at the age of 17, she had been struggling with pain for the previous seven years. She lived with her parents and a younger brother in an urban area. Her father worked in finance and her mother was a lawyer. She wanted to study to become a geneticist and was engaged in the work of a patient activist group for young people. She went to an elite private high school and was described by herself as well as by her family as having high ambitions. Her symptoms started when she was 10 years old after an injury to her leg when playing tennis. The injury never healed, and her pain intensified up until the point where she could no longer walk, making her dependent on a wheelchair to be able to move around. She was undergoing extensive examinations in hospital, but the cause of her pain could not be determined. After several months, she was referred to Birch Hill for physical rehabilitation. She eventually regained strength in her legs, the pain subsided, and she was able to walk again. This could have been a success story, had it not been for the fact that after a couple of years, the pain gradually came back. After some time, she was back in the wheelchair and her pain was so intense that she had problems concentrating and sleeping. She also had severe symptoms of fatigue, although the pain was her main concern.

At some point over these years and after further examinations and differential diagnostic testing with almost 30 different doctors, she was diagnosed with CFS/ME and CRPS (complex regional pain syndrome), although Alicia still had her doubts that these were the correct diagnoses. She was still looking for answers and had tried *"everything"* in terms of treatment, in both alternative and conventional medicine. She said that her understanding of her condition was that it was a neurological disease, but that it was also quite complex and that her tendency to push herself too hard probably had not helped in her recovery:

"Everything is connected, the nervous system, the body, the mind. If you push yourself too hard, eventually the rubber band will snap."

Her goal for her stay at Birch Hill was to gradually regain strength in her feet and legs, and her long-term dream was someday to be able to climb Mount Everest.

Early in her stay at Birch Hill it became clear that the staff understood Alicia's symptoms as *"functional"* or *"complex"*. These labels were used interchangeably by staff to describe and explain contestation and conflict in the clinical encounters, failings in treatment and to provide causal theories for the patient's symptoms, often in contrast with labels like *"classic"* or *"real"*. The *"functional"* or *"complex"* labels were often equated with psychosocial theories of causation, and often with an implicit message of the symptoms not being quite legitimate. The way the staff referred to their understanding of functional illness was not always aligned with the scientific use of this concept (Fink & Rosendal, 2015), but was intermingled with concepts like *"difficult"*, *"made up"* or *"all in the mind"* of the patient in question.

In Alicia's case, the *"complex"* label was first introduced to explain that her symptoms had come back after her previous stay at the center that to the staff had seemed a success in most respects, and thus to explain shortcomings and failings in the treatment. The wheelchair became a symbol of these failings, and the removal of the chair therefore quickly became the treatment goal for the staff. In the first treatment meeting, the problem of the wheelchair was brought up:

Staff 1: "*Yes. Alicia. 17 years old. Ehh. She has been here previously. Ehh. She came in a wheelchair that time as well. Walked out. And was now back in the wheelchair. She doesn't think she has ME. Struggles with pain in her legs. She's also this kind of good girl I think that... ehh... that actually functions quite well in many areas, but still ends up back in a wheelchair. (...) In relation to these paralyses... or these pains that makes it necessary for her to sit... there was no paralysis… I straightforwardly asked her what the cause was since they don't find anything physical on the tests... and she had been informed... that it probably is complex. But still she seemed eager for physical measures exclusively... It's a bit interesting… Since she's here on a CFS program (...) She also has high ambitions. She wants to become a doctor and is quite determined in this goal. She is completely convinced that her pain is caused by something we don't yet understand, but that we in the future will understand as something physical.*
(…)
Staff 2: *"It's too bad that they get the best wheelchairs. They get the smoothest sports chairs that weigh about two kilos, so they can just cruise around. Instead of giving them one of those prewar models that you really want to get out of. One of those that doesn't fit your body. Now it fits her like a glove."*
(…)
Staff 1: *"Yeah, you could say that... ehh. If it had been a spinal... Or something real that required her to sit in that chair... but she has no reason to be in that chair in the first place! So I don't think we'll bother with that… We're just going to get her out of that chair… as soon as possible."* (…)
Staff 3: *"I'll try to set up some climbing with her, see if I can trick her up on her feet!"*

As in the case of Madeleine, the story of Alicia begins with scene-setting. Previous studies have demonstrated that beginning a story at a particular place and time is an important aspect of attributing causes to illnesses (Horton-Salway, 2001, 2002). In the story presented by the staff in this extract, the beginning of the story is situated with Alicia walking out of Birch Hill after being in a wheelchair. This sets the stage for interpreting the symptoms as not caused by organic illness, but as something psychological. Staff 1 further underlines the fact that there is no paralysis and that they did not find anything physical on the tests, and confronts Alicia with this. The fact that Alicia in her answer persists in her explanation that the symptoms must be physical despite all the evidence presented by the staff to the contrary further establishes Alicia as a potentially complex patient, in which mutual contestation and unspoken conflict between the two parties can be expected.

Alicia's identity is constructed as someone with high ambitions, determined in her goals. This is in line with Alicia's own descriptions of herself, and therefore could be seen as supportive of her subjectification process. However, in contrast to the way Madeleine is constructed, where the description of being school-oriented and hard-working is used to establish her as a *"dream client"* with a positive coping style, the description of the high ambitions and determination of Alicia is directly preceded by a description of her stubbornness in her conviction that her symptoms are physical. The descriptions of these personality traits can thus be seen as a way to construct Alicia as a complex and troublesome patient, creating a troubled subject position.

