UiT The Arctic University of Norway

Faculty of Health Sciences, Department of Community Medicine

# Suffering, agency and care in medically unexplained symptoms (MUS)

An ethnographic study of the social course and reframing of MUS in Norwegian youth

Maria Fredriksen Kvamme

A dissertation for the degree of Philosophiae Doctor – February 2020

Table of Contents

# Acknowledgements

Many people have contributed to this thesis. First of all, I would like to thank the young people who have shared their time and experience with me. Their teachings and our mutual discoveries have been personally rewarding and have been essential for the findings and contributions presented in the following chapters. I would also like to thank their parents for extending their trust, allowing me into their homes and/or to be close to their loved ones. Secondly, I would like to thank the professionals in various roles who have extended their open-minded curiosity, invited me to their schools, recruited some of the young participants and participated in various forms of ethnographic conversations and interviewing.

This thesis has been financially supported as a faculty scholarship in the Faculty of Health Sciences of UiT The Arctic University of Norway. Additional funding was also provided by the General Practice Research Unit at the Institute of Community Medicine, where I worked and was supported by a warm and intellectually stimulating environment, excellent practical advice and scholarly supervision. My main supervisor, Mette Bech Risør, Professor of Medical Anthropology in the General Practice Research Unit, has demonstrated endless patience, competency and presence, warmly supporting my developing confidence as a researcher while simultaneously expecting the best. Catharina Elisabeth Arfwedsson Wang, Professor of Psychology in the Institute of Psychology, and Trond Waage of the Institute of Visual Anthropology in the Department of Social Sciences, have also supported this work as my co-supervisors. Catharina has provided amazing intellectual clarity, well-grounded knowledge and experience related to therapeutic work with young people with MUS and high-quality moral support. Trond has provided very inspiring conversations, visions and experience from visual methods in collaborative research with young people, as well as the methodological framework needed for our visual approach. I feel truly privileged for having had the opportunity to receive this scholarship and for having had access to such excellent supervisors.

Furthermore, in the initial planning, and in parts of my fieldwork and analysis leading up to the first paper, I have collaborated closely with clinical psychologist Silje Vagli Østbye, the other PhD student conducting psychologically oriented fieldwork focusing on the encounters of young people with MUS with specialist services. Silje has been a committed, reflective and enjoyable travelling companion, making my initial journey across epistemological and practical obstacles less lonely. Hanne Haavind, Professor of Social Psychology also contributed her framework for life form interviewing and her considerable experience to a most intellectually rewarding analytic process in the project group leading up to the first paper. Finally, Helen Brandstorp, leader of the Norwegian Centre for Rural Medicine (NSDM), located with the General Practice Research Unit, has offered a flexible and smooth transition from the final touches to this thesis and related tasks to a very relevant employment opportunity.

Last but not least, I would like to thank my friends and family for making this possible. When I first heard about the research fellowship leading up to this thesis, my family, close friends and women in my network strongly supported my decision to take the plunge. I would like to thank my parents who have always inspired me to explore. I am especially grateful for the unending patience, understanding and support from my children and the most amazing husband in the world.

# Preface

The project and work leading up to this thesis have been my introduction to the sub-field of medical anthropology. I have entered this field and the topic of medically unexplained symptoms in youth from a distinct angle, as a middle-class Norwegian woman performing fieldwork "at home" for the second time, after eight years as an outreach youth worker. The roles of the social worker and anthropologist differ in many respects, but also share a few characteristics that may have left their mark on this thesis, notably an engagement (preoccupation) with social aspects and methodological proximity to everyday life settings. Doing ethnographic fieldwork "at home" is a disputed endeavour, given that our object of research is often based on ideas of "the other within", whose experiences may differ considerably from one's own. My proximity to different research and practical fields concerning youth and public efforts to provide care and work with young people have changed over the years, with the changing topics of importance and with my private and professional roles. In my first fieldwork for a master's degree in visual and social anthropology as a relatively young student, I explored social processes of integration and marginalization in a class of young refugees. I performed participatory observation in the secondary school which I had myself attended (Kvamme Steinsvik, 2002). The pupils in this class expressed a strong community spirit as "the foreigners", across gender boundaries, nations of origin, world religions and languages, partly constituted by their mutual experiences of being "the others". Conversely, the ethnic Norwegian pupils distanced themselves based on the "foreign" pupils' inability to "be sociable" in what they took to be appropriate ways. Using film, I explored the parallel everyday life experiences of girls born in Somalia and the ethnic Norwegian classmates they were meant to "be integrated with" in school. To explore the potential for understanding, and inspired by the performative role of film (Rouch & Morin, 1961; Loizos, 1992), I then invited the girls to reflect upon the filmed material and saw them laughing together, perhaps for the first time.

As an outreach youth worker, I later saw sociocultural expectations and ideas about normal, healthy and good youth transitions expressed through categories of youth problems in health and social care policies and services, as well as in communities of exclusion among young boys and girls struggling with various health and social challenges. From different angles and roles in the community, I have found the balance between empowerment and recognition of various experiences of marginalization and suffering in youth a delicate one to tread. On the one hand, problem-focused encounters and gazes of concern in care professions and research (Henningsen et al., 2008; Sandberg & Pedersen, 2006) have the potential to promote rhetoric's of victimhood rather than change. On the other hand, strong rhetoric of empowerment risks excluding some, potentially adding the burden of failure to their suffering (e.g. Andersen & Pors, 2016). Using film and other engaging activities with young service users seemed in my experience to bring a complementary sense of understanding, beyond some of the potential limitations of relationships between youth and different kinds of carers.

Presentations of medically unexplained physical complaints were common among the young people considered by the municipality as "at risk", but were not our main concern at the time. Over the last five or so years, however, a new, local category of health challenges in youth began to be described informally. The "home sitters" (hjemmesitterne) were experienced as less verbally expressive than other young people receiving our services. They were defined by their absence from social settings such as school, street corners or spare-time activities and by presentations of often "diffuse" mental and/or physical complaints. Despite an overall understanding of underlying psychosocial aspects, a great deal of uncertainty existed across services about how to understand and help these, often silent, youngsters. Admittedly, I often left it to colleagues with more experience with "those kinds of problems" to attempt to make sense of their symptoms. In this research project, the concept of medically unexplained symptoms and the field of medical anthropology more generally have provided a new lens with which to explore illness experiences in youth and the care they receive. A basic assumption based upon previous research and practical experience has been that the lack of explanations according to certain criteria diverges from the way we organize health and sickness in our society and leads to communicative challenges in professional care encounters and everyday life contexts. Further, symptoms and illness experiences with no overlapping disease category are interesting anomalies to explore from the viewpoints of both social science and practice.

# Summary

This thesis focuses on the understanding and management of medically unexplained symptoms (MUS) in youth. Communicative challenges and the role of communication in making sense of symptoms are central to the research field of MUS, as shown in the scientific and biomedical conceptualizations of the phenomenon, in practitioners' experiences of dilemmas in health communication and in the challenges of patients with MUS to understand and manage their illnesses. Persistent MUS may develop into chronic conditions, with debilitating consequences for young people's social lives and transitions to adulthood, but most research has focused on etiology and adult sufferers of MUS. More research is needed to better understand young people's experiences, how they cope with their illness and the meaning of social and moral aspects in a contemporary context of youth.

The objective of this research project was to provide knowledge of perspectives, concerns and management strategies of young people with persistent bodily complaints, where initial medical examinations have been unable to fully explain their condition, and to explore patterned cultural and professional logics, perspectives and communicative practices that influence the development of young subjects and their health-seeking practices in everyday life and the primary health and social care sector. This thesis is a multi-sited assemblage ethnography based upon fieldwork over eighteen months in 2015 and 2016 in a northern Norwegian town. The fieldwork included participant observation in everyday school and home contexts of Norwegian youth, interviewing young participants experiencing persistent symptoms and professionals playing a part in communicative responses to MUS, and collaborative reflexive film dialogue with some of the young participants. The symptoms included fatigue, gastrointestinal problems and/or bodily pain. The professionals included school nurses, teachers, school advisors, social workers and GPs in three purposively selected high schools and primary health and social care settings. Analysis was informed by anthropological theoretical discussions on social suffering, subjectivity and youth.

Paper I demonstrates the concerns and extensive meaning-making efforts of a 16-year-old boy suffering from undiagnosed fatigue, and shows how our visual collaborative process facilitated the communication of embodied experiences and a mutual process of making sense of MUS in youth. Paper II identifies a broad range of professionals in school settings and

primary health care engaged in interpretation, care and routine management of young people's persistent symptoms. It also demonstrates an emphasis among all the professionals on social explanations as well as two modalities of what we have called *careful expression*, whereby the professionals tinker with a logic of care to counteract other logics involved, overcome communicative dilemmas and support the constitution of empowered subjects. Paper 3 illustrates the emphasis by the young participants on the social consequences of their illness and an orientation towards health as more than achieving a cure for their dys-appearing bodies. We identify two modalities of self-care, aimed towards "fixing" aspects in their lives to overcome their suffering and reflexively navigating temporal and relational aspects of their social environments. Their navigation seems informed by social and moral expectations and the quest for alternative qualifying subject positions, but also by subjectivity, ordinary ethical sensibilities and forms of creative cultural production.

Our findings adds to the literature and align with existing studies on the particular challenges facing young people experiencing MUS, to belong and participate in a context of youth. They demonstrate the importance of their own everyday life projects and efforts at meaning making that take place beyond the clinic, easily escaping the attention of professionals involved in their care. We also show that their efforts seem more oriented towards an imaginary of youth than towards a medical imaginary. Our findings furthermore demonstrate the central role of a logic of care in experienced professional´s communicative responses, and show an experience-based approach to achieving potentially empowering explanations, relevant for a broad range of professions in school and primary health and social care settings. An overarching theme in the field is of MUS in youth as a malleable "problem" and phenomenon, negotiated and formed through processes of reflexive negotiation of meaning that seems expressed and constituted by the "daily grind" (Wahlberg 2018, p. 13, 15) of responses in all sites. Our findings also suggest however, the need for additional reframing on higher levels of organization, to address social aspects of suffering beyond the level of the individual young person and health encounter.

# List of papers

Paper I:

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

Authors: Silje Vagli Østbye*, Maria Fredriksen Kvamme*, Catharina Elisabeth Arfwedson Wang, Hanne Haavind, Trond Waage, Mette Bech Risør

*These authors contributed equally and share first authorship

Journal: Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, published 2018

Paper II:

Title: Careful expressions of social aspects: How local professionals in high school settings, municipal services and general practice communicate care to youth presenting persistent bodily complaints

Authors: Maria Fredriksen Kvamme, Catharina Elisabeth Arfwedson Wang, Trond Waage, Mette Bech Risør

Journal: Health & Social Care in the Community, published 2019

Paper III:

Title: ‘Fixing my Life’: Young People’s Everyday Efforts towards Recovery from Persistent Bodily Complaints

Authors: Maria Fredriksen Kvamme, Catharina Elisabeth Arfwedson Wang, Trond Waage, Mette Bech Risør

Journal: Anthropology & Medicine, accepted for publication 2019

# 1 Introduction

This thesis focuses on meaning making and management of young people’s persistent and constraining bodily symptoms in light of their everyday experiences, their priorities and how they organize their lives in school settings and in routine primary health encounters. It stems from a broader multidisciplinary research project on communicative challenges in the understanding and treatment of medically unexplained symptoms in youth (COCHA), and builds upon ethnographic fieldwork in a Norwegian town and anthropological theoretical frameworks. The category “medically unexplained symptoms” (MUS) denotes a social situation and clinical predicament where persistent illness experiences do not overlap with biomedical frameworks and systems of classification (Kirmayer, 2000; Jutel, 2010). Although the concept originally emerged within biomedical frameworks in specialist care from the perspectives of health professionals (Creed et al., 2010), the contemporary research field of MUS includes social science perspectives in addition to medical and psychological perspectives, and focuses on several points of view and social settings beyond the specialist clinic, such as primary care and everyday life. Communicative challenges and the role of communication in making sense of symptoms are central to this broader field, as shown in scientific and biomedical conceptualizations of the phenomenon, in practitioners’ experiences of dilemmas in health communication and in the challenges of young people with persistent symptoms to understand and manage their illnesses. MUS is a designation and term that belongs admittedly to a medical vocabulary and a medical understanding of an illness phenomenon. Throughout the studies done for this thesis and throughout writing this thesis, I have reflected, scrutinized and examined what this term consists of, where it belongs in the landscape of either medical professional discourses, folk discourses or social science discourses, how I have myself been complicit in using it and probably influencing my field (though always followed up with extreme reflexivity), and ultimately how to grasp its ramifications for the lives of my young participants. Alternative terms I could have used are ‘contested illness’ or simply ‘persistent symptoms’ as I return to later. In the end, I mainly use the term MUS in the descriptions referring to medical research, but I hope to use it conscientiously and multi-facetted, critical, while presenting the different positions I think are necessary to lay out what the term contains. This is the way, the following paragraphs are to be read.

First, I begin by giving a brief description of the local Norwegian context in relation to educational conditions and health and illness in youth. I then present research literature from the field of knowledge relating specifically to MUS and communication, including the less developed topic of communication with young people with MUS. The presentation of background knowledge of MUS and communication consists of short introductions to three main topic areas. The first is the background framework represented by biomedical and epidemiological conceptualizations of MUS as a challenging phenomenon to grasp, classify, explain and treat. The second area is research on communicative challenges in MUS, particularly as manifested in clinical encounters in primary care. Finally, I consider contributions from qualitative research on patient experiences of communicative challenges and efforts of meaning making in health encounters, everyday life and youth relating to the phenomenon. In part 1.3 of the introduction, I move on to present the theoretical framework that has guided the analysis, related to anthropological conceptualizations of suffering, subjectivity and youth.

## 1.1 Health and illness in youth: The Norwegian context

*"Young people are stressing themselves sick. Increasing numbers are being hospitalized". (Front-page headline in national newspaper spring 2016, my translation)*

This thesis is based on fieldwork during 2015 and 2016 in a coastal university town in the north of Norway, a town with a history of old fishing traditions combined with urban and international impulses. As the biggest town in the region, it attracts young people from the surrounding districts to its many publicly funded educational institutions. Several different types of high schools with classes going from vocational training to university preparation are to be found in the city apart from a university that has integrated all colleges of higher education over the last decade. The city is in many ways characterized by its younger citizens and many services and institutions speak to their wishes - the many offers in sports and exercise, the lively cultural life (music, dance, exhibitions etc) and an expanding housing possibility for either rent or sale. Young people in this town seem to engage in education and leisure activities, creating their identities as young Norwegian citizens and moving towards a more and more knowledge-based society. Several scholars have explored societal changes in late modernity affecting the social constitution of youth and Norwegian socialization ideals. Øia and Vestel (2014) argue that the generation gap formed in the transition from industrial and agricultural society to the knowledge society is closing, due to new demands on all age groups to remain flexible and creative, and that a new, more adapting and compliant youth role has formed along with changed roles for their parents. Young people in the North of Norway have been affected by gradual changes in the labour market especially occurring in the 1990s, which reduced or postponed opportunities in the country as a whole to take up traditional occupations and manual labour (Gerard 1993, Pedersen & Moilanen 2012). These developments led to national state reform, granting all up until the year they become twenty years old the right to public education/high school (Pedersen and Moilanen 2012). Children and youth have been shown to spend more of their time in kindergarten and school than earlier, and their upbringing has become increasingly regulated and controlled (Nordahl, 2009, cited in Vike 1994). Gullestad (1996) also points to a potential convergence between new ideals she sees being transmitted to young generations in Norway by their parents, notably autonomous self-realization, creativity and flexibility, which are competences needed by capitalist liberal markets. Hegna, Ødegård and Strandbu critically ask whether a more achievement-oriented culture and communication “disciplining young people’s futures” (2013, p. 5) has emerged that may cause psychological stress (ibid.). Several debates in newspapers and among politicians and educational professionals have discussed ‘the right to education’ and possible consequences. Parts of the debates are concerned that “dropouts” are high simply because not all young people may be ready for high school, a problem that might create disappointment and low self-esteem in one’s life and personal skills. This in turn is easy to relate to poor thriving and possible ill health. Consequently, health problems have been associated with challenges in completing high school in Norway (De Ridder et al., 2013), and a number of front-line services and professions provide care and interpretation of young people’s health complaints, especially when these affect current or expected educational pathways.

However, the findings in this thesis must also be understood within the particular frame of the Norwegian welfare state. Public regulations, interventions and services in Norway aim to resolve social inequalities and enhance the health of the population, and are widely accepted as a common good in line with egalitarian ideals (Halvorsen, 2007; Vike, 1994). Critical approaches have argued, however, that ambitious “welfare state” intervention and a cultural and semantic confounding of equality with similarity in Norway produce narrow spaces of normalcy defined by the middle class (Gullestad, 2001; Rugkåsa, 2011; Vike, 1994, 2004, Lien 2001) contribute to reproducing inequality, intervene in people’s everyday lives and affect subject formation (Markussen 2009, Rugkåsa, 2010). Public concern about the problem of pupils dropping out of high school for example, may on the one hand be traced back to international efforts (involving transnational organizations such as the OECD and EU) to measure and rationalize young people’s transition into the workforce (Vogt, 2017). On the other hand, Norwegian definitions of what constitutes a “drop-out” are particularly inclusive, resulting in an “impatient” public discourse that defines as problematic young people who take their time to finish their education because they are struggling, or want to take a break or change paths (ibid., p. 10). As mentioned above, drop-out is even related to or explained within a health discourse, making a connection easy to draw between the expectations concerning health that the society puts on persons ‘at risk’ and young pupils in doubt about their capacities and competences. Still, if one looks at the statistics, young people/pupils do report to be suffering from stress and they have more psychological complaints every year since 2010 (e.g. Bakken 2018). On the other hand, Norway is a privileged welfare state where the population has the best living conditions ever, so what is the matter with us, really, asks psychology professor Ole Jacob Madsen (2018). Some of the answers may, according to Madsen, be found in a description of our society in terms of social pathologies and a therapeutic culture, with looping effects and self-fulfilling prophesies in language and the prominence of talking about ourselves in psychological terms (ibid.). However, he also argues that we still need explanations that emphasize what is real in young people's lives, as well as what has constituted these lives and regulates them.