Furthermore, these personality traits can be seen as a way to construct Alicia's illness as self-inflicted, as a result of her pushing herself too hard and being over-ambitious. Alicia thus fails to account for herself in a way that manages the delicate balance between activity and rest required by the norms and values of proper patienthood relating to CFS/ME. In this extract the staff also agreed that Alicia had no reason to be in a wheelchair, because she had no real injury such as a spinal injury. In a later interview with one of the staff, the conviction that Alicia's symptoms were not caused by physical illness but were rather a mental problem was further elaborated on:

"What we're doing now, anyone could've done. It's not physiotherapy. What matters is that I'm the one doing it, making her believe that what we're doing is serious and helpful. Her pain is all in her head."

Over the course of the four weeks Alicia stayed at Birch Hill, communication with the staff became more and more difficult. Alicia did not agree with the staff's explanations, viewing her illness as a neurological disease that needed to be treated accordingly, and feeling that the legitimacy of her experiences was being questioned. The staff became increasingly provoked by her manner and her refusal to accept their treatment approach, describing her as *"a diva"* and *"a spoiled brat"*. The backstage talk among the staff became increasingly heated, indicative of the frustrations they felt in not being able to fulfill their professional role:

Staff 1: *"We have to talk about Alicia"*
Staff 2: *"Absolutely! Yes! Ehh. Yeah… It is... Oh dear! Alicia is perhaps one of the most complex in the group right now or even maybe... ehh... it is a girl that in my view has a functional illness that has persisted for many years. (...) We see that she is becoming increasingly frustrated as time goes by. (...) Things aren't going that well to be honest. I think we are at a standstill" (...) "Patients like her are constantly looking for new diagnoses and new findings... (...) this is a girl that is in and out of the system. She is involved in patient activism. That's her whole identity. And this wheelchair and... I think it's quite... Yes, it's some of the most difficult... She is a very smart girl... And she exposes you. (...) if we don't speak the same language, she will tear you to pieces because this is a lady that's very attentive and alert." (...)*
Staff 2: *"Her mom described her as a girl that is very outgoing and active, and explained how fantastic it was when she got the wheelchair that made it possible for her to get around."*
Staff 3: *"Yes. In any case it's a girl that... There is no atrophy. She has a really bouncy behind... so this is a girl that clearly is up on her feet a lot. Not around us, but somewhere or other she is out and using her body..."*

In this extract the description of Alicia's personality is interwoven with an understanding of her malingering and manipulating symptoms. Her being smart, attentive and alert, as well as outgoing and active, is used to substantiate the claims of the symptoms not being justified or legitimate. She is described as someone who is using her smartness to shop for diagnoses for secondary gain in terms of achieving a position and identity. The fact that she has no atrophy in her legs and a *"bouncy behind"* is further presented as evidence that she is malingering, her symptoms not being real.

In the final meeting with Alicia, her father and two staff members before discharge, the tension between the staff and Alicia was exacerbated. The meeting ended with Alicia in tears, both staff members angry, frustrated and increasingly defensive, and no final solution or action plan for Alicia's discharge. In a staff discussion after this meeting, they were unable to reach a conclusion on whether to accept Alicia for another referral to Birch Hill at a later point, and they seemed to be at a loss for what to do next. Some of them saw it as a lost cause, because Alicia did not agree with them in their explanatory model and treatment approach. Since dialogue and communication with her had gone so far astray, they saw it as futile to try for another admission.

Zach was seen as getting back on track

Zach was 16 years old when he arrived at Birch Hill. He was the younger of two siblings. His sister had recently moved out. Zach's father was a mechanic and his mother worked in a nail salon. Zach began his illness story by explaining that his symptoms had started suddenly with stomach pain and nausea. He and his father went to their general practitioner to find out what caused the symptoms and he was referred for differential diagnostic testing at different specialized units at the hospital. The final diagnosis of CFS/ME was established two years before his arrival at Birch Hill. Zach was previously keen on snowboarding but had to cut down on his training after falling ill. Recently he had felt a little better and had started to gradually increase his training. His ambitions for the future were to be a carpenter and at the same time continue his snowboarding:

"The thing is, I want to become something, learn a craft and get a proper job. I think it's important to do something in life".

His goal for his stay at Birch Hill was to increase his activity level, to *"be able to get more out of life, get to know some people and work out a little"*.

In the first meeting with Zach and the staff, Zach seemed a little quiet and shy, with a hectic flush in his cheeks. He answered questions politely, but without elaborations. Zach's father was present, happily and talkatively elaborating Zach's answers. The father said that Zach's sister had the same diagnosis, but that she had been struggling a lot with emotional problems as well, dealing with depression and self-harm. He said that it was important for him to be present at Birch Hill to support his son if he needed him, but that he felt it was best to leave treatment to "*the experts"*.

Despite having two children with the same diagnosis, one of them struggling intensely, the father did not seem to ask himself too many questions or create hypotheses about explanations. This way of thinking seemed to be part of the family culture, as I also recognized it in Zach's way of describing his illness. In this way of presenting the illness story, it was the 'disease' or 'diagnosis' that was the reason for the difficulties, not any other themes or events in their lives that may have made an impact. As in the case of Madeleine, Zach and his father constructed CFS/ME as a recognizable illness by describing a specific starting point to the illness experience and by mentioning the physical ways it affected the body. To refer to CFS/ME as affecting the body is to place it in a medical model in which the body is seen as a physical entity made up of many parts that are susceptible to damage and disease, ‘the machine-body’, a common construction of the Western medical world (Lupton, 1994). This can be seen as a way to validate Zach’s claim of CFS/ME as a physical illness, removing himself from the potential stigma associated with mental health disorders. This non-problematizing way of describing the illness path and road to recovery was accepted by the staff, and they did not question the straightforward narrative, despite possible contradictory evidence in Zach’s family history. In the first treatment meeting this was the case narrative that the staff presented of Zach:

Staff 1: *“Well he’s had... been ill since 2012. He’s a previously active boy that has been... and is also currently snowboarding... mm. He did it a lot and has taken it up again now... ehh. He also has a sister with... a sister with ME.”*
Staff 2: *“He’s an incredibly skilled snowboarder, he has the national record for his age group. So, he’s a really excellent snowboarder!”*
Staff 1: *“Wow, that’s great!”*
Staff 3: *“He has a sister with ME as well?”*
Staff 1: *“Yes he has a sister with ME that does not want to come here. She is perhaps struggling a bit more. Because he seems to be on an uphill slope. At least that’s my impression. And he’s been waking up early in the mornings, been up when we come to wake him.”* (…)
Staff 3: *“His father is very active and positive in the parent group.”*
Staff 1: *“Yeah... Good circadian... Seems that his circadian rhythm is on track. Eats regularly. I don’t know if there is anything more to say about him at the moment.”*
Staff 4: *“Quiet and shy in the breakfast group.”*
Staff 1: *“Yes, he is the only boy in the group now.”*
Staff 4: *“The only boy in the group.”*
[Laughter]
Staff 4: *“Of course it is a bit unfortunate as well.”*
Staff 5: *“They usually take that in their stride.”*
[Laughter]
Staff 2: *“He is very well organized... Athlete... They are often better at that...”*

In this presentation of Zach, it is his skills as an athlete that take center stage. The sister with ME is brought up but is not given much weight in the presentation. Zach is presented in line with his own illness narrative, as someone who was previously active, was unlucky to become ill, but now was on his way towards recovery. His own presentation of himself as someone for whom important values were to get a proper job and to be active and social was corroborated by the staff's descriptions of him being well organized, such as waking up early in the mornings and being an excellent snowboarder. This worked well to establish him as a *"classic"* patient that fit with the ideals and treatment philosophies at Birch Hill. That he seemed quiet and shy in this narrative was easily dismissed as a result of his being the only boy in the group, not a sign of deeper psychological issues.

During his stay at Birch Hill, Zach was validated by the staff for his maturity and his goals, as well as for his bravery and skills in snowboarding. The staff seemed positive and optimistic when talking about and to Zach, and they praised him for his achievements and his efforts, telling him that he would probably get well soon. They laughed a little about him being the only boy in the group and teased him and joked about the girls being crazy about him. Zach was accepted as one of the *"classic patients"*, one of those who had been unlucky and caught a virus, but also one who with the proper adjustment of activity and rest would have a good prognosis. As one of the staff expressed it quite early on in his stay: *"He's a cute kid. I have faith in him"*.

Grace was seen as a very ambitious girl

Grace was 18 years old when she came to Birch Hill. Her symptoms had started as an epileptic-like seizure four years previously. She had undergone extensive examinations in the hospital to try to determine the cause of the seizures, but the tests had been inconclusive. She had weekly seizures, and in addition struggled with fatigue, concentration problems and memory loss. Grace explained that she was not initially given a diagnosis, but that her family was told by her physician that it could be *"post-viral"*. She started to feel better when she found out that "*others had the same experiences and that I wasn't alone*", and when the doctors "*started looking at the whole picture instead of just checking one symptom at a time*".

Before she turned ill, she used to be a serious gymnast, training for the Olympics. After falling ill, she had to quit all of her after-school activities but had continued taking all her classes at school. She wanted to study quantum physics after she graduated from high school. In an interview she said that she was very determined to get good grades and that she worked hard to attain her goals. She lived with her younger sister and parents in a suburban area. Her father was an architect and her mother worked in urban planning. When formulating her goals for her stay at Birch Hill, Grace seemed to have appropriated a therapeutic language:

"We haven't been that concerned with finding out why it started or what to call it, but more interested in finding ways for me to go on and to live in the here-and-now."(...) "Now it's important for me to find things that make me happy in my day-to-day life, things to look forward to and to set myself small goals that I can work towards."

Despite the fact that Grace described her problems and her goals for her stay in a way that was well aligned with the treatment approach at Birch Hill, the staff soon categorized her as one of the *"complex"* cases. An illustration of how this shared understanding was established can be seen in a discussion in the first treatment meeting:

Staff 1: *"Grace is 18... She's been ill since 2011. This is a... She goes to X sports school. She has had high ambitions... Been doing gymnastics on a national level. We get the impression of a very ambitious girl. (...) It's not the classical ME girl we're dealing with. She is by far the most active in the group. She is also very outgoing. She took control in the breakfast group. (...) This is a girl that's pushed herself both physically and at school and everything. Working out 18 hours a week. So, it's not that odd. I think they* [the family] *understood some of the explanations he* [the doctor] *gave, but still she'd hoped to continue to attend all the classes. And then her plan is to go straight to university to study quantum physics* [Laughter]*... So, there are big plans! Eh. I don't know how compatible that is with her exhaustion…"*
Staff 2: *"Or you could turn it around and say that it cannot be exhaustion when there are so high demands. Even though you're in recovery.* [Nodding in agreement around table]
(…)
Staff 3: *"With a patient with her activity level it cannot be defined like that* [CFS/ME]. *Because that's just plain wrong."*
Staff 1: *"So that's why we think it's no classic… Whatever that is…"*

Here the scene-setting begins with presenting Grace as a *"very ambitious girl".* This places the causes for Grace's symptoms in her personality traits and her ambitions and in the fact that she has been a professional athlete. In contrast to Zach, where his athletic skills were exclusively presented as an asset, helping him to be organized and deal with his symptoms, these skills are in Grace's case being used to substantiate the claim that she is *"not a classical ME girl".* In this staff discussion one can see the outline of an explanatory model that assigns responsibility for the symptoms to Grace herself: her high ambitions, the fact that she kept pushing herself even after falling ill, and her personality traits such as taking control in the group and being outgoing and active. The construction of a particular identity for Grace is used to support a psychosocial theory of the causes behind her symptoms. Even the reality of her symptoms is called into question in this discussion: Can it really be that she has symptoms of exhaustion when her activity level remains this high?