The challenges in new educational plans, policies and practices in Norway have been subject to several reports, surveys, examinations and studies either leading to or supporting regulations and institutional practices. A critical perspective on the results from for example surveys are that numbers "act as tools" to classify, "order" and "make sense of" complex concerns related to young people's health and wellbeing, and thereby to make them understandable and controllable for state and municipality officials (Hydle 2019, p. 8). These "objectivizing technologies", Hydle argues, are "closely linked to …state and municipality governance" of young people's lives (ibid., p. 10, cf. Larsen and Røyrvik 2018). During the fieldwork period, a new stricter national law regulating self-referred illness-induced high school absence was subject to heated public debate and was finally passed in the autumn of 2016, aiming to reduce the number of young people dropping out of school. A 30% increase in GP consultations for young people, and a small increase in the number of medical prescriptions compared to the previous year have been assumed to be connected to these new regulations and ensuing demand for medical documentation in the case of any absence period (Bakken et al., 2017).

An overall increase in state demands for regulation, objectivation, measuring and standardization have been shown to affect professional decision-making and care relationships in several different areas of contemporary Norwegian society (e.g. Larsen and Røyrvik 2017). Such practices of objectivation, quantification and standardization constitute a "cultural logic", Larsen and Røyrvik argue, that shape "meaning, representation, morality", and the way we understand persons and things (Larsen and Røyrvik 2018, p. 7). By objectivation Larsen and Røyrvik refer to the connected ways that "things", and "thinglike entities", for example categories or "facts" are produced and formed, as part of the cultural "infrastructure" of a society and according to particular political constellations and modes of production (ibid.). According to Larsen and Røyrvik these practices are performative, in other words; they "shape new ways of thinking and acting" (ibid., p. 9), instil new subjectivities and imaginaries and often alter the world they are aimed to neutrally and objectively reflect. The "Youth Data", a state funded registry based upon questionnaires from Norwegian high school students, has been interpreted as an empirical example and expression of this state-governing logic as "the most significant… tool for the perceived truth about contemporary Norwegian youth" regarding their health and wellbeing (Hydle 2019, p. 8).

On the whole, the context of Norwegian youth on a national level has seen increasing media and policy attention to health concerns during the years of planning, conducting fieldwork and writing this thesis, partly tied to national surveys such as Youth Data revealing a significant increase in self-reported illness and distress among young Norwegians, including constraining and persistent physical complaints (e.g. Eriksen et al., 2017; Bakken, 2018). According to these reports, Norwegian youth in 2015 and 2016 have been doing better in the sense that they are more conformist, compliant with school expectations and careful with risk behaviors. However, self-reported symptoms of mental and physical health complaints have increased in all regions, especially for girls. About 10% of boys and 20% of girls in Norway have reported daily headaches, stomachaches and backaches partially tied to stress or worry (Bakken, 2018). Self-reported use of painkillers among 15-16-year-olds has also increased considerably since 2001 (ibid.). Public discourse has explained the increase in self-reported illness and distress with modern pressures and a vulnerable generation of youth (e.g. Gran, 2014; Knapstad, 2013; Skårderud, 2014), and popular explanations in the media have had a tendency to emphasize vulnerable personality traits fostered in ambitious families (e.g. Lund, 2012). This is evident in the many labels applied to diagnose the state of contemporary youth, such as "generation me", generation achievement" and "morbidly perfect" (sykt perfekt). Furthermore, public narratives about vulnerable youth have had strongly gendered aspects, as may be illustrated by the uses of the "good girl syndrome" (Egedius, 2014; Wergeland, 2012) which is a frequent label in the many public comments about ambitious and "perfectionist" girls being at risk of stress-induced illness (Mæland, 2016).

Analysis of the survey statistics has nuanced such descriptions, indicating that school and social media stressors are the most significant, and showing that most young people in Norway seem to have strategies for coping with these pressures (Eriksen et al., 2017). In contrast to media panic focusing on a generation characterized by ambitious and vulnerable personality traits, the prevalence of physical and mental health complaints seems unevenly distributed based on material and structural factors (Sletten, 2017; Myrtveit Sæther et al., 2018). Furthermore, research is beginning to question the validity and ethics of narratives and explanations reproduced by some of the national surveys on young people's health and wellbeing in Norway. For example, the national Ungdata surveys have been criticized for focusing on individual factors in young people, especially young girls, and for using medicalizing language that may subsequently influence self-reporting practices, self-perceptions and enactment of youth roles (Schille-Rognmo et al., 2017; Solberg, 2018). Hydle similarly questions an essentializing ontology where findings from the Youth Data and other epidemiological sources are approached as taken for granted "truths" about Norwegian youth, with potential unintended consequences (2019, p. 8). Such technologies constitute "new subjectivities… worldviews and conceptions" (ibid., p. 9, Larsen and Røyrvik 2017) Through "introvert directed survey questions" for example, societal concerns may be undercommunicated or internalized, and "turned into (medical) individual physical and mental health questions and problems" (Hydle 2019, p. 11). The same may be said for the use of MUS, one could argue, and therefore, a discussion of the concept, the positions applying it and its implications is continued below.

Ultimately, complex historical and sociocultural relationships between societal change, public care interventions, normalizing pressures, governing technologies and medicalizing discourses all contribute to framing communication about health and illness in Norwegian youth. In turn, these aspects may affect experiences, understandings and management of symptoms with no apparent medical explanation and work towards "disciplining" the future of the sufferers to a greater or lesser degree.

## 1.2 How to understand MUS?

### 1.2.1 Challenging classification and explanation

> *"In classifying, medicine takes a snippet of nature but often fails to recognize that the boundaries of that slice are socially agreed on according to the dictates, conventions and abilities of the field rather than already existing objects waiting to be discovered." (Jutel, 2011, p. 38)*

Persistent symptoms that cause everyday worries and/or constraints, and that do not receive a full medical explanation, in other words, "that are not attributable to any known conventionally defined disease" (Fink et al., 2005, p. 772), despite medical consultations for more than six months, are often referred to in health research literature as medically unexplained symptoms (MUS) (Peveler, Kilkenny, & Kinmonth, 1997; Henningsen et al., 2011). Medically unexplained symptoms range from mild and self-limiting to severe and disabling conditions (Katon et al., 1991; Rosendal et al., 2007). In adult populations, various pains are the most common symptoms referred to as medically unexplained, but fatigue, dizziness and gastrointestinal intolerances are also common (Kroenke & Price, 1993; Hiller et al., 2006). In adolescence, the most common symptoms are headaches, body aches, fatigue and stomach aches (Rhee et al., 2005). They may cause significant suffering and functional impairment in adulthood and adolescence, reducing quality of life for the ill person and often leading to school absence (Schulte et al., 2010; Joustra et al., 2015; Konijnenberg et al., 2005, Zonneveld et al., 2013, Mikkelsson et al., 1997). For some, their symptoms are said to develop into chronic conditions that may lead to inconclusive and costly medical interventions with potential iatrogenic damage (Fink, 1992; Flynn et al., 2011). Causes of MUS are in general believed to be multi-factorial, however some predisposing factors are possibly identifiable. Research suggests for example that MUS in children and young people are associated with several relational and social factors including bullying, social exclusion and rejection by peers, experiences of abuse, illness in the family, family dysfunction, and poverty (Eminson 2007, e.g. Hansen et al. 2012, Kirkengen 2005, MacDonald and Leary 2005, Perquin et al. 2000, Schulte & Petermann 2011, Van Den Eede et al. 2012).

Much of the biomedical health research literature focuses upon describing MUS in terms of prevalence, medical explanations, diagnostic criteria, and terminology. However, this literature is diverse, despite countless efforts towards explanatory and classificatory clarity and consensus (Eminson, 2007; Eriksen, Kerry, Mumford, Lie, & Anjum, 2013, van Ravenzwaaij et al., 2010). Overlapping labels (Mayou et al., 2005; Rief & Hiller, 1999) are found for the same conditions or aspects of them across specialties and between “somatoform disorders” in psychiatry and “functional syndromes” in general practice. In pediatric literature, the main categories used are functional and psychosomatic symptoms (Eminson, 2007, p. 856). Due to variation in terminology and classification procedures, prevalence rates vary considerably (Haller et al., 2015; Rosendal et al., 2017). Aamland et al. (2014) found a consultation prevalence of 3% for persistent MUS lasting for more than three months and with function loss, indicating that symptoms in this category are common in Norwegian general practice even when relatively strict definitions are employed. Building on an eleven-year general population study in Norway, Leiknes et al. (2006) found that 8% experienced medically unexplained pain that persisted for several years. Retrospective studies of adults suffering from MUS point to early age onset and indicate that MUS in young age increases the likelihood of persisting symptoms in adulthood (Walker, Dengler-Crish, Rippel, & Bruehl, 2010). The phenomenon of MUS is also common in childhood and youth, according to this literature (Farmer et al., 2004), and is found in about 2-10% of children and youth in the general population and up to 25% of children and youth in specialist care (Eminson, 2007).

To further complicate matters, research is beginning to show that children and young people’s illness experiences differ from those of their adult family members (Taylor, Szatmari, Boyle, & Offord, 1996; Eminson, 2007, p. 856), but they are often filtered through parental report in both clinical and research contexts. As physiology, vocabulary and understanding about one’s body develop with age, early symptom presentations differ in some respects from those of adults (Eminson, 2007, p. 855). Also, young people may be more constrained agents in health care seeking than adult sufferers of MUS (Eminson, 2007, p. 856). Young people’s management of their health complaints such as health care seeking practices and lifestyle choices are influenced by financial dependency and family and other social contexts (Eminson, 2007; Weisblatt et al., 2011). Social processes of interaction between the young person, parents, involved professionals and the wider environment are also assumed to contribute by either exacerbating or decreasing the young person’s experience of symptoms (Eminson, 2007, p. 864; Weisblatt et al., 2011). Such linguistic, cognitive and social characteristics of MUS in young age have challenged clinical and research approaches, and research that focuses more on such challenges is needed (Eminson, 2007, p. 856).

Part of the challenge in conceptualizing these health complaints stems from their anomalous status in the contemporary biomedical system of classification, where they became categories of exclusion through historical developments that changed the role of symptoms (Aronowitz, 2001; Foucault, 1973; Leder, 1990). As symptoms lost their clinical significance to visibly demonstrable, organic signs, the role of doctors was changed from medical interpretation (Leder, 1990) to that of diagnosis and several symptom-based illnesses "with little clinical or laboratory specificity" (Aronowitz, 2001, p. 804) were no longer categorizable as "real" diseases. Patients suffering from residual conditions experienced stigma and/or became "medical orphans" (ibid., p. 803). Typically, several of the less specifically symptom-based diagnoses of diseases are negatively based on their lack of specific signs, such as non-ulcer dyspepsia (ibid., p. 804). Medically unexplained symptoms are one of several descriptive umbrella terms intended to capture phenomena that span across particular symptoms and partly overlapping labels and conditions (Kroenke, 2014, p. 579). The term MUS is, however, not often used clinically, and its use is disputed by patients (e.g. Stone et al., 2002) as are other alternative terms. Terms that directly describe bodily suffering and physical explanations, such as persistent physical complaints/symptoms, are preferred by some patients (Marks & Hunter, 2015; Picariello et al., 2015) and as the reader will notice I start using this term later on in this thesis instead of MUS because of its less disputed and more neutral status. Ultimately, MUS and related concepts in the biomedical research literature are said to derive from a dualist divide between psyche and soma (Creed et al., 2010; Stone et al 2002). Exploring the discursive construction of MUS in the medical literature as a "wastebasket diagnosis, a classification in which may be placed many conditions that do not easily fit elsewhere", Jutel (2010, p. 235), points out the limitations of approaching the phenomenon "as an entity" (p. 237), defined by an absence of explanation, and often used synonymously with psychogenic terms. However, these concepts do not necessarily imply a priori assumptions on etiology (Geist et al., 2008). Contrary to Jutel (2011) and others who argue that MUS and related concepts inherently imply psychological illness, Greco sees the concept of MUS as cautiously designed as a "noun without a clear and unambiguous referent" (2012, p. 2365), to bypass the question of etiology in anticipation of conflict, performativity and stigma attached to connotations of the psychological aspect (cf. Guthrie, 2008). Reviewing the vigorous debate across positions in the medical research literature on classification and nomenclature, and the cautiousness reflected in language use, Greco finds traces of a particular expression of a logic of care, where categories are approached as "tools" more than reflections of a "given reality" (Mol, 2008, p. 63; Greco, 2012, p. 2367). This caution and avoidance of psychological dimensions of

MUS is, however, paradoxical in that it reflects awareness of the role of language while at the same time indirectly constituting a disavowal that confirms negative and reductive connotations. Furthermore, Greco finds a similar cautious disavowal of psychological dimensions in the alternative, epistemologically "neutral", vocabulary used by many social scientists about "uncertain", "contested" and/ or "unnamed" conditions (ibid., p. 2364). Greco argues that the latter have also served to amplify conflictual dimensions; positively by making the experiences of suffering patients more clearly heard, but also negatively by reinforcing a "polemical knot" in the field between discursive figures of dismissive doctors and difficult patients (ibid., p. 2365). To counter this disavowal of psychological dimensions in the field of MUS, Greco calls for a more open approach to versions or dimensions of "the psychological", and the values involved. Furthermore, uses of the concept of MUS "somewhat like a placeholder" may illustrate the performative role of language and complicate polemical representations of relations (Greco, 2012, p. 2364). Summing up, at a theoretical level the use of the concept MUS poses epistemological problems and may at a practical level have unintended consequences such as the avoidance of psychological dimensions. In the Nordic countries, the use of the term in clinical consultations is to our knowledge rare and there is a well-established practice in all health sectors to approach complex patients with a biopsychosocial model. However, the structural division of the health system into somatic and psychiatric entities may still feed into how this approach is actually practiced.

Some have claimed that MUS are only unexplainable anomalies within a reductionist biomedical framework, whereas within other models of understanding they are rendered explainable (e.g. olde Hartman et al., 2009, Kirkengen 2005, 2018). The biopsychosocial model (Engel, 1977) has been promoted as a response to such challenges and is practiced in several clinical settings. According to the biopsychosocial model, symptoms may be understood as a result of a dynamic interplay between (disposing, triggering and maintaining) biological, psychological and social factors (Borrell-Carrió, Suchman and Epstein 2004, Kozlowska 2013, Gjems and Helgeland 2018). Some researchers claim that the biopsychosocial model has had limited power in classification and treatment practices (Ghaemi, 2009), and scolars have critizised the reliance in the biopsychosocial approach upon existing conceptual separation of bio, psycho and social aspects. However, the model is helpful in many clinical aspects. In Norway as well as in other countries, clinical education and practice values understandings of illness and disease where societal and life conditional dimensions of an illness situation is taken into account. It is still difficult though to integrate its application with particular patient concerns, in terms of following up the findings produced via the model. This is perhaps more due to constraints in collaboration across our health system than to the individual clinician's good intentions. In other words, translation of generalized bio-psycho-social scientific ideas into the particularities of ethical and living care practices is not straightforward and challenges related to these processes still require further attention (Rudebeck, 2011). Inspired by this, we may ask, if and how health professionals and social workers experience challenges with care and communication, and how they solve these challenges relying on both their established practice and tinkering with care, in the context of a health system which contains both promoting and constraining frameworks.

Kirkengen is well-known for her epistemological stance in debates about MUS when discussing medical knowledge and its implications. She describes how the bio-psycho-social approach to health communication ideally embraces "three types of knowledge.. considered true within three disciplines: the scientific of biology, the humanistic of psychology, and the hermeneutic of sociology" to take account of human complexity as "relational and social beings and creators and conveyors of meaning" (Kirkengen 2018, 1148). Kirkengen argues that lived experiences may be 'the most salient source of knowledge' about the origins and maintenance of an ill person's health problems (ibid.). Health professionals are *still* mainly socialized into relying upon the scientific type of knowledge in health assessments, however, "grounded in the episteme of the natural sciences", even more so with the introduction of evidence based medicine (Kirkengen 2018). The "transformation of a particular person into one or several defined disease entities" promoted by this episteme according to Kirkengen, provokes "alienation" of particular persons from their lifeworlds, "imposing a 'thingification' to serve such medical purposes as taxonomy and classification" (2018, 1147). Contrary to this, Kirkengen refers to new evidence in the field of neuroscience, or psycho-neuro-endocrino-immunology (PNEI), explaining how "experiential hurt or trauma can evoke inflammation" and other bodily responses and/ or processes on the physiological level (2018, 1146, e.g. Coe and Laudenslager 2007, Shonkoff, Boyce and McEwen 2009, McEwen and Getz 2013). In line with this, Shonkoff, Boyce and Evans (2009) introduced the notion of "toxic" stress, as opposed to "positive" stress (i.e. the kind of challenges we need to develop and grow) and "tolerable" stress (alleviated by working interventions or other positive factors in our lives). From this perspective, stress may become "toxic" on several levels, and may cause damage in the form of complex health conditions on a cellular level. Especially so if social disadvantage, challenging life situations and/ or integrity violations (e.g. childhood bullying, abuse and neglect) remain unacknowledged and/ or unresolved over time (Shonkoff, Boyce and McEwen 2009, e.g. Kirkengen 2005). This understanding of causal factors for somatic symptoms is important as an explanatory model that speaks together with an ideal use of the biopsychosocial model.