Grace was not one of those patients who were initially seen as *"difficult"* because of the way she acted, but as in the case of Alicia, she too caused frustrations and conflict because her symptoms mystified the staff; they could not seem to agree on the causes and were unable to find ways to help her. One of the staff members described her frustrations like this:

"We're completely stuck with Grace. She came in like a freight train, she didn't want to change anything, so we weren't able to agree on anything to work on."

During Grace's four-week stay at Birch Hill, communication difficulties between her and the staff increased. As with Alicia, the staff could not agree on the causes of Grace's symptoms or the right treatment approach. Her symptoms even seemed to get worse during her stay and culminated in a rather dramatic hospital admission after a 12-hour long seizure-like episode following a climbing session. The staff struggled with how Grace's symptoms best should be understood, and different explanations vied for center stage over the course of her stay: the symptoms were linked to Grace's personality traits, to her ambitions, to a hypothesis of too much pressure and stress, to a potential underlying trauma of some kind, and eventually to family dynamics. Common to all the various explanations offered throughout Grace's stay was that they called the validity of the symptoms into question.

After a particularly difficult session with Grace in which the staff explored her progress, made suggestions for treatment and presented their theories on causality linked to family dynamics, while Grace resisted their attempts to arrange a family meeting, the staff talked amongst themselves. Here they elaborated on their explanatory theory in which Grace's mother was portrayed as being fragile, possibly struggling with anxiety, the father as putting too much pressure on Grace to perform at school and in sport, and the family as having difficulty in expressing and tolerating emotions, lacking an *"emotional language"*. *"This is so functional"* they concluded. They also expressed their frustrations at not being able to help Grace:

"She's miles from the bigger picture. We're sending her home in the exact same condition as before she came, maybe even worse! It's catastrophic!"

Discussion

The analysis of our four cases has demonstrated how patients were being "talked up" as suffering from either *"classic"* or *"complex"* illness in the interpersonal encounters of a clinical rehabilitation setting. Using an analysis inspired by discursive psychology has provided us with insights into how categories that are mobilized through discourses of illness, suffering and adolescence also intersect with categories such as gender and class in the construction of patients' subjectivities. This process can create either troubled or untroubled subject positions (Wetherell, 1998), leading to conflictual dimensions and unresolved illness paths, or to constructive dialogue and positive coping.

The staff at Birch Hill engaged in a form of diagnostic typecasting that linked different social categories and illness attributions in a way that classified patients as suffering from "real" or "factitious" illness. These categorizations did not correspond to different diseases or diagnoses, as all the adolescents in the group had already been defined as suffering from the same illness and diagnosed with CFS/ME before coming to Birch Hill, but were connected to moral aspects of the understanding of the patient as a person. For the patients in our study to be considered to suffer from legitimate illness and to be construed as credible and morally worthy of treatment, they needed to follow certain obligations and rules and work to fit in with normative ideals and regulations connected to several intersecting social categories.

In the *"classic"* cases, both patients and family members complied with these rules and regulations. There were no apparent communicative difficulties in the clinical encounters; patients and staff were able to come to an agreement on the explanatory model and the goals for treatment. The illness narratives and subjectification processes of the adolescents were supported by the staff.

The way that the *"classic"* patients presented themselves and wished to be seen by those around them was in alignment with the way staff and family members presented them. Psychosocial evidence was in their cases constructed in support of a physical illness attribution, further establishing their symptoms as legitimate and real. The interpretation and values connected to the personality traits, interests and social roles of the classic patients were furthermore used as corroborating evidence in the construction of their illness as "real" and of physical origin. They were not giving in to their illness and were positive copers, the contrast between who they were before they became ill and how they functioned now was emphasized, and evidence of potential psychosocial explanations (e.g. a sister with ME, an overinvolved mother, shyness or being too much of a "good girl") was played down and not given much weight in the presentations. This concurs with Horton-Salway's (2002) description of different kinds of narratives that construct "genuine physical cases" in GPs' reasoning about ME patients.

There can be several possible explanations for Zach and Madeleine being construed as *"classic"* patients with genuine physical illness. One is that both Zach and Madeleine fulfilled their roles as compliant patients; they did what they were told and did not ask critical questions that counteracted the staff's expertise and ability to uphold their role of being sympathetic and rational professionals. In this way, they complied with the signs, values and norms connected to the social category of appropriate patienthood. In addition, the way Madeleine and Zach performed other social categories like those of gender, class and age possibly intersected in a way that was in accordance with rules, norms and values in the specific context of Birch Hill and the majority culture in Norway at the time. Both Madeleine and Zach were of working-class traditional backgrounds, following in their parents' footsteps regarding occupation and education. They were described as active and social, as well as skilled in their highly gendered activities, being goal-oriented but never over-ambitious. The way adolescents come to understand themselves and their illness and the way they are understood by others are the result of how they position themselves within a variety of discourses (Staunæs, 2005). Because both Zach and Madeleine worked on discourses that were easily recognizable and normative in the social landscape to which they belonged, their subjectification in the process of becoming an adolescent on the way towards recovery from illness was perhaps more easily confirmed by those around them.