Eventually, the sum of several, smaller stressors may also trigger debilitating MUS in children and young people (Gjems 2014). Helgeland and Førde describe the process whereby they work out a holistic, biopsychosocial understanding at a specialized hospital facility for unexplainable bodily symptoms of children and young people (2017). When somatic disease is ruled out, the patient and family needs a meaningful explanation for the symptoms (ibid.). Through “mutual, trusting collaboration” (my translation), knowledge is shared about symptoms, possible connections, experiences, needs and values and new and expanding perspectives are developed for the patient, family and professionals alike (Helgeland and Førde 2017). Helgeland and Førde also share some still remaining challenges however, in understanding of MUS in a Norwegian context of care (Helgeland and Førde 2017). In their experience, the health system as a whole seems to struggle with the management of these patients due to varying professional expertise, a lack of knowledge promotion, and poor organizational structures for cross-disciplinary, holistic approaches (Helgeland and Førde 2017). A typical misunderstanding still encountered in the Norwegian public and among professionals outside specialist facilities, is that a lack of physical disease means that the symptoms are merely psychological and with no physiological reality (Gjems and Helgeland 2018). This may be the default attitude even though the biopsychosocial model is part of much clinical practice – the model is a challenge to apply and follow-up. Also, according to Helgeland and Førde, professionals with knowledge and experience with young people with MUS are lacking, at all service levels and in the schools (Helgeland and Førde 2017, 13).

The organisation of our health system, the priorities and practices which result from this influence several down-to-earth practices and clinical approaches. In other words, the biopsychosocial approach may be well-known and used as mentioned above but still difficult to apply in complex cases. Some argue that there is a need for changes in health care which should reflect increased understanding of biopsychosocial processes (e.g. Canavera et al., 2018, Kirkengen 2005, 2018, Helgeland and Førde 2018), followed up by others who argue for the central role of good communication in the understanding and management of MUS (Heijmans et al.; 2011; Henningsen et al., 2018; Kroenke, 2014; Malterud 2000; Malterud and Taksdal 2007). Following on from this, recently published guidelines for MUS in primary care emphasize the role of communication skills (e.g. Olde Hartman, 2013, IAPT, 2014, Rosendal, Christensen, Agersnap, Fink, & Nielsen, 2013). In the multidisciplinary network ”Symptoms as a source of knowledge”, 23 researchers from five countries including

Norway sought to overcome abovementioned inadequacies in the traditional disease-oriented medical frame of reference in understanding the meaning of MUS among women and develop new, more empowering approaches for communication in regular primary care encounters (Malterud 2000, Malterud and Taksdal 2007, Malterud 2018). Patient´s subjective and contextualized experiences and explanations of their symptoms, or the "voice" of their lifeworlds, were often excluded from medical discourse when authority and "privilege of knowing" was assigned to the "voice of medicine" (Malterud 2000, 605, c.f. Mishler 1984) but these experiences were however the most accurate sources of knowledge in the understanding and management of their MUS (Malterud and Taksdal 2007, e.g. Werner 2005).

The study of illness experiences initially aimed to disturb biomedical ethnocentrism and to critically explore clinical miscommunication due to the differing explanatory models of patients and healers. Kleinman defined illness as "the way individuals and the members of their social network perceive symptoms, categorize and label those symptoms, experience them, and articulate that illness experience through idioms of distress and pathways of help seeking" (1986, p. 225). He defined explanatory models (EMs) as "the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" (p. 105), and advocated using illness narratives to elicit patients' EMs related to their context and overcome communicative and cultural barriers in clinical health encounters. Kleinman's concepts have had a broad influence in health research and have been developed in several directions. Young (1982) defined sickness as the socialization of illness and disease through for example legitimate categories, local ideas about causal connections and the resources received for different kinds of illness, thereby adding a social perspective. Furthermore, Hahn (1983) suggested replacing the distinction between illness and disease with a notion of human suffering, claiming disease is only one of the many ways suffering is understood and responded to according to different ideologies and frameworks. For Kleinman (1995) and others, experience of illness and/or suffering is intersubjective, and explanations are interpretive resources that are often pragmatically applied (Good, 1986), according to corresponding idioms of distress that seem to be available in specific contexts (Risør, 2009). In anthropology, the phenomenon and concept of MUS, despite its shortcomings as will be described in the next paragraphs, is interesting because it demonstrates that symptoms and explanations are intersubjective phenomena. In this understanding of the term, and of symptoms and explanations more broadly, MUS as a phenomenon does not denote a "specific disorder" (Kirmayer et al., 2004, p. 669) or entity in the ill person's body or mind. Rather, the term draws attention to "a social situation" (ibid.) consisting of complex sociocultural relationships in which the meaning of distress is subject to interpretation, contestation and negotiation. These insights from medical anthropology on symptoms and explanations have also contributed to the broader field of MUS and communication, providing useful conceptual frameworks for exploring symptoms as a generic phenomenon involving whole human beings and arising in social situations, such as health communication in clinical encounters and everyday life setting.

### 1.2.2 Challenges and solutions in practice: Professional encounters with MUS

This thesis is a study that has its focus on the clinical reality (Kleinman 1981) of young people's everyday life and their points of interaction with professional healthcare providers and other professionals involved in care and support. Following the terminology of Kleinman one could say that I explore overlap and interaction between the popular sector and the professional sector, the latter however limited to what is called primary care in common health care vocabulary. In the following I will therefore present and discuss how specifically professionals in primary care meet, manage, and understand patients who seek help for persistent physical symptoms with an emphasis on constraints, challenges and solutions in practice. This first part concerns MUS patients in general, not specifically young people.

Communicative challenges are well documented in research on primary care consultations involving MUS (Johansen & Risør, 2017; May et al., 2004; Rosendal & Fink, 2005; Henningsen et al., 2018), leading to negative experiences, and tied to excessive somatic interventions with potential iatrogenic harm (Barsky et al., 2005; Stanley et al., 2002; Kroenke & Mangelsdorff, 1989). A main theme in the literature on professionals' experiences is GPs' challenges and experience based solutions to achieve a shared understanding and mutually acceptable explanation with the patient (Kirmayer et al., 2004). From different angles and approaches, these contributions build upon Kleinman's conceptual framework and emphasis upon explanations and illness experience for clinical encounters. Studies have for example shown how inexperienced GPs struggle to reconcile epistemological and conceptual incongruences between ideal biomedical models and the real life complexity of patient distress (May et al., 2004; Johansen & Risør, 2017). Following from this, GPs report negative experiences of uncertainty, frustration with the patient, being stuck, feeling helpless and lost in their struggles to fulfill their role in terms of a purely biomedical framework (Salmon et al., 2007; Wileman et al., 2002; Stone, 2014; Mathers et al., 1995; Hahn, 2001). More specifically, GPs have been shown to experience dilemmas when attempting to communicate potential psychological and psychosocial causes or contributing factors without straining the care relationship (Aiarzaguena et al., 2009; Eminson, 2007; olde Hartman et al., 2009; van Ravenzwaaij et al., 2010). The same dilemmas have been indicated in primary and specialist care encounters with young people and their parents, who are also said to insist on organic pathology and resist psychosocial explanations (Geist et al., 2008; Furness et al., 2009) Hulberg et al. (2019, 2020) demonstrate similar dilemmas for a Danish context but also emphasize the impact these dilemmas may have on for example parental coping and identity in the case of family therapy for functional disorders. We know most about GP's experiences with adults though, and there is limited knowledge of the experiences of frontline health and social care professionals supporting young people with persistent symptoms and conditions (Hinton & Kirk, 2016).

Interestingly, several studies on MUS in general practice have nuanced notions of the somatizing patient, pointing instead to iatrogenic or therapeutic processes in the health encounter. Research has shown how aspects of framing in the clinical setting and professional communication strategies may in themselves have observable "somatizing" effects (Salmon, 2007). Studies based upon data from video or audio taped consultations found that patients indicated psychosocial explanations, but that their GPs often ignored their cues (Salmon et al., 2004) and physical interventions were most often suggested by the GP (Ring et al., 2005; Salmon et al., 2006). Furthermore, certain kinds of communicative interaction seem to encourage mutual exploration of links to aspects of psychosocial illness while others seem to provoke or intensify a dynamic where patient and doctor inhabit separate conceptual grounds (Salmon, 2007; May et al., 2004). Identifying a typology of explanatory strategies in audiotaped primary care consultations, Dowrick et al. (2004) found that patients seemed reassured when the professional offered tangible explanations that also addressed the patient's own concerns, whereas normalizing explanations relating symptoms to bodily functions without consideration of the ill person's concerns seemed ineffective in eliciting a shared understanding. Responses without any explanation such as reassurance of a negative test result provoked new and intensified symptom presentations from patients perhaps trying to validate their suffering and concerns (cf. Hadler, 1996). These findings illustrate how clinical and other encounters where illness is interpreted are social sites involving ongoing interpretation and negotiation of meaning, and drawing upon broader discourses and rhetorical uses of language (cf. Kirmayer, 2000).

Several studies have also explored GPs' active efforts and strategies to reframe the encounter, in order to reach a shared understanding and explanation about illness aspects poorly captured by dualist explanatory models and categories. Reframing efforts have evolved over time and have differed in scope and clinical success (Stone, 2013, 2014; Johansen & Risør, 2017). Firstly, studies have described attempts to educate the ill person on assumed connections between somatic symptoms and psychosocial life world challenges (e.g. olde Hartman et al., 2009; Woivalin, 2004). The biopsychosocial model mentioned earlier (Engel, 1977) has provided new conceptual tools for reframing and is increasingly referred to by GPs, but criticism has it that the model does not *in itself* facilitate a shared understanding, as it is still conceptually tied to epistemic dualism and, several approaches, seem to lack the patient centeredness needed to fulfil its promise (Butler et al., 2004; Smith et al., 2013). Hence, efforts of reframing at this level are often balanced with the fear of threatening the patient-doctor relationship and the need to develop a therapeutic alliance (e.g. olde Hartman et al., 2009). In the lack of conceptual and epistemological congruence, GPs have thus been shown to invest in relational congruence through engaging in forms of ritual care (Johansen & Risør, 2017), which may in time facilitate new attempts to change the conceptual agenda (olde Hartman et al., 2009). Secondly, a more radical form of reframing involves adjusting professionals' own understanding and communication according to experience-based forms of knowledge, perceived cultural meaning and clinical and social consequences of their communicative practices (e.g. Malterud 2000, Malterud and Taksdal 2007, Aamland et al., 2017; Rasmussen, 2017; Mik-Meyer & Obling, 2012). The research initiative network mentioned earlier, "Symptoms as source of knowledge", produced much input to such reframing and found that changes in communication can turn encounters with patients into a shared reflective space where their experiences are acknowledged as valid sources of knowledge, and where new narratives about their health complaints may be co-constructed that challenge medical discourse (Malterud 2000, Malterud and Taksdal 2007). Action-research based studies performed by members of the network implemented shifts in communication; for example from a focus on risk factors to self-assessed personal health resources (Hollnagel and Malterud 1995), and by increased recognition and acknowledgement of the ill person's experiences to include them in the development of clinical interpretation process (Steihaug and Malterud 2002, Steihaug, Ahlsen and Malterud 2002, Werner and Malterud 2005). In a synthesis of qualitative studies on communication with patient's diagnosed with CFS, Larun and Malterud similarly argue that GPs can help by supporting patient's strengths and their re-constructions of identity (Larun and Malterud 2007). This level of reframing shifts the professional's focus from identifying and curing disease to coping and caring (Stone, 2014), and explanations are judged pragmatically, based more upon their clinical efficacy than their accuracy in relation to biomedical “facts”. In the metaethnography by Johansen & Risør (2017), a central finding is that the older the studies, the more stuck GPs seem to be in their clinical encounters with MUS patients. In other words, they show a shift in understanding and management through time, pointing to a possible influence from e.g. the above efforts to change agendas.

Nordic GPs have been shown to develop innovative and pragmatic explanations, to bypass conventional answers, recognize and legitimize sources of suffering that extend the scope of a medical framework and vocabulary (e.g. Aamland et al 2017, 2015, Mik-Meyer & Obling, 2012, Rasmussen 2017). Exploring Danish GPs classification practices, Mik-Meyer and Obling for example found that they included knowledge about the patient’s lives and social challenges in their assessments and that they constructed new “social diagnoses” to legitimize illness for patients whose complaints were medically unexplained but understandable from a broader perspective. As moral entrepreneurs (cf. Becker, 1997), they worked to integrate psychosocial aspects while also reflecting the prevailing societal norms (Mik-Meyer & Obling, 2012). Rasmussen (2017, 1236) similarly found a “utilitarian” diagnostic orientation among Norwegian GPs’ in relation to patients with MUS. Faced with the limitations of the International Classification of Primary Care framework (ICPC-2, see WHO 2003), the GPs preferred descriptive symptom diagnoses for their open-ended character and uses in consultation processes, but these were less accepted by the Norwegian welfare bureaucracy/ Norwegian Labour and Welfare Administration (NAV). Ultimately, a “logic of anticipation” concerned with social responses and consequences for the ill person seemed to underlie diagnostic classification practices (p 1228). These findings illustrate, Rasmussen argues, how imposed standards, e.g. “a standardized set of diagnoses” without the support of biomedical evidence produces “work-arounds” in practice (2017, 1238, cf. Bowker and Star 2000). In a later study, Rasmussen and Rø elaborate on how their participants alternate between two medical “frames” (2018, 1, cf. Goffman 1974), that seemed to organise their understanding of MUS and enable different patient management approaches and outcomes. Institutional and cultural pressures, such as reliance on biomedical diagnoses in welfare benefit bureaucracy, actualized a frame “centred on disease”. This frame invited the GPs to draw upon biomedical “formal and scientific knowledge”, focus on the lack of biological evidence and disregard patient testimonies as unreliable (Rasmussen and Rø 2018, 3, cf. Malterud and Taksdal 2007). More experienced GPs seemed however to depart from this framing based poor consultation outcomes and to rely more consistently upon a second biopsychosocial frame “centred on the sick person” and approaching illness testimonies as valuable sources of information.

Professional experience and experience based ways of knowing, “contrasting top-down scientific and evidence based knowledge” thus seemed to support biopsychosocial practice in a “reciprocal relationship” (Rasmussen and Rø 2018, 7).

Furthermore, Andersen, Tjørnhøj-Thomsen and Reventlow (2019) found that Danish GPs work to balance their professional opinion with the role of diagnoses in “bureaucratic pathways to care” in cases where young adult patients suffered from complex psychosocial problems (p 14). The GPs experienced diagnostic uncertainty due to the young patient’s complex health and living conditions, but also had to take account of rigid psychiatric care packages standardized for clear diagnostic categories, systemic difficulties with managing complex problems, limited resources and interprofessional boundary work. Diagnostic practices and care work were thus complicated by the bureaucratic management and organization of care in a “complex infrastructure network” involving psychiatry, municipality services and the young adults (p. 1). Finally, Laursen, Delholm-Lambertsen et al’s findings on young patients from a Danish multidisciplinary hospital pain clinic (2019) may further illustrate how explanations are constructed that may as much adapt to moral as well as social contextual expectations and consequences. While the therapists referred to their understanding of functional somatic pain symptoms as biopsychosocial and their approach as holistic, all patients had been through comprehensive biomedical examinations where organic disease had been ruled out, and were primarily regarded as suffering from a form of somatisation. Focus was on psychosocial aspects and the youngsters were intentionally referred to as “not sick” (p. 231). Therapy aimed to restore “capable selves” through narrative reconfiguring of causal pathways and future potential and to re-establish “normal lives” despite pain symptoms, according to morals and interests of the sociocultural context (239-240).

These insights from qualitative research on the role of professional communication with mainly adult patients with MUS in primary care illustrate the value of a wider communicative focus in health encounters, in order to achieve co-construction of meaning for distress In today’s clinical encounters for both adults and adolescents, a development in clinical practice has taken place towards a conscious and skilled approach to complex patient cases of several types. This goes for both British/European countries as for the Nordic countries, and accounts for mainly physicians and psychologists. The development is characterized overall by a flexibility in approach, working both on a medical basis and on a pasient-centered, biopsychosocial basis (Johansen & Risør 2017). Still, health professionals struggle to work within biomedical discourses and still manage and work with the uncertainty and complexity of e.g. MUS patients as shown in the Norwegian study on specialist health professionals (Østbye et al 2018). These professionals develop creative approaches trying to balance expertise and humility – however whether this also goes for less educated counsellors, school nurses and social workers and what constraints they deal with, is something we still know little about.

More research is consequently needed to identify and share experience-based strategies to less experienced professionals and to further develop communicative practices (olde Hartman et al., 2017, Aamland et al 2017, e572, Malterud 2000, Rasmussen and Rø 2018, Yon, Nettleton and Walters 2015), in a broad range of frontline settings involving interpretation of the meaning of persistent bodily symptoms with young people.

### 1.2.3 Patients' experiences and strategies related to MUS

In this section, I focus on the reactions from patients with persistent symptoms when seeking help from health care professionals. The research literature comprises several examples, most of them from interview studies and just a few, recent studies from videorecordings of consultations by a prominent Dutch group (Houwen et al 2017, olde Hartman et al 2013). Hyden and Sachs have observed the dialogue and assessment of chronic fatigue syndrome between patients and GPs (1998) but otherwise observational data are scarce. Hence the emphasis below is on interview studies with patients and the main constraints they experience

A main theme in qualitative research on the perspectives of patients with MUS is the extent to which the above-mentioned conceptual and communicative challenges in health encounters cause marginalizing experiences of de-legitimation, disrupt sense-making processes and provision of care, adding emotional and social layers to the patients' bodily suffering. Several studies exploring the experiences of adult patients have illustrated problematic meanings assigned to psychological explanations in health encounters (e.g. May et al., 2000; Houwen et al., 2017; Peters et al., 2008), experiences of having the reality of one's sensations questioned by doctors (Peters et al., 1998, 1999), and the need to work hard to achieve "permission to be ill" (Nettleton, 2006, see also 2004, 2005) and become credible patients according to biomedical criteria and terminology (Werner & Malterud, 2003; Glenton, 2003; Dalsgaard, 2005). Parallel findings in a Nordic study show that patients experience being questioned for their moral character and the veracity and accuracy of symptom descriptions, leading to a feeling of stigmatization (Åsbring & Närvänen 2002) Lack of legitimate sick roles is a common experience and has also been shown to affect the everyday quality of life of the ill person (e.g. Stanley et al., 2002).

In line with the theme of social framing in clinical encounters, studies have also explored what explanations make sense to patients with MUS, and how these may contribute to their meaning-making processes and provide guidelines for action in different contexts. In health encounters, patients have emphasized empathic support, engagement and understanding from professionals more than medical accuracy or a cure (Nordin et al., 2006; Peters et al., 1998), as well as tangible explanations that validate the illness experience without assigning blame, and provide meaning and guidance for self- management (Anastasides et al., 2019; Salmon et al., 1999, 2005). A study based on interviews with British patients with persistent symptoms, for example, found that most found their doctor's explanations to be "at odds" with their own understanding (Salmon et al., 1999). A few explanations were, however, accepted and seemed to lead to patient empowerment in the sense that they reconciled lay and professional explanatory models and removed a sense of personal moral blame, for example by the use of common metaphors for tangible physical causal mechanisms that also allowed for explorations of what could be done to cope with and reduce their suffering in terms of everyday life adjustments (ibid.). Other studies have explored how ill persons explain their symptoms in detail, and how this understanding may or may not be expressed in health encounters. Kirmayer et al. (2004), for example, found that most of their study participants with medically unexplained symptoms had personal or culturally based explanations available that tied symptoms to stressors and challenges in their social environment, providing meaning to distress and guiding help seeking, but they had not yet been able to share them with their physicians. Kirmayer et al. contend that this is often the case, as such explanations do not fit well with dominant biomedical frameworks of physio- or psychopathology, and constructing a meaningful illness narrative may take longer than an average consultation. Thus the cultural meaning is often not acknowledged in health encounters, and a breakdown in communication may occur. Mediating processes between illness aspects inherent in personal or cultural explanations, as may be illustrated by common metaphors such as the body as a mechanical system, may not be measurable according to biomedical criteria and may require "explanatory generosity" (ibid., p. 668) from the professional to be validated. Risør (2009) similarly found that her Danish adult participants alternated pragmatically between different, concurrent explanations, according to their utility and acceptability in different contexts. In clinical settings, explanations of symptoms and a search for a cure seemed most significant for many patients, paralleling the paradigmatic idiom found in biomedicine. In everyday settings with friends and family, however, the participants more readily mentioned equally significant personal explanations of internal imbalances in need of adjustment, social explanations of constraints in their environment, and moral explanations indicating what was existentially at stake. Their alternating explanations seemed tied to differing cultural and moral vocabularies for shared understanding, resembling embodied expressions of lived life. Furthermore, the significance of each idiom seemed to develop along with sociosomatic meaning-making processes. Thus, they were based upon everyday forms of reasoning that differed in important respects from the psychosomatic or bio-psycho-social dimensions proposed by professionals in the field, founded upon a biomedical form of reasoning. Over time, a mutual exploration of their meaning remained unarticulated in the clinical setting. As indicated in other studies (e.g. Salmon 2004, Lidén et al., 2015), such lack of articulation of a shared understanding involving life experiences did not, however, indicate denial on the part of the participants, but seemed to result from the clinical framing and the forms of expression it seemed to promote.

Finally, research is beginning to elaborate more on how the ill person experiences and copes with illness beyond the clinic, through everyday communicative meaning-making processes and practices oriented towards other domains than medicine. Ware's work on the narratives of American CFS patients (1998, 1999) explores how illness experience is constituted and resisted in a broader cultural context and through various interconnected microsocial processes. Drawing on Kleinman's symptom-focused concept of sociosomatic relations (1986), Ware proposes a revised conceptual model with a broader focus on the social course of illness, as the socially constituted "experiences of life with illness over time" (1999, 304). Ware shows how specific "qualities of distress", such as functional impairment by near-chronic and de-legitimate fatigue, intersect with certain cultural role expectations, such as being a productive citizen, to activate "microsocial processes of marginalization" (1998, 1999, p. 322). However, Ware also identifies huge efforts by her participants to negotiate the meaning of their illness and preserve or re-make valued roles and identities, such as passing as healthy, channeling energy to work-related tasks or finding flexible arrangements. Ware thus finds that the social course of CFS moves along a continuum of marginality, following the ebb and flow of symptoms, but also constituted by social processes in specific social contexts. Exploring the social course of illness among young adult patients at different stages of un-named MUS, Risør (2010) found a similar pattern in that bodily and social restrictions were dealt with through extensive efforts and acts of planning, managing and strategizing. However, rather than being oriented towards an already established continuum of marginality, Risør's participants seemed more oriented toward healing in a broad sense, including everyday engagements with symptoms, professionals, relationships, roles and visions for the future, in order to cope and move on and "heal or re-perform" (Risør, 2010, p. 141) parts of their lives in new, morally acceptable ways. Within the frameworks of the ill person's everyday life, the management of medically unexplained illness may thus take the social course of an "ongoing reflexive healing process" (Risør, 2010, p. 143). More research is still needed, however, to better understand the social course of medically unexplained illness in different contexts, such as that of Norwegian youth, the subject of this thesis.

### 1.2.4 Young patients' experiences and practices related to MUS

Fewer studies have explored young people's experiences and practices in relation to MUS and communication. In a narrative review of the literature on perceptions of healthcare for children and young people with MUS, Hinton et al (2016) find similar communicative challenges to those described by adults in connection with MUS.

A recent study found that most young patients diagnosed with functional disorders and their familymembers in Danish hospital based treatment expressed monocausal illness perceptions, and resisted psychosocial explanations presented by the health care professionals within a biopsychosocial communicative framework (Hulgaard et al. (2020). Huulgard et al. (2020) argue that monocausal illness perceptions seemed framed by a still remaining split between psyche and soma in the Danish healthcare system. All the families had been through repeated physical examinations to "rule out" phsycial disease leading up to referral from a somatic to a psychiatric specialist treatment setting. While the two departments shared a biopsychosocial understanding, assessment and treatment for somatic and psychiatric illness was mainly provided separately. Referral seemed to symbolize for the patients and their parents a shift from somatic to psychiatric settings and monocausal explanations. Most families who agreed to take part in the system-based psychoeducative family therapy provided in the psychiatric hospital setting reported positive experiences (Hulgaard et al 2018). Therapy seemed to offer a space for dialogue where tangible explanations could be expressed that resonated with their experiences, many of which applied a multifactorial notion of stress. Empowering explanations focused on concrete solutions in the family rather than blame, thus offering hope for concrete ways they could act as resources to reduce the symptoms (ibid.). However, the young and their parents also experienced negative processes with breaks in the dialogue when they did not feel heard or blamed. In a series of studies performed with young Swiss MUS patients, Moulin et al. (2015a, 2015b) similarly found additional stress and anxiety from the lack of legitimizing diagnoses, difficulty in sharing and explaining the condition to family and friends and a desire for explanations to alleviate disbelief among peers and to find solutions.

The participants particularly emphasized experiences of de-legitimation, threats against their social identities and role-constriction in relation to their peers (Moulin et al., 2015a). The importance of belonging and expectations about fitting in among peers seemed to influence their experiences of life with illness and their coping strategies. In order to keep their illness from defining who they were, several described containing their illness in public by for example smiling to hide their suffering to appear normal among their classmates (Moulin et al., 2015a). Rather than expressing a need to share and openly discuss the symptoms like their parents, the adolescents seemed to cope through spending time with and receiving social support from close friends (Moulin et al., 2015a). A study from Denmark on young adults with common mental health problems and psychosocial problems demonstrates that their interaction with care professionals and services often is characterized by a lack of recognition of being a social person, visible, heard and remembered (Andersen 2019). This was mostly the case when care professionals/services were dominated by institutional goals and regulations. In other words, despite intentions to provide person-near care, constraints at other levels may interfere.

The emphasis upon negotiating constraints to participation, or identity and belonging with one's peers has been found among young people suffering from other chronic illness (e.g. Forgeron, Evans, McGrath, Sartain, Clarke, & Heyman, 2000; Stevens & Finley, 2013), but may prove even more pressing for young people with MUS (e.g. Kashikar-Zuck et al., 2007; Suris, Belanger, Ambrosin, Chabloz, & Michomel, 2011). A few Norwegian studies are done with young CFS/ME patients, who draw forward existential feelings connected to hopes for the future, fear of being 'shut out' and that life will go on without them. Evidently, there is much emphasis on isolation from peers (Winger et al 2014), as well as reporting negative experiences with health encounters of not being taken seriously or heard (Hareide et al 2011). In relation to health encounters, the participants in the study by Moulin et al. described feeling more distressed about a lack of understanding of their condition than about lacking treatment options. They expressed a need for more inquiry from professionals about everyday emotional strain in youth with illness, and more support to build their "morale" for coping (Moulin et al., 2015b). These findings suggest that communication that addresses these challenges and alleviates additional stress and anxiety stemming from them is key to support for young patients but more research on young people's experiences of health communication regarding MUS is still needed (Hinton et al., 2016)

Although knowledge of the perspectives of young people experiencing MUS is scarce, related literature on young people with diagnosed conditions such as non-epileptic seizures and

CFS/ME confirms experiences of de-legitimation tied to conceptual challenges threatening who they are as persons and the need for communicative coping strategies that negotiate these threats. Karterud et al. (2015) found that young patients diagnosed with non-epileptic seizures at a university hospital in Norway experienced references to psychogenic illness as illegitimate, affecting their social identities. To protect their senses of self from de-legitimating illness experiences in public, some withdrew socially (Karterud et al., 2016). However, explanatory phrases associated with biomedical and physical processes made the young people feel understood and believed, in turn enabling exploration of a multifactorial, bio-psycho-social approach with the professional that integrated personal experiences from their lives (Karterud et al., 2014). Similarly, a review of the qualitative literature on young patients with CFS/ME emphasizes how bodily suffering and the isolating effects of symptoms are augmented by diagnostic challenges and stigma, threatened identities, loss of relationships and uncertain futures, but the young people seem to benefit from building credible explanations (Parslow, 2017).

In a qualitative study based on interviews with adolescents with CFS/ME recruited from a Norwegian hospital, Hareide et al. (2011) found that their participants presented explanations based on personal experiences and accessibility, engaged in extensive meaning- making processes to understand and cope with their illness, and flexibly experimented with coping strategies (p. 2261). Their explanations seemed shaped by the ability of communication in different contexts to validate their experiences. Furthermore, the ability of explanations to support positive meaning-making processes whereby their experiences could be placed within frameworks of agency, exculpation and personal growth seemed more important than medical accuracy for more active and integrated forms of coping. For example, ideas about somatic causality seemed to provide adaptive defenses against outer lack of validation for some, enabling continuous social participation. The findings of Hareide et al. nuance previous results of questionnaire-based studies (e.g. Richards et al., 2006), that have defined the explanations communicated by young people with CFS/ME and their coping strategies as “maladaptive”, and point out the importance of professionals validating and facilitating the ways young people adapt explanations and coping strategies to their personal circumstances. They therefore call for, and, I would add, demonstrate the relevance and need for, complementary relational perspectives in future research (ibid., p. 2262).

## 1.3 Theoretical framework

### 1.3.1 Suffering

Suffering has been conceptualized in different ways. Foundational insights into suffering as a phenomenological and existential experience have especially been developed around the phenomenon of acute and chronic bodily pain. The literary theorist Elaine Scarry (1985) famously described how suffering shifts embodied experience, potentially resulting in an "unmaking" of the ill person's lifeworld. The impact of the suffering experience on our "capacity to live" (Parish, 2008, p. 127) may, for example, halt or "disrupt" imagined biographical life paths (Bury, 1982) or cause existential questioning and even the experience of a loss of self (Charmaz, 1983;). Corbin and Strauss emphasized the enormous amounts of work performed in their lives by chronically ill persons that may evade their professionals' attention and recognition, such as managing their symptoms, caring for themselves and reconstructing a sense of biographical continuity (1985, 1988). A main theme in the literature on suffering as a theoretical construct is thus a sense of difficulty and a struggle to understand, give meaning to and communicate aspects of the experience (Wilkinson, 2001). Some researchers have emphasized the private and isolating aspects of experiences of suffering that resist representation though language (Wilkinson, 2001). In contrast, this thesis is based on an theoretical emphasis on social aspects of suffering (see Smith-Morris, 2018; e.g. Good, 1994; Kleinman, Das, & Lock, 1997; Ware, 1998, 1999) and on how cultural representations of suffering "shape it as a form of social experience" (Kleinman, Das, & Lock, 1997, pp. xi– xii). Suffering as a social experience derives from a network of forces, involving both the body and more general issues (e.g. Jadhav et al., 2015). In the context of a local moral world, suffering may, for example, take the shape of a "delegitimation of experience" (Kleinman, 1992, p. 75). Suffering from illness and disease in this perspective occurs not only in the body, but also in a specific space and time in history (Good, 1994).

Using a case study of a young boy suffering from chronic pain, Good demonstrates how experiences of a phenomenological "unmaking" of the lifeworld are socially mediated by dominating medical practices and interpretive labels and narratives that fail to objectify the boy's illness experience. In the boy's efforts to construct a working narrative of his experiences through art, and his containment of pain to keep a meaningful career, Good also identifies intensive efforts to counter such processes of unmaking and maintain his relation to a social order. In order to explore experiential dimensions of human suffering, Good thus argues for systematic investigations of such interconnected phenomenological and social processes whereby everyday worlds are "unmade", as well as the human efforts directed to find meaning and "reconstitute" (1994, p. 128) those worlds. Good emphasizes symbolization practices and narrativization, in the form of diagnostic labels and explanatory stories respectively, as challenging but perhaps even more central in reconstituting responses to suffering related to medically unexplained illness. Furthermore, everyday practices may constitute additional modalities of efforts to repair, to reconstitute worlds unmade by bodily and social suffering, such as efforts to counteract processes of marginalization in chronic CFS/ME (Ware, 1998, 1999), or oriented towards continuous healing processes to cope and find a way to move on in life, as in the case of MUS (Risør, 2010).

According to Kleinman, Das and Lock (1997), the most important and interesting questions to ask when encountering challenges in communicating suffering deal with "cracks" between categories and pragmatically separated services and expert domains, and with sociocultural processes whereby suffering may or may not be recognized. Cultural patterns of recognition, naming, categorization and assigning causes to disease states and health problems act as "framing phenomena" (Aronowitz, 2008, p. 2) that invoke illness realities and affect health-seeking behavior, health service practices and societal reactions more broadly (Austin, 1975). Firstly, institutional orders such as states, markets or medicine work to frame, enable and constrain responses to suffering (Thornton & Ocasio, 1999). Thornton and Ocasio (1999, p. 804) provide an anthropological definition of institutional logics as "the socially constructed, historical patterns of material practices, assumptions, values, beliefs and rules by which individuals produce and reproduce their material subsistence, organize time and space, and provide meaning to their social reality". In health care, economic rationalities may for example "exclude" certain forms of knowledge and practice (Kleinman, Das, & Lock, 1997, p. xx), reduce care to a mechanical task that objectifies the suffering of patients to make it manageable (Kleinman, 2013), limit available choices for patients and professionals and serve to "mute" moral and emotional expressions in health encounters (Kleinman, 2012, p. 1550; e.g. Frank, 2016). Secondly, cultural models and expectations about how suffering should be endured and fought as a patient may provide support and pride for some, but may increase the experience of suffering for those who struggle the most to engage with them (e.g. Hay, 2010; Greco, 1993). Finally, such models, rationalities, and/or logics may be traced in the vocabularies most readily available for health communication (e.g. Scott et al., 2000), as is perhaps especially evident in literature exploring challenges in communication and illness experiences relating to MUS (e.g. Kirmayer, 2000, 2004). Challenges to represent certain aspects of suffering may thus be tied to limitations in the cultural resources available for expression, and responding to unheeded pleas for recognition may require the development of new vocabularies (e.g. Das, 1997).