Several studies have demonstrated that the intersecting of social categories can create either troubled or untroubled subject positions, supporting or obstructing adolescents in their developmental paths (Haavind, 2014; Jansen, 2010; Staunæs, 2003, 2005). In order to understand how subject positions are created, we have to examine how various discourses come into play, and how actual persons make sense of them and accept, reject, oppose, reframe or ignore these discourses in an effort to make themselves intelligible. Subjectivities are constructed *in situ* to support an attributional story that manages such issues as accountability and blame. In CFS/ME, the physical impact of the illness is an important aspect and an especially controversial one because the precise medical status of the illness is at stake. Where the legitimacy of an illness itself is at stake, one is more likely to be treated as the type of person who is looking for secondary gain (Horton-Salway, 2001). For the patients, a continual distinction between mind and body in causal theories of disease therefore raises delicate issues affecting their subjectivities and credibility. Patienthood, illness attributions and subjectivity are thus linked in complex ways that affect adolescents' accountability as persons.

In contrast to the classic patients, Alicia and Grace did not manage to construct themselves in accordance with the rules and regulations connected to the social categories and discourses involved, thereby creating troubled subject positions (Wetherell, 1998). In cases such as those of Alicia and Grace, a struggle for power between the patients and the health professionals is seen as a result of the patients not readily accepting the professionals' explanations and treatment plans, being critical and opposing the suggestions being offered. By being active and ambitious, taking control and leadership in the group, and expressing their own opinions, these patients did not comply with the norms and regulations of the social categories to which they belonged. Both Alicia and Grace challenged the normativities at stake in their social landscape and had more unusual ways of positioning themselves within discourses of adolescence, gender and illness. Other studies have found that unusual intersections of social categories may result in troubled subject positions, making adolescents subject to policing practices and rendering them "the other" (Staunæs, 2005). In our *"complex"* cases, this could be seen as communicative challenges and contested issues in the clinical encounters and in the backstage talk of the staff.

In Alicia and Grace's presentations of self, they were unable to give convincing accounts of themselves as people who managed the delicate balance of fighting the illness and resting appropriately. Their illness attributions were treated by the staff as dysfunctional and as constituting part of the illness cycle itself, giving support to psychosomatic theories of causation. Psychosomatic illnesses are often treated as a category of "not quite legitimate illness", equated with the imaginary and contrasted with "real" disease (Kirmayer, 1988). It has been argued that psychosomatic explanations are often used as a moralistic device to shift the blame for the failure of medicine to understand, explain and treat illness (Yardley, 1996).

Doubt, contradiction and confusion are externalized to the uncooperative patient with several diffuse and vague symptoms, rather than being seen as a sign of the dubious or contradictory nature of clinical practice itself (Harper, 1999). The patients are seen as simply in denial of the real origin of their symptoms, and the refusal to agree with the staff in their explanatory theories is taken as further support for the claim that these patients are *"complex"*. The fluctuating intensity and character of their symptoms also complicated the staff's ability to perform their professional duties, and their abilities as competent and empathic helpers came under scrutiny and suspicion from both patients and parents, and possibly also from other professionals. Through their relapses and failure to recover from the symptoms, both Alicia and Grace thus failed to comply with the requirements of appropriate patienthood as defined by the staff.

Other studies have also found that in order to be considered to suffer from legitimate illness and to be construed as credible, patients need to follow certain obligations and rules connected to social categories. Patients have to get better as soon as possible, accept help, cooperate with health professionals and work to fit in with normative, gendered, biomedical expectations of correctness regarding symptomatic expression, assertiveness and appearance (Koekkoek, Hutschemaekers, Meijel & Schene, 2011; Li & Arber, 2006; Ryn & Burke, 2000; Werner & Malterud, 2003; Willems, Maesschalck, Deveugele, Derese & Maeseneer, 2005). Werner and Malterud (2003), for example, found that women with chronic pain had to work hard for credibility and dignity, making their symptoms socially visible, real and of a biomedical origin when consulting their doctors. This included finding the delicate balance between not appearing too weak or too strong, too healthy or too sick, too smart or too disorganized in the eyes of the doctor.

The communicative challenges that could be observed in the encounters between patients and staff at Birch Hill can be interpreted as the result of a complex interactional process in which normative conceptions of in/appropriateness connected to social categories played an important part. The categories involved in the local context of Birch Hill were those of classical/real CFS/ME and factitious/complex CFS/ME, but also other intersecting categories like those of gender, adolescence, personality, social status and class. In this article, these categories are not treated as indicating what is inherently wrong with the patients but rather as illness attributions that are discursively constructed by speakers in the situated context of accounting for themselves to other people. In this way, the categories are never completely fixed but are fluid and changing. The analytic framework in this article is concerned with the rhetorical and interactive context of the speakers and how illness attributions work to manage blame and personal accountability (Edwards & Potter, 1992; Potter & Wetherell, 1987). We are looking at how local conceptions of appropriate patienthood are “made” in the daily interactions and talk between staff and patients, how the patients place the social categories that they are offered to use in their own self-understanding and their management of their illness, and how this creates challenges or opportunities in their way towards recovery.

Conclusions and implications

Through our analysis of four cases, we have demonstrated that for adolescents diagnosed with CFS/ME following a rehabilitation program based on a biopsychosocial understanding, the process of recovery might take two rather different directions. Either the adolescents’ understanding of their own suffering and future prospects in life is confirmed in the ongoing communication in the clinical encounters, or it brings forward contested issues about being a proper patient and an accountable person. All of the patients presented here struggled to achieve credibility and validation of being legitimately ill, and to define their subjectivities as adolescent girls or boys with plans and dreams for the future in their trajectory towards adulthood. Our study demonstrates how several intersecting categories might be involved, creating certain spaces of possibilities for being in the world, while excluding others. The processes of categorization thus work to feed back onto the people that are categorized, changing interactional patterns, illness experiences, senses of self and perceptions of possibilities. The process of categorization can therefore be said to have implications for adolescents’ illness paths and subjectification processes. To encourage mutual recognition in clinical encounters and lay the foundation for more constructive interactions, health professionals need to reflect upon the hidden discourses and norms on which they base their understanding and categorization of their patients. In order to create clinical relationships that cultivate an atmosphere of trust, empathy and spaces for intersubjective relatedness, professionals working with challenging cases should be given the opportunity and time for advice and reflexive conversations with other experienced professionals.