Kleinman and Van der Geest emphasize an attitude of “care-fulness”, doing good to others and oneself, as fundamental human and moral experiences that ameliorate and remake suffering (2009). An attitude of care involves a relational reciprocity affecting the subjectivities of all involved, more closely related to gift exchange than measurable economic transactions implied by new vocabularies applied to health care (ibid.). Kleinman notes how, despite the above-mentioned communicative and framing constraints, professionals are found who work to do good and to tie reciprocal relationships through everyday care practices and open conversations that maintain and create meaning (Kleinman, 2013). In response to these observations, Kleinman calls for a reconsideration of the nature and place of caregiving in education, practice and health research (2012).

In parallel, a turn to care within anthropology (cf. Smith-Morris, 2018; e.g. Pols, 2003; Mol, 2008) seeks to explore ongoing efforts to include different values in practices of care, and to describe what good care might entail in its “own terms” (Mol, 2008, p. 84). Taking account of the dilemmas professionals are facing, Moser and Pols (2010, p. 14) thus define care as “persistent tinkering in a world full of complex ambivalence and shifting tensions”. Good communication may constitute a central modality of such tinkering. In her anthropological fieldwork in a diabetes clinic, Mol identifies a logic of care alongside a partly competing logic of choice, informing the professionals’ encounters with patients and their approaches to suffering. While the logic of choice puts value upon autonomy, Mol finds that the logic of care is “attuned to people as belonging to collectives” (2008, p. 62) and to unhelpful conditions complicating ideals of liberation and self-management. Thus, the logic of care makes professionals craft care relationships and actively support patients in care teams. Rather than being based on pre-given individuals, caring may involve careful processes of individuation where the ill person reflects upon existing relationships, crafts new selves and experiments with new forms of interdependence. Furthermore, while the logic of choice values neutral facts as the basis of well-informed choices, a logic of care asks caregivers to carefully experiment with and adapt categories and other technologies to the inconsistencies of everyday life.

Inspired by Kleinman’s call (2012) for consideration of the place and nature of care in responses to suffering, and of Mol’s invitation to extend, or translate, her notion of a logic of care to other settings, this thesis explores and seeks to articulate in its own terms what care might entail in terms of communicative responses to bodily and social aspects of suffering related to young people’s experiences of persistent bodily complaints.

### 1.3.2 Youth

The concept of youth in this thesis builds upon foundational anthropological assumptions, emphases and insights deriving from a large body of ethnographic work developing our understanding of the contextual and flexible meaning of generational categories, ages and transitional phases (e.g. Amit-Talai & Wulff, 1995; Christensen, Utas, & Vigh, 2006; Cole & Durham 2007; Gilroy, 2002, McRobbie, 1999; Mead, 1928; Wulff, 1994; Willis, 1977). Relating to this complexity and flexibility, Durham has compared the concept of youth to a “shifter” in linguistic theory, a category of concepts that are difficult to fully determine and define as they take much of their meaning from simultaneously situated and context-renewing uses (Durham, 2000, 2004). According to Durham, this characteristic of the social category of youth is, however, also what makes it a powerful analytic for exploration of a multitude of culturally and historically varying experiences, interconnected domains and social relationships, such as role expectations, trajectories of personhood and forms of moral agency (Durham, 2000, 2004). Building upon ethnographic work in an African context, Durham illustrates how youth as a social category “acts” as a social shifter in the field (2004, p. 590), “engaging the social imagination” (2000, p. 113), in the sense that the recurrent and increasing discourse on youth as a problem addresses issues related to historical shifts, tensions and power relations in Botswanan society at large. Furthermore, as young people apply the concept of youth, they situate themselves in social environments in dynamic and imaginative ways (Durham, 2000, p. 116), taking part in pragmatic processes of redefinition (Durham, 2004, p. 593, cf. e.g. Christensen et al., 2009 and Dalsberg et al., 2014).

In an influential review, Bucholtz (2002, p. 535) advocates an anthropology of youth that forefronts young people’s own perspectives, experiences and the practices through which they “relate, adapt to and negotiate often untenable situations”. This helps to recognize and contribute to a fuller acknowledgement of the ways in which young persons are socially and culturally made and identified, which includes how they “shape their worlds” through everyday forms of cultural critique and production. This thesis is inspired by insights from approaches within an anthropology of youth that, in line with Bucholtz’ call, focus on how young people make meaning in relation to temporal and spatial aspects of their social environments (Christiansen et al., 2006; Vigh, 2006, 2009; Dalsberg et al., 2014; Durham, 2000, 2004; Bucholtz, 2002).

To overcome longstanding scholarly tensions between constraints and agency in the anthropological study of youth, and illustrate how young people in the field deal with unpredictable social situations, potentially constraining categorizations, conditions and social pressures, Vigh (2009) has developed the concept of social navigation as a metaphor for practice. According to Vigh, young people navigate, or move, in their social environment in ways related to experiences of positioning, shelter, level of control in different aspects of life, and the possibilities and trajectories they envision for themselves. As pointed out by Christiansen et al. (2006), young people may be ascribed generational and other positions, but they also act to position themselves as agents. In this view, youth is both being and becoming, a “position in movement” (Vigh, 2009, p. 11). Christensen, Utas and Vigh thus argue for a dual perspectival analysis of youth focusing upon young people’s experiences in relation to social aspects in youth (ibid.).

Vigh also applies the concept of social imaginaries as useful for exploring how young people interpret and face social pressures, expectations and constraints (Vigh, 2006). The idea of the social imaginary as a symbolic matrix within which people collectively engage in “world-making” (Gaonkar, 2002, p. 1), was initially elaborated by Castoriadis (1987/1997) in response to determinist Marxism to account for the potential for creative agency and change despite macrosocial structural forces of power. In later conceptualizations, Charles Taylor (2002) emphasized the central role of social imaginaries in everyday local interpretation, understanding and practice. As a carrier of ideas and images of a moral order, a social imaginary affects interpretive processes and health-seeking practices relating to symptoms and constraints by giving meaning and legitimacy to them and to symbolic forms and influencing how we see ourselves in space and time. This includes how young people in the field “imagine” (Taylor, 2004, pp. 23-26) their social existence, a sense of expectations and legitimacy, and how they “fit together with others” (ibid.). Vigh (2009, p. 483) defines a social imaginary as the “sum of one’s social horizons” of experience, exploring retrospectively where his young interlocutors in the field experience that they come from, introspectively their sense of who they are today, extrospectively how they experience their place with others and prospectively “framing their realm of possibilities” (ibid.). Through ongoing interplay between agency and social forces, social imaginaries are constantly reconfigured. Thus, as young people with persistent symptoms and related constraints move in, or navigate, spatial and temporal aspects of their social environment, their horizons, and ensuing movements, may change.

Whereas previous analytical approaches to youth have tended to privilege space over time, evident in geographic metaphors referring to marginality, navigation, youthscapes or youth spaces (Cole & Durham, 2008, p. 5), the often central and pragmatic functions of temporal aspects in the lives of young people have received increasing attention from social science in recent years. Building on their own and several other ethnographic descriptions from different corners of the world (e.g. Barrett 2004), Cole and Durham argue that while the idea of youth as a social category is a well-established foundation for an anthropology of youth, such a category is in many settings defined empirically as a temporal period of transition between childhood and adulthood. Because of this, young people are often expected to relate to their futures in specific ways (ibid.). In particular, studies are beginning to illustrate how ideas of proper and improper transitions constitute cultural constructions of youth-related problems such as school dropouts or teenage pregnancies. Those who struggle to achieve "good" transitions are in many cases considered as problematic and/or at risk (e.g. Dalsgård et al., 2008, 2014). However, young people also negotiate their possibilities through their challenges (Dalsgård et al., 2014) and may seek imagined futures and "carve out new temporal dimensions" for themselves (Cole & Durham, 2008).

Dalsgård et al. (2014) take up Cole and Durham's call to explore how contextual configurations of time take on certain meanings by focusing on reflexive experiences of temporal "tensions" and/or discontinuities (Fredriksen & Dalsgård, 2014, p. 2). Dalsgård et al. (2014) illustrate some of the local forms of expression such temporal tensions and efforts may take, such as waiting in a state of "suspended action" with no plans or prospects after finishing school in Cameroon and the United States (Johnson-Hanks, 2014), notions of "burnout" in Denmark (Krøijer, 2014), of boredom and depression in Georgia (Frederiksen, 2013, 2014) or anxieties and hopelessness in Recife, Brazil (Dalsgård et al., 2008; Dalsgård, 2014). In Recife, Dalsgård, Franch, and Scott (2008) found that local perceptions of youth and dominant ideas about "proper" transitions clashed with the actual experience of young people. Young people from low income backgrounds with the fewest opportunities to follow the cultural script of linear progressions through higher education were cast as problematic, irresponsible and at risk (Dalsgård, Franch & Scott, 2008, p. 51). All young people, rich and poor, expressed affective experiences of frustration, uncertainty, anxieties and struggle to keep up with this cultural script

(Dalsgård, 2014). Inspired by Flaherty's concept of "time work", the ethnographic descriptions and analyses in Dalsgård et al. (2014) explore their young interlocutors' efforts towards "producing or preventing various temporal experiences" (Flaherty, 2011, p. 11). Experiences of time may be represented and "worked with" through material objects such as names, statistics, unfinished buildings or symbolic pieces of clothing. They may also be worked on through relations and practices, for example by active "discernment" of affective states inflicted by one's social situation, verbal expressions and "bodily mirroring" that make one stand apart from one's social situation and the way it makes one feel. Or they may be worked on through imagining an "unspecified but promising" future that acts on the present bodily and emotional experience as the confidence (Dalsgård et al., 2014, p. 114), to alter who one is (Frederiksen & Dalsgård, 2014).

### 1.3.3 Subjectivity

The concept of subjectivity in contemporary anthropological thought directs attention to "actors' thoughts, sentiments and embodied sensibilities, and, especially, their sense of self and self-world relations" (Holland & Leander, 2004, p. 127; Luhrmann, 2006). To further explore experiences of illness and communication, and strategies of health seeking in relation to the crafting of agency and personhood by young people suffering from persistent bodily symptoms in a contemporary Norwegian context, this thesis turns to recent anthropological developments of the concept of subjectivity and to theory that approaches it as a "strategy of existence" as well as a "material and means of sociality and governance" (Biehl & Moran-Thomas, 2009, p.272). Looking back at the development of social and cultural conceptualizations of the role of social beings as persons, subjects, actors or agents, Ortner (2005) credits proponents of so-called practice theory (e.g. Bourdieu, 1977, 1990, 2000; Giddens, 1979) for having brought back the acting subject to social theory from over-deterministic approaches, and for inspiring her own research (e.g. 1984, 1996, 1999a). However, she also suggests a certain "thinness" in their work concerning the question of subjectivity, by which she means "the view of the subject as existentially complex, a being who feels and thinks and reflects, who makes and seeks meaning" (ibid., p. 33). Ortner sees subjectivity as a necessary basis of agency, and thus a more robust anthropology of subjectivity is central for understanding how people act or try to "act on the world even as they are acted upon" (ibid., p. 34). Although Clifford Geertz contributed an early version of a subjectivity-oriented theory of culture (e.g. Geertz, 1973), endowing the Balinese with complex subjectivities such as fear of failure, his subjects are presented as culturally produced by cultural consciousness (Ortner, 2005, p. 39). For Ortner, people are at least partly knowing and reflexive despite dominant cultural formations and power structures that affect them, and a cultural consciousness may also provide grounds for questioning the relationship between them and their world (pp. 45-46).

Similarly, Biehl et al. (2007) argue that more research is needed to develop our scholarly understanding of the ways in which persons are constituted through social experience (2007, p. 13), to leave theories of subjectivity that have been too dehumanizing, and to account for our interlocutors' everyday reflexivity and "depth of personhood as vulnerable, failing, and aspiring human beings". Biehl et al. recognize modes of subjectivation through multiple hierarchies, memories and markets, patterned and mediated by cultural forms, institutional settings and historical transitions. However, they see subjectivity as irreducible to social control or the unconscious, as it also provides the ground for subjects to think, feel and inwardly endure otherwise unbearable experiences and circumstances (p. 14) as well as engaging with identity and their predicament in ways that change their world (p. 4). In line with new understandings of culture as "emerging from institutional and intersubjective interactions and as an evolving phenomenon, constantly remade through social encounters, ethical deliberations, political processes - and writing" (ibid., p. 7; e.g. Clifford & Marcus, 1986; Fischer, 2003; B. Good, 1994; Ortner, 1999), Biehl et al. ask how this remaking of culture is mediated by individual lives and how modes of subjectivity are intertwined with configurations of e.g. medical institutions (2007, p. 8). To capture/explore these concerns, Biehl et al. further argue that experience-near analyses are needed, grounded in a clear understanding of what we mean by experience. They define experience as a "felt flow of interpersonal communication and engagements" in particular social spaces and as a medium where "collective and subjective processes fuse, enter into dialectical relationship, and mutually condition one another" (ibid., pp. 53-54). Subjectivity in these perspectives does not pre-exist, but is "made through dialogue" (Fisher, 2007, p. 442; e.g. Das, 1997), within shared practices of everyday life. From different angles and through different approaches, Biehl et al. thus explore human conditions, with a particular interest in ongoing trajectories of unfinished and "unfinishable" persons (2007, p. 15), their inner "reworkings of the world", in other words, everyday processes of meaning making in their lives related to moral questions and what is most at stake (ibid., p. 15), such as how they value relationships and what an adequate life may contain and how they "enact the possibilities they envision" for themselves (ibid., p. 8). For Das and Das, for example (2007, p. 67), illness experience explored in open-ended ethnographic interviewing among urban poor families in India shows subjectivities that are "deeply enmeshed" in everyday life set in specific social spaces, local ecologies and conditions. Many illness stories and everyday management strategies relate to the felt quality of social relationships and financial possibilities and constraints of the urban poor, and to notions of a “relation of failures of the body to failures of one’s social world” (ibid., p. 69). Furthermore, the language used for making bodily and social suffering knowable relates to “bureaucratic machineries”, but is also reworked for domestic and personal needs (Biehl et al., 2007, pp. 30-31). In this way, language is not just a medium of communication or misunderstanding, but “an experience which allows the subject to be projected outwards” (Das & Kleinman 2001, p. 22). According to Das, subjects are made through “forms of inhabiting the world in which one tries to make the world one’s own, or to find one’s voice both within and outside (available)… genres” (Das, 2007,p. 216). She argues that this often involves a “descent into the ordinary” (2012), in other words an ethical cultivation of sensibilities, or heightened awareness within everyday life settings (Lambek, 2010), where what is “right” is developed through practical and performative judgements and acts that relate reflexively to discourse and external criteria.

At this point I would like to summarize briefly the main insights from anthropological debates on suffering, youth and subjectivity that have supported my exploration into and analysis of how MUS in youth is understood and managed in my field context. Firstly, this theoretical framework has opened up for an analysis that takes account of social aspects of suffering. Secondly, it has provided fruitful concepts for youth as a social experience and expectation involving temporal aspects, and for how young people’s management strategies relate to, navigate and “work” on their constraints. Thirdly, recent conceptualizations of subjectivity have been a fruitful entry point to explore how young people with persistent MUS seek and make meaning, and how they may become persons, in the face of debilitating illness and challenging social situations.

## 1.4 Aims

The research project leading to this thesis has been part of an overarching interdisciplinary collaboration between three departments of UiT The Arctic University of Norway: The General Practice Research Unit (AFE), the Department of Psychology (IPS), and the Department of Visual Cultural Studies (VCS). The project is one of two separate but partly interconnected sub-studies based upon the theoretical fields and methodological tools of ethnography and psychology respectively. Whereas the psychologically oriented study focused on encounters in specialist care, the present ethnographic project has been based and positioned in the General Practice Research Unit (AFE), focusing on everyday life and primary health and social care settings. The general aim of both projects was to explore communicative challenges in the understanding and management of medically unexplained symptoms (MUS) in Norwegian youth.

This thesis seeks to explore the phenomenon of MUS and contribute with insights relating to young people with persistent bodily symptoms and their illness experiences, concerns and management strategies. Little is still known about the social factors, sociosomatic relationships and meaning-making processes that contribute in defining young people’s experience of medically unexplained illness and its social course. Furthermore, research has demonstrated the value of a wide communicative focus in health encounters to achieve co-construction of meaning for distress, in addition to the central role of crafting shared explanations that address the concerns of the ill person. More research is however still needed to identify experience-based strategies and further develop communicative practices in a broad range of everyday life and primary health and social care settings where early symptom interpretations take place. Theoretical conceptualizations of symptoms and explanations as fluid and emerging through socially and culturally informed processes of interpretation provide foundational and useful entry points for this project. Likewise, the theoretical lenses of suffering, youth and subjectivity support exploration into social aspects and care responses to suffering, young people’s experiences and practices relating to constraint and potential, and how illness experience and subjectivity are shaped in social contexts. Applying the above-mentioned concepts as tools to explore the phenomenon of MUS in youth places this thesis in dialogue with ongoing discussions in social science, and may also enhance such discussions. These may be related to suffering as a social experience, mediated by for example cultural patterns of recognition, categorization, explanation and moral expectation, and the question of what the nature and logic of care in responses to suffering might entail, in relation to the ill person’s constraints and efforts to overcome them, and the subjectivities that form in these processes.

As will be further elaborated in the methodology section, this thesis also seeks to explore and potentially contribute to methodological approaches to health communication and research with young people, by including collaborative, visual methods in the research design. Findings related to these areas may prove transferable to practitioners and researchers involved with young people in a broad range of problem areas, topics and settings.

The overall aim of this thesis is

1) to provide knowledge of perspectives, concerns and management strategies of young people with persistent bodily complaints, where initial medical examinations have been unable to fully explain their condition, and

2) to explore patterned cultural and professional logics, perspectives and communicative practices that contribute to the development of young subjects and their health seeking practices

Specifically, this thesis is based on three research questions:

1. How do young people attempt to make sense of and cope with embodied and social aspects of their illness experience, and how may the use of collaborative, reflexive filmmaking in this context facilitate understanding across communicative barriers and support efforts at meaning making?

2. From the perspective of care providers, what are the communicative dilemmas and the performative role of language in encounters between professionals and young people who present persistent bodily complaints in high school settings, municipality services, and general practice?

3. What are the everyday strategies of young people with persistent and medically unexplained bodily complaints? More specifically, what are the constraints they experience and how do they counter them, what do they hope to achieve and what do they consider ‘good’ in relation to others in this process?

# 2 Methodology and design

In the following I will present the overall ethnographic methodology in this project, the recruitment rationale, brief elaborations on the methods used, the analysis, ethical considerations and strengths and limitations of my methods.

Etnography as a term that characterizes a specific research approach is less well-defined than one may think (Hammersley & Atkinson). Over the years it has been reinterpreted and recontextualized to adapt to specific circumstances, specific disciplines and it has been influenced by a variety of theoretical ideas. It has also been used pragmatically as an umbrella-term for several qualitative approaches and methods. Nonetheless, ethnography has a core definition when referring to what one usually does in ethnographic research: study people’s actions and accounts in everyday context, in the field/gather data from a range of sources/data collection proceeds ‘unstructured’, making space for categories from the field to be generated/focus on usually a few cases/analysis is interpretive (ibid., 3). This definition applies well to the methodology of this study.

However, one thing is to define ethnography in terms of practice, another thing is to reflect on ethnography as a specific methodology, and what this means. Carter and Little (2007) explain that a methodology is a “reconstructed logic” that formulates and evaluates a specific logic-in-use or a strategy of inquiry; it is a theory on how to proceed with research. This means, in this case, that there are procedures, more or less clearly phrased, on how to formulate, prepare, sample, collect and analyse data from methods used in ethnographic research (Carter & Little 2007). Such logic-in-use justifies methods, which again inform the way you consider the researcher’s role, the status of informants/interlocutors, the status of data and finally how to work analytically and report one’s research results for a specific methodology. Ethnographic studies basically involve the researcher in a co-construction of data, considering informants to be active participants and knowledge to be produced in interaction and relationship with participants. Observations and talk is all to be contextualized, situations are dependent on time and space, and all procedures are followed up by constant reflexivity and an interpretive approach. In this way, ethnography is not just a technique but it is based on the choice and use of specific methods, methods that then again need to be applied with reference to the specific intellectual and philosophical history of understanding and theories of knowledge that have developed this specific methodology and informs it.

The way ethnography is informed may however still result in different ways of applying it. For some, an ethnographer does ethnographic research as “a way of looking”, with an emphasis on how to look, how to encompass all possible ways of directing one’s attention to a research field, as a set of qualitative methods for gathering data (Wolcott, 1999, p.46). In this thesis, ethnography is more than fieldwork techniques, it is a methodology as described above that also implies “a way of seeing”, a way of attuning one’s mindwork to the study of human social behaviour, a preoccupation with cultural interpretation and social processes. However, the way to study social and cultural processes may differ, and my own research has its limitations, in scope perhaps more than in depth. My fieldwork is based on entering several social settings and getting to know the people involved in them and their engagement with the research topic, participating as much as possible with key informants, developing relations and learning while observing and being engaged in the daily life of others. This includes several social processes and interactions pertaining to all the participating professionals and youths, but because my focus right from the beginning was on the youths and their understanding of persistent bodily symptoms, I chose to follow and study the immediate arenas the young participants were part of (school, home) and how they sought help, care and support. This led me to choose to explore the ‘other side’ of the shared complexity of distress, the ‘home’ of the professionals, rather than pursue arenas where the main parties actually met in a care relationship or to. In other words, studies on concrete interaction and social processes in care provision were not realized but gave way for exploring settings that I hope provided a broader impression of the assemblage of MUS.

## 2.1 Assembling an ethnographic field

This thesis is based on ethnographic fieldwork in a Northern Norwegian town lasting for eighteen months in 2015 and 2016. The fieldwork design was inspired by ethnographic approaches to phenomena that are challenging to account for in a single site and/or understand from a single point of view (e.g. Marcus, 1995, 1999, Wahlberg, 2018). Insofar as I stayed within the borders of a northern Norwegian town, the fieldwork was geographically bounded. However, approached as a social predicament with communicative challenges and as a space of problematization (Foucault, 1984; Greco, 2012), MUS in youth is a “multiply situated” object of study (Marcus, 1995, p. 102). Somewhat related to constructivist cinema montage (e.g. Vertov et al., 1929), multi-sited ethnographies “define” their objects of study through tracing a complex cultural phenomenon within different settings (Marcus, 1995, p. 106). The phenomenon in question may be “given an initial, baseline conceptual identity”, in this case communicative challenges of MUS, “that turns out to be contingent and malleable as one traces it” (ibid., p. 106). My fieldwork has been multi- sited in the sense that I have explored local, contemporary forms of problematization regarding young people’s persistent symptoms, and the malleable nature of MUS, in different sites within the urban community (see 2.2).

According to Foucault, forms of problematization emerge when a “group of obstacles and difficulties” is transformed through a collection of thought processes into “problems” accompanied by more or less conceivable responses, or attempts to solve the problem (Foucault, 1984, pp. 388-389). Exploration of local and situated solutions also provides insight into how a problem is framed and understood. As a historian, Foucault traced how different problematizations and responses to them, in the areas of mental illness, sexuality and crime, emerged over time within larger grids (apparatuses or dispositifs), containing discourses, institutions, regulations, scientific explanations, morals “and everything said or not said” (Frederiksen et al., 2015, p. 205). Contemporary, ongoing forms of problematization may be explored using e.g. interviews and observation, based on practices and discourses gathered around an experienced difficulty (ibid.). Inspired by Foucault’s concepts, Ayo Wahlberg coins assemblage ethnography as a particularly suitable methodology for generating insight into “the ways in which certain problems, or better yet problematizations, take form” (2018, p. 196, cf. Ferguson, 1990), and for mapping the cultural logics or patterned knowledge practices that characterize the making of a particular phenomenon. These are, according to Wahlberg, manifest in and constituted by the “daily grind” of practices (ibid., pp. 13, 15). To attend empirically to how the understanding and management of MUS in youth are formed in various everyday and routine health and social care settings, I have in a somewhat similar manner looked for particular sites where I could explore how “configurations of patterned knowledge-practices” (Wahlberg, 2018, p. 11) are manifest in daily routines, practices and emergent forms of communicative experimentation.

Fieldwork has enabled me to identify and engage with young people suffering from persistent symptoms and with professionals playing a care role for young people between 14-23 years of age in the local community, and to explore the social context of young Norwegians (Emerson, Fretz, & Shaw, 2011; Hammersley & Atkinson 2007). Even though I have focused particularly on individual young people’s and professionals’ experiences and practices, it has also been important for me to study local patterns in the understanding and managing of symptoms emerging across individual illness experiences and professional boundaries. Although different professions such as nurse, GP, teacher and social worker are often approached as communities of practice in their own right, I will show that commonalities, patterns and themes may also be traced that link them (to paraphrase Wahlberg, pp. 15-16) to the extent that it makes sense to talk about specific modalities of communication with young people that emerge in daily routines of interpreting, communicating and managing their symptom presentations. These may be partially reflected in the social formation of illness experiences and self-care practices of young people, e.g. when they seek help.

Participant observation, forms of interviewing and film interventions provide complementary forms of data, and may serve to validate or adjust each other (Hammersley and Atkinson 2007). The material generated through fieldwork consisted of field notes, local news reports, website content directed at young service users, analytic memos, interview transcripts, video files and short films made in collaboration with the young people with persistent symptoms. In the following, I will discuss in more detail how the different sites, participants and methods have supported me on the ethnographic path leading to this thesis.

## 2.2 Fieldwork

My fieldwork involved participant observation, ethnographic conversations and interviewing in sites that provided opportunities to explore how the understanding and management of MUS in youth was being formed, and how "configurations of patterned knowledge-practices" (Wahlberg, 2018, p. 11) were manifested and constituted in daily routines and practices. First of all, this included everyday life settings of young people, such as the schools and their homes, which enabled participation and observation of the "daily grind" (cf. Wahlberg, 2018, p. 13) of practices performed by the young people to cope with their illness. To meet young people in everyday settings, potentially prior to long assessment processes, and to participate with and observe them in a peer context, three local high schools were chosen as fieldwork sites (see 2.2.1). The schools also provided access to the routine practices performed by various professionals working to prepare and adapt each pupil's school days and support them to get through their school year despite their complex challenges. Thus, fieldwork also involved the offices of various health and social care professionals, identified during fieldwork as involved in interpretation with and responses to young people about their symptoms. To explore the understanding and management of MUS in the context of the overall organization, classificatory practices and professional responsibilities regarding different health conditions and challenges in youth, I briefly included as fieldwork sites specific offices, professionals and a panel in the town hall, where the overall organization of municipal responses to young people's health challenges was being evaluated and developed at the time. Finally, my fieldwork also involved sites that were more explicitly determined by the research process, such as interviews, focus group discussions and collaborative film sessions and processes. Sites engaging directly with key participants with MUS were treated more "thickly" than other sites (Marcus, 1995 p. 10).

### 2.2.1 Identifying young participants with persistent symptoms

The main participants in this project were young people presenting persistent bodily symptoms aged 14-23. MUS was used as a sampling criterion and was defined as:

(a) ) the young person suffered from physical symptoms for more than six months;

(b) the symptoms caused distress and possible impairment; and

(c) the person had consulted his/her GP without receiving an adequate or satisfactory medical explanation/diagnosis from the GP or other health professional (cf. Peveler, 1997)

The criteria by Peveler et al were developed especially to help GPs point out patients with MUS in relation to research protocols and have been used successfully in other studies. However, even though they look straight forward, there are also reports showing that health professionals become in doubt when they try to apply the criteria to a particular person. Real patients are always more complex than a 'map' and the notion of what is explained or not is not a given fact. These were difficulties that our health professionals also experienced recruiting eighteen young people aged 14-23 experiencing persistent symptoms. All of them were of course much more than that, presenting lives, dreams, challenges and suffering of all sorts and they contributed in different ways during the fieldwork period. Eleven of them were girls and seven were boys, and the average age was 17 years. These participants were recruited through two main channels: Ten were referred via local health and social care professionals. Initially, eleven were recruited through this channel, but one of the girls decided to quit after the first day of the film course, as she felt uncomfortable with the group of young people there. Hence, only ten of the eleven recruited through this channel are included in this thesis. The project team, consisting of PhD students and supervisors, approached school nurses, school advisors,

**Young participants experiencing persistent symptoms**

| | Age | Recruitment path | School/work/ sick leave | Self-reported symptoms *Terms used by referring professsionals in italics* | Methods |
|---|---|---|---|---|---|
| Boy | 16 | Psychologist | Sick leave.<br>Quit School 3 | Headaches, *fatigue*, dizziness<br>dreamlike states | 6 interviews<br>P. observation |
| Girl | 14 | Pedagogical-psychological services | Secondary school | Headaches,<br>*non-verbal,* stomach problems, *t*iredness | 1 interview<br>Participant observation<br>Film |
| Boy | 18 | Psychologist | Sick leave.<br>Quit School 1 | *gastrointestinal problems*, headaches | 1 interview |
| Girl | 16 | Psychologist | School 2, part time | Tiredness, problems with concentration | P.observation<br>Film |
| Girl | 16 | Psychologist | Sick leave | Fatigue, food intolerance | P.observation<br>Film |
| Boy | 22 | Social worker | Quit School 2 | Headaches, back pain | P. observation<br>Film |
| Girl | 19 | Social worker | Quit School 2 | Pain in several parts of her body | 1 interview |
| Girl | 20 | Social worker | Adapted part-time work | Headaches,<br>back pain | 2 interviews |
| Boy | 15 | Hospital ward | Sick leave | *diffuse case* | P. observation<br>Film |
| Boy | 20 | Social worker | Sick leave | Shoulder and back pain | 1 interview |
| Boy | 17 | School nurse | School 3 | Stomach pain | 2 interviews |
| Girl | 19 | School 1 | | Back pain, paralysis episodes | P.observation<br>1 interview |
| Boy | 17 | School 1 | | Back pain, recurrent headaches | P.observation<br>1 interview |
| Girl | 17 | School 2 | | Pain in several parts of her body | P.observation<br>1 interview |
| Girl | 17 | School 2 | | Jaw and joint pain | P.observation<br>3 interviews |
| Girl | 17 | School 3 | | Stomach problems | P. observation<br>1 interview |
| Girl | 17 | School 3 | | Joint pain<br>Easily sick | 3 interviews |
| Girl | 17 | School 3 | | Daily headaches | 1 interview |

social workers and specialist psychologists through phone calls to the services and oral presentations in existing meeting venues. We asked these to contact the researchers if they knew young persons with debilitating bodily complaints that had remained unresolved for more than six months despite medical consultations and that were challenging to understand and manage. The professionals received information letters, flyers and informed consent forms, which they presented and distributed to their young service users. Peveler's concrete criteria a-c (above) guided the professionals' selection of relevant participants. I arranged introductory meetings with potential participants and the referring professional and/or consenting parent, where they received more information about the project before making their final decision about participation. The participants referred by professionals, with one exception, were out of school and work or had a high absence from school due to complex health challenges.

In addition, eight participants were recruited directly from three purposefully sampled high schools, using the same criteria of MUS as above. To gain access to the schools, we presented the project at an existing meeting for the heads of the seven high schools in the town. They discussed amongst themselves and with us the relevance of their particular school for our topic. They highlighted practical curricula of two schools as most relevant, based upon multiple pupil challenges, including "diffuse" bodily complaints. To balance the selection with a broader demographic sample, and because it was often mentioned as relevant in initial fieldwork meetings, we also included a third school offering specialization more oriented towards higher education and elite sports curricula (School 3). I began my fieldwork in the schools with ethnographic conversations and participant observation among teachers, school nurses and school advisors, and introductory presentations of my project followed by participant observation in classrooms of the selected subjects. Interested students contacted me directly, but discretely, in the schools. These received more information in an initial meeting where they related their symptom experiences to my presentation and decided if, and how, they would like to participate. The participants recruited directly in the schools were less debilitated by their health challenges, but experienced their symptoms as significantly interfering with their everyday life. While the participants recruited by professionals were current service users and more deeply involved with health services at the time, all participants were current or previous users of school nurses, social workers and/or mental health services. Some had previously been diagnosed with anxiety, depression or PTSD. None had as yet received a label for their persistent bodily symptoms. All the participants were asked to attend an initial life mode interview, and to consider participation, in a combination and intensity of their choosing, with one or more subsequent interviews, participant observation by me and/or with collaborative film methodology. Thus, the methods and extent of contact differed from participant to participant, as will be specified in the table below and in relation to each method in sections 2.2.3-2.2.6.

### 2.2.2 Identifying additional key participants during fieldwork

During fieldwork, I encountered other interlocutors who proved relevant for the understanding and management of the young participants' symptoms. These were additional professionals, peers in school and some of the parents. Twelve professionals were identified through fieldwork as experienced and routinely involved in communication with young people about persistent symptoms. These were identified through participant observation and ethnographic conversations in the schools, and through initial recruitment dialogue in health service meetings and in phone calls.

I initially identified the school nurses, all women, working part of their week in the schools as particularly relevant for routine health communication with students about their symptoms. Students with health challenges were routinely sent to talk to the school nurse, and many, especially girls, sought out the nurse by themselves to present different worries. During the school-year before my fieldwork, seven extra nurses had been hired by the municipality in order to perform initial consultations with all new high school students in the town as an extra precaution to prevent students from dropping out of school. I also discovered the central role of teachers, school advisors and social workers for early interpretation of young people's health complaints in relation to school expectations and overall wellbeing. Students who risked failing a subject because they had been absent from too many classes were routinely sent to speak to the school advisor, and some had connected with social workers and had regular chats with them about their troubles.