References

Aronoff, G. (1985). *Evaluation and Treatment of Chronic Pain*. Baltimore: Urban and Schwarzenberg.

Aronowitz, R. A. (1998). *Making Sense of Illness. Science, Society, and Disease.* Cambridge: Cambridge University Press.

Åsbring, P. & Närvänen, A. L. (2003). Ideal versus Reality: Physicians' Perspectives on Patients with Chronic Fatigue Syndrome (CFS) and Fibromyalgia. *Social Science & Medicine, 57*(4), 711-720. DOI: 10.1016/S0277-9536(02)00420-3.

Beard, G. (1881). *American Nervousness, Its Causes and Consequences: A Supplement to Nervous Exhaustion.* New York: Putnam.

Boulton, T. (2018). Nothing and Everything: Fibromyalgia as a Diagnosis of Exclusion and Inclusion. *Qualitative Health Research, 29*(6), 809-819. DOI: 10.1177/1049732318804509.

Buchbinder, M. (2011). Personhood Diagnostics: Personal Attributes and Clinical Explanations of Pain. *Medical Anthropology Quarterly, 25*(4), 457-478. DOI: 10.1111/j.1548-1387.2011.01190.x.

Burman, E. & Parker, I. (eds.) (1993). *Discourse Analytic Research: Repertoires and Readings of Texts in Action.* London: Routledge.

Burr, V. (1995). *An Introduction to Social Constructionism.* Florence, KY, US: Taylor & Frances/Routledge.

Crenshaw, K. (1994) Mapping the Margins: Intersectionality, identity politics, and violence against women of color. In M. Fineman & R. Mykitiuk (Eds.). *The Public Nature of Private Violence.* New York: Routledge.

Davies, B. Harré, R. (1990). Positioning: The Discursive Production of Selves. *Journal for the Theory of Social Behavior, 20*(1), 43-63. DOI: 10.1111/j.1468-5914.1990.tb00174.x.

Desjarlais, R. (2000). The makings of Personhood in a Shelter for People Considered Homeless and Mentally Ill. *Ethos, 27*(4), 466-489. DOI: 10.1525/eth.1999.27.4.466.

Edwards, D. (1997). *Discourse and Cognition.* London: Sage.

Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129-136. DOI: 10.1126/science.847460.

Fink, P. & Rosendal, M. (2015) (Eds.) Functional disorders and Medically Unexplained Symptoms. Assessment and Treatment. Aarhus: Aarhus University Press.

Fordyce, W. (1976). *Behavioral Methods for Chronic Pain and Illness.* St. Louis: C. V. Mosby.

Foucault, M. (1977). *Discipline and Punish: The Birth of the Prison.* Hammondsworth: Penguin.

Foucault, M. (1988). Madness and Civilization. A History of Insanity in the Age of Reason. New York: Vintage Books.

Furness, P., Glazebrook, C., Tay, J., Abbas, K. and Slaveska-Hollis, K. (2009). Medically unexplained physical symptoms in children: exploring hospital staff perceptions. *Clinical Child Psychology and Psychiatry, 14*(4), 575-587. DOI: 10.1177/1359104509338437.

Goffman, E. (1971). *The Presentation of Self in Everyday Life.* Harmondsworth, Middlesex: Penguin.

Goffman, E. (1981). *Forms of Talk.* Oxford: Blackwell.

Good, B. J. (1994). *Medicine, Rationality, and Experience: An Anthropological Perspective.* Cambridge: Cambridge University Press.

Good, B. & Good, M. J. D. (1993). Learning Medicine: The Constructing of Medical Knowledge at Harvard Medical School. In S. Lindenbaum & M. Lock (Eds.) *Knowledge, Power and Practice. The Anthropology of Medicine and Everyday Life* (pp. 81-107). Berkeley: University of California Press.

Goodman, N. (1978). *Ways of Worldmaking.* Indianapolis: Hackett.

Grabowski, D. & Rasmussen, K. K. (2014). Adolescents' health identities: A qualitative and theoretical study of health education courses. *Social Science & Medicine, 120*, 67-75. DOI: 10.1016/j.socscimed.2014.09.011.

Gremillion, H. (2003). *Feeding Anorexia. Gender and Power at a Treatment Center.* Durham: Duke University Press.

Haavind, H. (2007). Accountability in persons: What is in the telling to others about yourself? In D. Staunæs & J. Koefoed (Eds.) *Magtballader (Plays in Power)* (pp. 159-178). Copenhagen: Danmarks Pædagogiske Universitets Forlag.

Haavind, H. (2014). «Who does het hink he is?" Making new friends and leaving others behind – on the path from childhood to youth. In R. M. Scott & D. M. Søndergaard (Eds.) *School Bullying: New Theories in Context* (pp. 129-158). Cambridge: Cambridge University Press.

Hacking, I. (1986). Making up People. In T. L. Heller, M. Sosna, & D. E. Wellbery (Eds.) *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought* (pp. 222-236). Stanford, CA: Stanford University Press.

Hacking, I. (1995). The Looping Effects of Human Kinds. In D. Sperber, D. Premack, & A. J. Premack *Casual Cognition: A Multidiciplinary Debate* (pp. 384-394). Oxford: Claredon.

Hacking, I. (1999). *The Social Construction of What?* Massachusetts: Harvard University Press.

Halligan, P. & Mansel, A. (2006). *The power of belief: psychosocial influences on illness, disability and medicine.* Oxford: Oxford University Press.

Harrington, A. (2008). *The Cure Within: A History of Mind-Body Medicine.* New York: W. W. Norton.