Some of the teachers I met seemed more at ease with the topic than others and with managing the extra work that came with having pupils with complex and "diffuse" health complaints who barely passed the term work. I grew curious about the teachers' solutions to some of the communicative dilemmas they mentioned, such as frustration and uncertainty about the lack of documentation and uncertainty about when they had actually “had enough” assignments from each student to be able to grade them. Some applauded the upcoming national regulations that would formally limit to 10% the hours a high school student could be absent from each subject without documentation, as this would make it easier to “draw the line”, place responsibility on the student, and “drop” the students with the most absence from their to-do list. Other teachers, however, seemed more intent at “getting them through” the school year. Finally, professionals in the field often mentioned informally referring the young person to see his/her GP, and some suggested particular GPs as especially experienced in managing “these kinds of cases”. I therefore asked the school nurses, school advisors and relevant teachers working in the schools, as well as public social workers visiting the schools, to assist youth at risk to participate in one interview each (see 2.2.4). I also approached two GPs who were recommended by other professionals as experienced, interested and relevant collaborators in caring for young people with MUS, and sent out an open email invitation to local GPs with an invitation to an interview. One GP replied to the open invitation and was included with the other two. Ten out of the twelve professionals recruited for interviewing were women, reflecting an overall higher percentage of women in the schools and other professional settings. All had ten or more years of professional experience and showed interest in our topic.

In the schools, I identified the central role of classmates for my main participants’ understanding and management of their symptoms. Because the topic I was exploring was often not expressed in the form of very visible practices and/or much seemed to be left unsaid and only hinted at through body language, I felt a need to create an alternative setting where understandings and responses related to different symptoms in the peer setting could be more easily verbalized. I therefore organized two group discussions with other students from the schools to gain access to explicit communication and group interaction relating to my topic and explore emerging themes relating to my main participants’ management practices vis-à-vis their peers in school (see 2.2.5.). The students that volunteered had not presented persistent symptoms themselves, and most of them were outspoken and seemingly popular girls. These group discussions were used to explore emerging themes in field observations, but have not been used explicitly as empirical material in the three papers of this PhD.

Following my main participants outside of school, I subsequently met and spoke to a few of their parents. These were mainly parents of the youngest participants, and/or those with the most debilitating symptoms. In most cases the participants had developed relatively independent relationships with their families, to the frustration of some of the teachers trying to warn parents about their son’s or daughter’s absence from class. Some had had to move away from their home area to start high school and now lived alone for the first time. Many also described quite complicated relationships with their parents as potential causes of their health problems, or frustrations about lacking recognition at home for their challenges. During participant observation in the home of my youngest participant, I became aware of the central role of her mother, in relation to making sense of and managing their everyday life with symptoms. She plays a part in Paper III.

### 2.2.3 Participant observation and ethnographic conversations

Participant observation in fieldwork may be described as a cyclical process, where theoretically informed analysis of recorded ethnographic data that is performed routinely and from an early stage generates new, and hopefully more focused and selective, research questions (Hammersley & Atkinson, 2007; Spradley, 1979, 1980; Fangen, 2010). Traditionally associated with long-term immersion in far-off, isolated villages, participant observation in urban fieldwork situated in societies closer to home, as in my fieldwork, has required that I responded and adapted “flexibly to social circumstances” as they arose, and that I was “open to a wide variety of different types of relationships and interaction” (Amit, 2000, p. 10). Spradley describes ethnographic interviewing as a “series of friendly conversations into which the researcher slowly introduces new elements to assist informants to respond as an informant”, or a kind of teacher (1979, p. 59). This involved, among other things, clarifying a purpose and directing the conversation into a direction that lead to the discovery of cultural knowledge using different kinds of ethnographic questions. After every contact with the field, “thick”, first-order descriptions of observations of situations, actions and speech acts were written down in the form of field notes (Emerson et al., 1995).

Participant observation with young people at the high school included periodic presence in class teaching, group assignments, student presentations and breaks in the selected subjects following presentation rounds where I had asked the class and their teacher, before anyone had replied to my invitation to participate, if I could spend some time with them in class. I also “hung out” with students at special school events, such as a sports day. To manage my “front”, avoid being ascribed unwanted identities and affiliations (Hammersley and Atkinson 2007, cf.

Goffman 1959), and to reduce potential barriers between me and the students based on my adult age, I bought new clothes for fieldwork that were deliberately as neutral as possible. For example, I bought the kind of parka jacket that "everyone" below 40 seemed to wear at the time, but chose a brand that was not too expensive or "posh". Some of the students commented that I was "cool for an adult", but I suspect this had more to do with my pattern of behavior and interest in their social life that contrasted with other adults in their life at the time, than with my appearance. Others ignored me. During this period, groups of students would share their views on health in youth on a general basis. Individual students discretely texted or approached me with questions regarding the topic of my study. Most participants expressed a certain sense of shame or a lack of understanding from many of their friends and classmates about their symptoms. More often than not, the participants who were in contact with me outside of the classroom remained a secret to all but a few. Quite often, their suffering was endured in silence, making it a more challenging phenomenon to observe directly. Being periodically present in the different classes, I tried to observe the unsaid as well as verbal and body language concerning health, presences and illness-related absences, expectations and roles that could be elaborated on and explored in subsequent interviewing.

Participant observation also involved following the young people to other settings, such as their homes. There I met some of their parents, which enabled exploration of understanding and management strategies in their family context. Most lived on their own, however, and participant observation outside the schools was in many cases with the young person alone. At home, some would show me their new small apartments and their most prized possessions, and explain how they usually moved about and what their everyday routines were. This often included mutual exploration in the virtual worlds of social media, computer gaming and/or the dark web. Participant observation with the young people with persistent symptoms also involved texting, walks in the woods, visits to youth activities with one of them, and trips to health care facilities and research activities. One key participant and one of his parents invited me to consultations with the participant's GP and psychologist, but the other parent's permission was needed. This proved to be challenging as it might stir up old and painful conflicts regarding the nature of the participant's symptoms. Another key participant explained that he did not dare to risk disturbing the important supporting role his mother played in health encounters by my presence. By offering to drive participants to and from health appointments, I could, however, attend to their expectations and goals for the consultation, and how they felt it went.

I also performed participant observation in the teachers' lunch rooms in the three schools and visited the offices of teachers, school nurses and school advisors for informal and ethnographic conversations. The numerous encounters and ethnographic conversations with various local professionals and heads of services, especially during the initial recruitment phase, provided interesting dialogue and emerging themes on communication practices and rationales that I included in my ethnographic field notes and analytic memos. The professionals found it challenging to invite me to consultations that they deemed relevant, however, as it would imply a front stage categorization of their service user's symptoms as MUS, or, to use their term, as "psychosomatic".

Finally, as will be further elaborated in the sections describing interviews and film collaboration (2.2.4, 2.2.6), encounters facilitated by the research process were also approached as particular forms of social events, where meaning is co-constructed (cf. Atkinson et al., 2003; Haavind, 2011; Waage, 2014), and where the interviewer and participant are both participant observers (Hammersley & Atkinson, 2007, p. 120).

### 2.2.4 In-depth interviewing

In-depth interviews were conducted with 14 young people experiencing persistent bodily symptoms and with 12 professionals identified as engaged in care practices for young people in the community. All interviews were performed by me, except for the six interviews with the young participant "Peter", which were conducted by the other PhD student and psychologist in the overarching project, Silje Vagli Østbye. This formed part of a case study collaboration where I performed six of the fourteen film sessions alone with Peter (see Paper I and section 5.2.6 on film).

In addition to the six interviews with Peter conducted by the other PhD student, I performed 19 in-depth interviews with 13 young participants, giving a total of 25 interviews with the 14 young people experiencing persistent bodily symptoms. Of these 14, seven were referred by a professional, while seven were recruited directly in the schools. Nine were girls and five were boys. The four young participants who were not interviewed had been recruited by health and social care professionals. They expressed explicit interest in and chose to take part in the visual methods (see 3.1.5, 3.1.6 for descriptions of the film dialogues) but decided against the interview format. In one of these cases, the person was described by the referring professional as verbally withdrawn. A few expressed interest and were offered a meeting to talk the topic over and what participation involved, but chose not to participate. One of these expressed concern about involving her parents for consent. One wanted initially to participate, but decided against it, since she felt that her bodily symptoms were insignificantly debilitating compared to her social anxiety. Nine chose only one interview, but their interview was supported by other methods and/or used in comparison to data from other young people.

The 25 interviews with young people took place at the university (15, including six with Peter), in their school (4), in their homes (4) and in the town library (1), according to the participants' wishes. All interviews lasted about 90 minutes. They were based upon an adapted version of the life mode interview format (Haavind, 2007, 2014; Jansen, 2011; Andenæs, 2012, 2007). The life mode interview format was originally developed as a clinical instrument to elicit data that could assist in making connections between a care provider's everyday practices and his/her children's involvement in everyday life (Haavind, 2011, p. 134). Later, the format was adapted to conversations with the children and young people themselves (Andenæs, 1991; Gulbrandsen, 1998). The format is structured around time, following a recent day from morning to night and placing events in that day in relation to everyday rhythms and patterns, and what is considered typical for the young person (see guide, Appendixes). Follow-up questions were asked about the day and the relationships involved, such as what happened next, who were there, and how was that for you? Overview questions were also asked about the past week. Themes introduced by participants were explored as much as possible in the context where they seemed to "belong" in their narrative, rather than the interviewer posing direct themed questions. An underlying assumption was that subjective experience is situated in concrete events and specific ways of living (Haavind, 2011, p.134-135). The life mode concept directs attention to how events are anchored in time and space, and how they are subjectively composed and interpreted by the person (ibid., p. 134).

On the one hand, the life mode interviews provided the opportunity to explore themes emerging in the schools, as well as to explore in depth young people's everyday experiences and understanding of their challenges and management strategies. On the other hand, the interviews represented a specific kind of encounter where meaning was co-constructed. Following descriptions of events, and how the participant endowed them with meaning, the conversations were directed towards the person's engagement in the world and what Mette Bengtsson has called "the young person's project" (Bengtson, 2007). From a psychological point of view, telling a story about oneself in the course of the conversation contributes to the development of self (Haavind, 2011). Referring to Bruner (1990), Haavind describes a duality built into a first-person story, where the protagonist in the event emerges as both the same as and different from the narrator (Haavind, 2011, p. 137). Interviews may thus open up a reflexive space in which the interviewees begin to view their experiences anew, put them into words and/or position themselves in new ways. By confirming that she has heard and understood, the interviewer recognizes both protagonist and narrator as subjects. In relation to my background experience and preconceptions as a social worker, the structuring life mode format may have kept potential unconscious framing habits in check, such as a possible "problem focus" (cf. Bucholtz, 2002), or "gazes of concern" (Henningsen et al., 2008), especially concerning structural, social or illness-related constraints. On the other hand, the format may have contributed to an emphasis on, and co-construction of, empowerment and agency in the encounter and in the young person's presentation of self (a theme I will return to briefly in the ethics section).

In April to July 2016, a 60-90 minute individual interview was conducted with each of twelve professionals (see sampling procedures, 2.2.2). These interviews were partly structured by an adapted form of the life mode format (cf. Andenæs, 2012, 2007; Jansen, 2011, see appendixes), with the aim to explore in depth examples of concrete events involving communicative interaction with young people. Without exception, I performed these interviews at the professional's workplace. For the teachers, this was often a deserted classroom. For other professionals, it was their consultation rooms. As a pragmatic decision to allow for more extensive fieldwork with other methods, I limited these interviews to twelve participants. I asked the professionals to describe specific care interactions with young people presenting persistent symptoms for more than six months where medical consultations had been inconclusive, including ongoing as well as long-term interactions as they had occurred over time. I asked them to share success stories as well as communicative dilemmas they had attempted to overcome in relation to patterns, present practices and ongoing care processes. To prompt the description of concrete events, I had to spend some time to inform the participants about ways to ensure confidentiality, such as not using any names and anonymizing details. Their stories were probed during interviewing for explanatory models, goals, communicative challenges and strategies involving language use. In addition, the interview guide contained structured questions about explanatory models and communication goals, in line with a qualitative semi-structured format (Kvale & Brinkmann, 2002).

On the one hand, the understanding of persistent bodily complaints and the experiences of communicative dilemmas expressed by these professionals reflected emerging themes across professional sites in the field. However, the professionals interviewed were presented in the context as the most experienced in the management of “diffuse” health challenges in young people, and were the ones who expressed the most interest in my topic. The interviews with teachers were performed at possibly the busiest time of the year, when examinations were underway. Despite their busy work schedules, and stressed-out colleagues coming knocking on their doors for advice, they prioritized spending more than an hour with me, and expressed concern and long-term care and engagement for their students’ wellbeing. To prevent understanding too soon in a field close to my own work experience, I explained that I needed to get detailed descriptions “on tape”, and to be sure that I knew what they meant. The role I sought with these professionals despite my now adult age and experience in social work was thus to a certain extent that of the “naive student” (Hammersley & Atkinson, 2007, p. 71) and “marginal reflexive ethnographer” (ibid., p. 91). Although the selection of mostly women could be due to a better rapport with other interlocutors of my gender, it also reflected an overall distribution of more women than men in the field. All interviews with young people and professionals were audio recorded and then transcribed. I wrote analytic memos after each interview, and drew charts of domains and semantic relationships to guide the development of my analytic reflection on each interview as a particular kind of social situation and the overall fieldwork (Spradley, 1979).

### 2.2.5 Group interviewing

Group interviews may provide considerable insight into participant culture (Hammersley & Atkinson 2007, pp. 111-113). One format of group interviewing sometimes used by ethnographers is the focus group interview (Hammersley & Atkinson 2007, p. 112). Focus groups can provide concentrated information on a topic in people’s lives that is only sporadically or superficially available to the ethnographer (Bloor et al., 2001, p. 6). Broadly defined, focus group discussions are group conversations where the researcher encourages and pays attention to group interaction (Barbour & Kitzinger, 1999, p. 20). Focus group interviews are for example suitable for exploring group processes among those who are hard to reach, taken for granted attitudes, discursive repertoires and rhetorical strategies (Hammersley & Atkinson, 2007, pp. 113-114). To explore and supplement emerging insights on understanding and management by health and social care services and school representatives in a community policy context, and to investigate communicative interaction on an otherwise under-communicated topic among young people, I arranged five group interviews loosely inspired by focus group methodology (Barbour & Kitzinger, 1999). Rather than following specific sampling procedures and streamlined interview guides typical of focus group studies, however, I purposefully sampled existing local groups, one in the town hall, and four in the schools, and approached the groups with three different guides with quite open questions relating to themes and adapted according to their different ages and the purposes of the interviews (see appendices). I arranged the focus group interview in the town hall relatively early in the fieldwork period, while the focus group interviews in the schools were held in the final months of fieldwork, to explore themes that had emerged through participant observation.

To explore how persistent symptoms in youth were conceptualized and to trace underlying logics in a broader local context, I arranged one group discussion in a meeting room in the town hall based on a municipal panel of 11 persons meeting regularly to evaluate and improve health and social care services for young people. The group discussion in the municipality included professional leaders involved in critical and innovative development of health services for children and young people, with goals based on a national service integration reform, the Coordination Reform, service leaders responsible for specific service areas, some of them still involved in direct health communication, and one young adult user representative. In the schools, one focus group of professionals was a team of four collaborating teachers in School 3. Another group consisted of a resource team in one of the more practically-oriented schools, with six professionals, including school nurses, school advisors and school leaders, who met regularly to discuss problems and find solutions, e.g. by involving other services or adapting the school day to students' challenges that affected their school life and performance. The dynamics in this group was affected by communicative barriers between the different professionals in the team, who had confidentiality restrictions regarding the specific health challenges of students. I therefore invited one of the participants to an individual interview, which proved easier. Finally, the group discussions with peers included final year classes in the selected tracks in schools 1 and 3. In School 1, a group of five girls and one boy from the same class participated, while in School 3, the group consisted of ten girls and one boy from the same class. Most of the pupils who volunteered from these classes were quite outspoken girls. The focus groups of peers provided insights into peer categorization practices and expectations relating to the communication of health challenges.

Group discussions took place after written and oral information was provided and consent received form all participants, including the parents of students under 18. I ordered pizza or sandwiches for the participants and lit small candles on the tables to create an open atmosphere (Krueger & Casey, 2009). In the existing groups, I had the impression that other participants were equally relevant audiences as I was myself. Normative expectations especially influenced the town hall discussion and the discussions among peers. However, these interaction dynamics were interesting to observe and challenging to access in other, more "naturalistic" settings. All the focus group discussions were audio recorded and transcribed and analytic memos were written as a supplementary source of knowledge in the overall fieldwork process.

### 2.2.6 Reflexive film dialogues

Ethnographic filmmaking used as a tool in research may enhance analytical understanding in relation to theory development (Ruby, 2005), and has the potential to expand its scope with kinds of knowledge less accessible via text-based methods (MacDougall, 2006; Pink, 2006, 2007). MacDougall has especially emphasized the ability of the film medium to place the subject concretely in its world, capture embodied aspects of experience and convey empathic communication of knowledge and experience transculturally across communicative barriers (MacDougall, 1997, 1998, 2005). As will be elaborated on below, visual materials and methods used as means for dialogue between researchers and informants may also enhance the processes of discovery that constitute interpretive research (e.g. Waage, 2007, 2018). Visual collaborative methodologies are often applied in youth research as tools to promote more empowering research relationships and to facilitate understanding (Chalfen & Rich, 2007; Johnson & Alderson, 2008; Waage, 2013, 2016), and research has highlighted their potential in the study of health and illness (e.g. Chalfen & Rich, 2007).