Harper, D. J. (1999). Tablet talk and depot discourse: Discourse analysis and psychiatric medication. In C. Willig (Ed.) *Applied discourse analysis. Social and psychological interventions* (pp. 125-144). Buckingham: Open University Press.

Harsh, J., Hodgson, J., White, M. B., Lamson, A. L. & Irons, T. G. (2015). Medical Residents' Experiences with Medically Unexplained Illness and Medically Unexplained Symptoms. *Qualitative Health Research, 26*(8), 1091-1101. DOI: 10.1177/1049732315578400.

Hauge, M. I. (2009). *Doing, Being and Becoming. Young people's Processes of Subjectivation Between Categories of Age.* (Doctoral Dissertation). Department of Psychology, Faculty of Social Sciences, University of Oslo, Norway.

Helsedirektoratet (2015). *Nasjonal Veileder. Pasienter med CFS/ME: Utredning, diagnostikk, behandling, rehabilitering, pleie og omsorg* [National Guidelines. Patients with CFS/ME: Diagnostics, treatment, rehabilitation, and care] Helsedirektoratet, Avdeling rehabilitering og sjeldne tilstander. Retrieved from: https://helsedirektoratet.no/retningslinjer/nasjonal-veileder-pasienter-med-cfsme-utredningdiagnostikk-behandling-pleie-og-omsorg

Horton-Salway, M. (2001). Narrative Identities and the Management of Personal Accountability in Talk about ME: A Discursive Psychology Approach to Illness Narrative. *Journal of Health Psychology, 6*(2), 247-259. DOI: 10.1177/135910530100600210.

Horton-Salway, M. (2002). Bio-psycho-social reasoning in GP's case narratives: the discursive construction of ME patients' identities. *Health: An interdisciplinary Journal for the study of Health, Illness and Medicine, 6*(4), 401-421. DOI: 10.1177/136345930200600401.

Jansen, A. (2010). Victim or Troublemaker: Young People in Residential Care. *Journal of Youth Studies, 13*(4), 423-437. DOI: 10.1080/13676261003801770.

Jones, G. (2009). *Youth.* Cambridge: Polity Press.

Kirmayer, L. J. (1988). Mind and body as metaphors: Hidden values in biomedicine. In M. Lock &D. R. Gordon (Eds.) *Biomedicine Examined* (pp. 57-93). Dordrecht: Kluwer Academic Publishers.

Kirmayer, L. J., Groleau, D., Looper, K. J. & Dao, M. D. (2004). Explaining Medically Unexplained Symptoms. *The Canadian Journal of Psychiatry, 49*(10), 663-672. DOI: 10.1177/070674370404901003.

Kitzinger, S. & Wilkinson, S. (1996). Theorizing Representing the Other. In S. Wilkinson & S. Kitzinger (Eds.) *Representing the Other: A Feminism and Psychology Reader* (pp. 1-32). London: Sage.

Kleinman, A. (1994). Pain & Resistance: The Delegitimation and Relegitimation of Local Worlds. In M. J. D. Good, P. E Brodwin, B. J. Good & A. Kleinman (Eds.) *Pain as Human Experience. An Anthropological Perspective* (pp. 169-197). Los Angeles: University of California Press.

Koekkoek, B., Hutschemaekers, G., Meijel, B. V., & Schene, A. (2011). How do patients come to be seen as 'difficult'?: A mixed-methods study in community mental health care. *Social Science & Medicine, 72*, 504-512. DOI: 10.1016/j.socscimed.2010.11.036.

Kornelsen, J., Atkins, C., Bronwell, K., & Woollard, R. (2016). The Meaning of Patient Experiences of Medically Unexplained Physical Symptoms. *Qualitative Health Research, 26*(3), 367-376. DOI: 10.1177/1049732314566326.

Kotarba, J. (1983). *Chronic Pain, Its Social Dimensions.* Beverly Hills: Sage.

Li, S. & Arber, A. (2006). The Construction of Troubled and Credible Patients: A Study of Emotion Talk in Palliative Care Settings. *Qualitative Health Research, 16*(1), 27-46. DOI: 10.1177/1049732305284022.

Lian, O. S. & Lorem, G. (2016). "I Do Not Really Belong Out There Anymore": Sense of Being and Belonging Among People With Medically Unexplained Long-Term Fatigue. *Qualitative Health Research, 27*(4), 474-486. DOI: 10.1177/1049732316629103

Lian, O. S. & Robson, C. (2017). "It's incredible how much I've had to fight." Negotiating Medical Uncertainty in Clinical Encounters. *International Journal of Qualitative Studies on Health and Well-Being, 12*(1), 1392219. DOI: 10.1080/17482631.2017.1392219

Lupton, D. (1994). *Medicine as culture: illness, disease and the body in western societies*. London: Sage.

Malson, H. (2013). Qualitative Methods from Psychology. In I. Bourgeault, R. Dingwall & R. DeVries (Eds.) *The Sage Handbook of Qualitative Methods in Health Research* (pp. 193-211). London: Sage.

Mischler, E. G. (1984). *The discourse of medicine. The dialectics of medical interviews.* Norwood, NJ: Ablex.

Nettleton, S., O'Malley, L. Watt, I. & Duffey, P. (2004). Enigmatic Illness: Narratives of Patients who live with Medically Unexplained Symptoms. *Social Theory & Health, 2*(1), 47-66. DOI: 10.1057/palgrave.sth.8700013.

Østbye, S. V., Kvamme, M. F., Wang, C. E. A., Haavind, H., Waage, T. & Risør, M. B. (2018a). 'Not a film about my slackness': Making sense of medically unexplained illness in youth using collaborative visual methods. *Health: An interdisciplinary Journal for the study of Health, Illness and Medicine,* 1-21. DOI: 10.1177/1363459318785696

Østbye, S. V., Wang, C. E. A, Granheim, I. P., Kristensen, K. E. & Risør, M. B. (2018b). Epistemological and Methodological Paradoxes: Secondary Care Specialists and their Challenges working with Adolescents with Medically Unexplained Symptoms. *International Journal of Mental Health Systems, 12*, 52. DOI: 10.1186/s13033-018-0232-0.

Potter, J. & Wetherell, M. (1987). *Discourse and Social Psychology.* London: Sage.

Radley, A. & Billig, M. (1996). Accounts of health and illness: Dilemmas and representations. *Sociology of Health & Illness, 18*(2), 220-240. DOI: 10.1111/1467-9566.ep10934984.

Rebman, A. W., Aucott, J. N., Weinstein, E. R., Bechtold, K. T., Smith, K. C., Leonard, L. (2015). Living in Limbo: Contested Narratives of Patients With Chronic Symptoms Following Lyme Disease. *Qualitative Health Research, 27*(4), 534-546. DOI: 10.1177/1049732315619380.

Rhodes, L. A. (1991). *Emptying Beds: The Work of an Emergency Psychiatric Unit*. Berkeley: University of California Press.

Riessman, C. K. (1993). *Narrative analysis.* London: Sage.

Ring, A., Dowrick, C. F., Humphris, G. M., Davies, J. & Salmon, P. (2005). The somatising effect of clinical consultation: what patients and doctors say and do not say when patients present medically unexplained physical symptoms. *Social Science & Medicine, 61*(7), 1505-1515. DOI: 10.1016/j.socscimed.2005.03.014.

Ryn, M. V. & Burke, J. (2000). The effect of patient race and socio-economic status on physicians' perceptions of patients. *Social Science & Medicine, 50*, 813-828. DOI: 10.1016/S0277-9536(99)00338-X.

Salmon, P., Ring, A., Dowrick, C. F. & Humphris, G. M. (2005). What do general practice patients want when they present medically unexplained symptoms, and why do their doctors feel pressurized? *Journal of Psychosomatic Research, 59*(4), 255-260. DOI: 10.1016/j.psychores.2005.03.004.

Shotter, J. (1993). *Conversational Realities: The Construction of Life through Language.* London: Sage.

Sowinska, A. & Czachowski, S. (2018). Patients' Experiences of Living with Medically Unexplained Symptoms (MUS): A Qualitative Study. *BMC Family Practice, 19*(23). DOI: 10.1186/s12875-018-0709-6

Sowinska, A. (2018). "I didn't want to be Psycho no. 1": Identity Struggles in Narratives of Patients presenting Medically Unexplained Symptoms. *Discourse Studies, 20*(4), 506-522. DOI: 10.1177/1461445618754433.

Søndergaard, D. M. (2002). Poststructural Approaches to Empirical Analysis. *Qualitative Studies in Education, 15*(2), 187-204. DOI: 10.1080/09518390110111910.

Sønderggard, D. M. (2005). Making Sense of Gender, Age, Power and Disciplinary Position: Intersecting Discourses in the Academy. *Feminism & Psychology, 15*(2), 189-208. DOI: 10.1177/0959353505051728.

Staunæs, D. (2003). Where Have all the Subjects Gone? Bringing Together the Concepts of Intersectionality and Subjectification. *Nora: Nordic Journal of Women's Studies, 11*(2), 101-110. DOI: 10.1080/08038740310002950.

Staunæs, D. (2004). *Køn, etnicitet og skoleliv* (Gender, Ethnicity and Life at School). Copenhagen: Samfundsliteratur.

Staunæs, D. (2005). From Culturally Avant-Garde to Sexually Promiscuous: Troubling Subjectivities and Intersections in the Social Transition from Childhood into Youth. *Feminism and Psychology, 15*(2), 149-167. DOI. 10.1177/0959-353505051719.

Werner, A. & Malterud, K. (2003). It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Social Science & Medicine,* 57, 1409-1419. DOI: 10.1016/S0277-9536(02)00520-8.

Werner, A., Steihaug, S. & Malterud, K. (2003). Encountering the Continuing Challenges for Women With Chronic Pain: Recovery Through Recognition. *Qualitative Health Research, 13*(4), 491-509. DOI: 10.1177/1049732302250755.

Wessely, S. (1997). Chronic fatigue syndrome: A 20th century illness? *Scandinavian Journal of Work, Environment & Health, 23*(3), 17-34.

Wetherell, M. (1998). Positioning and Interpretative Repertories: Conversations Analysis and Poststructuralism in Dialogue. *Discourse and Society, 9*(3), 387-412. DOI: 10.1177/0957926598009003005.

Williams, P. G., Holmbeck, G. N. & Greenley, R. N. (2002). Adolescent Health Psychology. *Journal of Consulting and Clinical Psychology, 70*(3), 828-842. DOI: 10.1037/0022-006X.70.3.828.

Willems, S., De Maesschalck, S., Deveugele, M., Derese, A. & De Maeseneer, J. (2005). Socio-economic status of the patient and doctor-patient communication: does it make a difference? *Patient Education and Counseling, 65,* 139-146. DOI: 10.1016/j.pec.2004.02.011.

Wilson, A. C., Moss, A., Palermo, T. M. & Fales, J. L. (2014). Parent pain and catastrophizing are associated with pain, somatic symptoms and pain-related disability among early adoloscents. *Journal of Pediatric Psychology, 39*(4), 418-426. DOI: 10.1093/jpepsy/jst094.

Yardley, L. (1996). Reconciling discursive and materialist perspectives on health and illness: A reconstruction of the biopsychosocial approach. *Theory and Psychology, 6*(3), 485-508. DOI: 10.1177/0959354396063008.