My approach, and that of the overall interdisciplinary project group (COCHA), is inspired by collaborative methodology (e.g. Worth & Adair, 1972; Rouch, 1961, 2003 [1973]; MacDougall, 1998), and its use and development at the Centre for Visual Cultural Studies in Tromsø, Norway, where I graduated in 2004. The centre has a long history of combining academic and applied objectives through the use of visual interventions and participatory, or "shared", methods of knowledge production, some of which have been performed in the north of Norway (Pink, 2007, p. 7; e.g. Holtedahl, 1986, 1987e; Wang et al., 2012; Waage, 2014, 2016). The concept of "shared anthropology" was developed by the French filmmaker and anthropologist Jean Rouch (2003[1973]) to denote the role of film in ethnographic, collaborative knowledge production. Rouch was inspired by the 1920s work of the Russian filmmaker Dziga Vertov and the Irish -American researcher Robert Flaherty, especially by Vertov's notion of *cinematic* truth (kinopravda) resulting from particular ways of seeing and hearing using film equipment, and Flaherty's early uses of an explicitly participating camera as a technique in the field (Rouch 2003 [1973]). As a research tool, according to Rouch, the camera could open up for open-ended and mutually engaged interaction in the field that supported cross-cultural learning opportunities (Jørgensen 2007, Rouch 2003 [1973], Piault 2006).

The idea of a shared anthropology manifested in different ways in Rouch's work. Firstly, Rouch found that "feedback" screenings with filmed subjects as a "first audience" (2003, p. 43), could trigger their engagement and open up a reflexive space for the ethnographer (ibid., pp. 18-19; Pink, 2007), for example by critical corrections, new information about issues that were harder to approach through observation, or ideas for new collaborations. Secondly, Rouch understood ethnographic knowledge as ideally the result of ongoing and mutual "ethno-dialogue" (2003 [1973]). Using Vertov-inspired concepts, Rouch described how the ethnographer "modifies" him or herself in the field, with a camera more visibly so, (she "cine/ethno-looks, cine/ethno-observes and cine/ethno-thinks"), and the people he or she encounters there who give their trust are modified in similar ways (they "cine/ethno-show", -observe and think) (ibid.,p. 100). Rouch purposively facilitated spaces where he attempted to utilize the potential he saw in juxtapositions between himself and actors in the field constructively, by turning so-called distortions, such as reactions and emotions, into dialogue (Jørgensen 2007). Dialogic aspects in Rouch's shared anthropology praxis were perhaps most developed in his collaborative "ethno-fiction" DALAROUTA projects. These were performed with a group of key participants in Niger who worked as co-directors and film assistants, and who improvised acted roles that evoked central themes and culturally patterned sense experiences in their own unscripted lives (Jørgensen 2007, Mortimer 2007 cf. MacDougall2006). Rouch's work has also received considerable critique however, for its lacking political engagement and allegedly implicit influences from colonialism. Based on later exploration of Rouch's collaborative relationships, Jørgensen argues that these projects were dialogical in three main ways that still may inspire future researchers; Firstly they were based upon a method of conscious modification of both ethnographer and participants, "collaborative imagination and narrative openness" (2007, p. 63). Secondly, they seemed to produce a dialogic epistemology in the sense that it profited from an "exchange of knowledge" and dialogic space for them to ethno-talk, think and reflect in new ways on their experiences (ibid., p. 67). Thirdly, the films entered into dialogue with different audiences although this aspect could have been further developed to the benefit of the Nigerian participants and their social environment (ibid.). In later anthropological works, similar principles of shared anthropology have been used to establish a space for collaboration between anthropologist and participant with the potential for both to "advance their own goals through hybrid products" (Flores, 2007, p. 209). Careful attention is, however, required to how "subjects become objects and are objectivized in one's anthropological practice" (ibid., p. 221), for the "shared" quality of the relationship and knowledge produced to become more than illusory. This topic will be returned to in the ethics section (2.4).

The particular visual method applied in this project was based upon the Youth-Gaze method (Ungdomsblikk) initially developed in 2005 at the Centre for Visual Cultural Studies as a tool to achieve credible descriptions of young people's lifeworlds and a more comprehensive understanding of their meaning-making processes (Waage, 2014, 2016; Wang et al., 2012). Waage (2018) argues that the use of a camera in these encounters helps the adult researcher to access a relevant fieldworker role (cf. Wadel, 1991) in research with young people and to catalyse emotive "engagement" in the young informant turned partner. This engagement in turn opens up for a dialogue that allows the researcher to understand, or "grasp", the young person's choices, orientations, ways of living, and interpretation processes (ibid.). The Youth Gaze method invites young people to learn about filmmaking and to make reflexive films in small groups about a topic close to their own experience. Through mutual reflection on visual material they have filmed, and the process of making a film with a potential audience in mind, participants reflect upon their gazes upon themselves, their environments and practices, and how they are seen by others. The method has since been adapted to different target groups and settings, in collaboration with the Department of Psychology at UiT, and supported by collaborating health and social care services, including the outreach service where I myself took part as a social worker (see Wang et al., 2012 and Waage, 2014, Hope forthcoming). These collaborations have illustrated the potential for synergy effects to take place in the course of reflective dialogue and feedback settings, opening up reflective processes where individual interpretations and dilemmas may be explored (Wang et al., 2012; cf. Carlson et al., 2006; Johnson & Alderson, 2008).

In the course of the research project leading up to this thesis, six young people, three boys and three girls, all referred by professionals, participated by using reflexive film dialogues (see table and further descriptions on recruitment in section 2.2.1). I organized one Youth Gaze film workshop with the other PhD student in the overarching project where four of them participated, and later performed two individually adapted film processes alone with the two others, who were referred at a later stage. We arranged the initial Youth Gaze film workshop at the university campus, and I performed the individually adapted film processes in the young people's homes. One of the girls decided to quit after the first film workshop day, expressing discomfort with the social setting with the other young people, and was not included among the four. Another of the girls, who suffered from undiagnosed fatigue and food intolerance, took part in the first half of the group workshop but later reported that her health worsened. She did not finish a film of her own, but has been included.

The Youth Gaze film courses have typically been organized as weekly sessions over eight weeks with participant filming in between sessions, culminating in a closed "world premiere" screening with an audience specially invited by participants and course leaders. In this project, we initially followed this structure for the group setting. The first sessions involved a learning by doing group assignment, where the group made a short film together on the topic "a good day" or "a bad day", which soon cast the participants into the practical and storytelling devices of filmmaking as well as triggering relevant group discussions on everyday life experiences. The group made a short film together and then screened it in a small premiere with the participants and course leaders only, foreshadowing the forthcoming "world premiere" of their separate films. Following from this, the participants received a small video camera to film start-up assignments, to film a place where they spent a lot of time and to draw mind-maps of relevant topics and potential scenes relating to a topic of choice. The participants shared filmed material during the process and reflected upon the meaning of the events, relationships and/or places on film with the workshop group and/or with me alone. This led to the development of new ideas for filming and for the meaning of their films. The three remaining participants in the group film workshop made separate films. These processes took longer than the designated eight weeks to finish, mainly due to health constraints and a period spent elsewhere for assessment, and required extensive adaptation and additional individual editing sessions with the participants in order to finish. We arranged a total of eight workshop sessions with the group, and nine additional individual sessions with two of the workshop participants.

The use of this visual method with the six participants resulted in field notes from participant observation and video-elicited ethnographic conversations related to the film workshop setting and the reflexive dialogue processes, in addition to five films: two roughly 15-minute long films that were screened at the “world premiere” at the university campus, two films screened by the young persons alone in their separate school settings, and one shorter film shown at home to invited social workers. The participants in the workshop setting and in individual film dialogues were aware of our interest in their persistent symptoms but were allowed to choose for themselves a topic for their film close to their experience. One of these processes from the workshop setting (“Peter”), extended over one year, and is analysed in depth in Paper I. One of the film reflection processes performed individually in the young person’s home (“Anne”) is covered in Paper III.

## 2.3 Analysis

Analysis of ethnography is not a clearly delineated stage of a research process. Already embedded in the researcher’s “ideas and hunches”, it begins in the early phases where research questions are formulated, and it lasts well into the writing process (Hammersley & Atkinson, 2007, p. 108). Characteristic of much theoretical analysis is to choose an approach that follows abductive reasoning rather than being merely inductive or deductive. According to Timmerman and Tavory (2012, p. 170) ”abduction refers to an inferential creative process of producing new hypotheses and theories based on surprising research evidence. A researcher is led away from old to new theoretical insights” and relies on biography, conditioned ways of seeing and familiarity with broad theoretical fields. Theoretical repertoires become sensitizing notions that inform the empirical data and are developed throughout the research process. Supported by the theory presented in the introduction of this thesis, I tried to let myself be surprised and to take surprising findings seriously (cf. Agar, 2006), to generate new questions and angles and to develop concepts, e.g. by writing analytic memos, drawing charts and applying sensitizing concepts. In line with a general interpretive framework, key themes and patterns emanating from the field (Geertz, 1973; Wadel, 1991) are interpreted and related to the research questions as well as analytical theories and concepts through abductive, iterative and recursive reasoning or inference (Maxwell, 2005; Pierce, 1979; Agar, 2006). This entails a concern with meaning and context, skepticism of ready-made explanations and taking seriously, i.e. letting oneself be "led away" by, surprising insights in the field to explore repeated themes and "construct new understandings based on new concepts" (Agar, 2006, pp. 71-72). Early abductive moves constrain subsequent exploration from initial open questions posed to the field (Agar, 2006, p. 74). Thus, ethnographic fieldwork involves a series of choices during the process, partially grounded in epistemology, theory and pre-understanding, but also prompted by findings in the field. Ethnographic validity may be accounted for by close description of these choices, and of one's resulting "ethnographic path": What was done and why, whom one talked to and learned from, and what was brought back to document it (Sanjek, 1999).

In the following, I will briefly describe the three studies that explore the understanding and management of MUS in youth from different angles and with slightly differing analytic approaches that have led to the final papers in this thesis.

### 2.3.1 Study 1: A narrative case study

The final analysis for the first study was done in collaboration with the second PhD student in the overarching study (see 6.4 for a description of the research group). This part of the analytic process was closely supported by monthly analytic discussions with the interdisciplinary project group consisting of the three supervisors and one additional researcher, Hanne Haavind, the developer of the life mode interview format (2011, 2014). Due to the extensive material regarding a key participant, "Peter", and the way our mutual experiences with him shed light on questions of how young people make sense of and manage constraints relating to persistent symptoms, we chose to perform an in-depth case study. Peter's case exemplified ways to find meaning in everyday life with debilitating MUS, to manage oneself and one's suffering, that began to provide answers to and focus our questions related to subjectivity, social suffering and agency in youth. We based the analytic process on ethnographic observation field notes from 14 film workshop sessions over one year, Peter's film "Derailment", as well as six interviews held concurrently with the filmmaking process. To support analysis of embodied aspects of Peter's account, we supplemented our main theoretical interest in subjectivity, social suffering and youth (Biehl et al., 2007; Good, 1994; Bucholz, 2002) with a sociocultural approach to embodiment (Csordas, 1994). We began by exploring the themes that had emerged in dialogue with Peter in the film making process and that stood out in the material and film narrative, based on a general approach to thematic analysis.

The theme 'derailment' first arose in reflections with Peter as an emic term during the editing of his film and was further developed into two main themes in discussions with the research group. In the course of developing and consolidating the analysis through shared reflection and interpretation in the research group, we became interested in performative aspects of Peter's constructions of himself as a young subject and our own roles and those of other audiences in the process of developing a particular narrative. Further, to capture such performative aspects, we chose a dialogic-performative approach to narrative analysis (Mattingly, 1994; Riessman, 2008; Frank, 2010; Holquist, 2002; Riessman, 2008; Shotter & Billig, 1998), shifting the analytical focus from the 'told' to the 'telling' (Mishler, 1995). Through a dialogic-narrative re-contextualization of the research material, a larger narrative about long-term illness management and legitimacy in youth emerged. The overall analytical process elicited themes of moral expectations in illness and youth, and of future aspirations, that played a central part in Peter's understanding of his illness and his coping strategies.

### 2.3.2 Study 2: Professional communicative responses

In encounters with professionals in the field, the project group defined MUS as persistent and debilitating bodily complaints that the young person had experienced for more than six months, and that had proved challenging for health professionals to medically explain, understand and manage (Peveler, 1997). Although these criteria helped to guide the professionals' selection of cases, the term MUS was new to them. In my early analysis of the encounters with several primary health and social care professionals, I was especially surprised by an almost indignant certainty in very *different* professional settings, of *"knowing"*, on a generalized level, what “*really*” was affecting young people suffering from persistent symptoms beyond medical explanations. This led to subsequent explorations into challenges and solutions in practice, i.e. their uses of language and approaches to care were also explored. For this group and in my fieldwork in general, the concept of MUS and existing explanatory frameworks served as an initial heuristic and sensitizing lens (Fangen, 2011). In this case, it brought on a de-familiarization process of taken-for-granted professional rationales and categorizations and shed light upon dilemmas tied to understandings and explanatory frameworks across different professions in the field.

To further explore experienced professionals’ understanding of and communicative responses to the suffering of young people presenting persistent symptoms, and their solutions to communicative dilemmas expressed in the field, I started analyzing transcripts from 12 60-90 minute long in-depth interviews conducted from April to July 2016 with these professionals (see 2.2.4). Supported by my supervisors, I initially analyzed the interviews according to general principles for thematic analysis, applying a constructionist and theoretically informed inquiry into latent and semantic levels of meaning (Braun & Clarke, 2006). I coded the transcripts by hand and explored themes within each interview, then within professions and across professional boundaries. Finally, I compared overarching themes to initial themes in individual interviews for consistency and variation. The notion of care stood out as descriptive of the professionals’ main concern. Therefore, to capture and understand their care responses, and the performative role of language, particularly of explanations, the analysis was inspired by an anthropological approach to care (e.g. Mol, 2008) and anthropological accounts of performative aspects, e.g. how language ‘does’ reality and crafts subjects and bodies (Kleinman, Das, & Lock, 1997; Kirmayer, 2000). This produced an abductive analytic process and showed in particular the significance of the two main modalities of communicative care responses, constituting “careful expressions” (see analysis section 2.3.2, findings section, paper II).

### 2.3.3 Study 3: Young people´s experiences and strategies

The analysis of the third study was based on field notes, video material and interview transcripts relating to 17 of the 18 young participants in my study. As our experiences with “Peter” were extensively covered in study 1, we decided not to include material from his case.

To explore in depth the participants’ concerns and everyday management strategies relating to their experiences of persistent and medically unexplained symptoms, I initially analysed the material using thematic analysis, applying a constructionist informed inquiry into latent and semantic levels of meaning (Braun & Clarke, 2006). I manually coded the transcripts and field notes by hand, explored themes within each item, within the material relating to each participant, and across the overall material. Finally, supported by my supervisors, I compared overarching themes to initial themes relating to individual participants for consistency and variation. Analysis was further informed by impressions from fieldwork of the participants' navigation and orientation in everyday life and research settings where I encountered them, where they managed the social constraints that they related to their symptoms just as much or more than they managed their bodily suffering. This spurred the analysis towards theoretical discussions on youth, subjectivity and everyday forms of agency (Biehl, Good, & Kleinman, 2007; Dalsgård et al., 2014; Das, 2012; Lambek, 2010; Vigh, 2006, 2009a, 2009b). We thus became curious about what the young participants' constraints were, but also about how they countered them, what they were hoping to achieve in their everyday lives, what they experienced as "good" in relation to others in this process, and the subjectivities that formed in these processes. We found three management strategies across the material, i.e. modalities of self-care, (see findings section .3).

## 2.4 Ethical considerations

This project was presented to the Regional Committee for Medical and Health Research Ethics (REC) and was found not to be within the jurisdiction of the Health Research Act as a biomedical health research project (Decision 2014/1023/REC North), according to the Health Research Act, §§ 2 and 9, and the Research Ethics Act, § 4. The project was also reported to the Norwegian Centre for Research Data (NSD), which provided approval in August 2014 (ID 39362). Adhering to the Norwegian Personal Data Regulations, guidelines from the American Anthropological Association (1998) and the National Committee for Research Ethics in the Social Sciences and the Humanities (NESH 2006, §12) regarding sensitive topics, children and young people, I provided face-to face, age-adapted and individual information and obtained written, informed consent from all young participants as well as from the parents of participants under 18 years. I also provided information for the schools about my presence and aims, and obtained informed, written consent from the professionals and peer groups invited to individual and/or group interviews. I informed the participants about their freedom to withdraw at any point and/or make changes in their participation in one or more of the levels of investigation, such as interviews, participant observation and/or film reflections. In line with international guidelines for ethical visual research methods (Cox et al., 2014), I approached consent as a continuous process, thus as an issue that had to be raised again at different stages, for example in deciding what scenes to shoot, where to screen the film and whom to invite as an audience.

Although the study was deemed to be outside of the jurisdiction of REC, health information is regarded as sensitive (Personal Data Act, 2000, Section 2a, Personal Data Regulations 2014, §7-27). Visual and in-depth interviewing on sensitive issues, especially with potentially vulnerable groups, may potentially arouse painful emotions from recalling previous experiences (e.g. Harper, 2002). I was prepared to support the participants if they should express a need to contact a health professional. In my project, those with the greatest health problems had regular appointments with the referring professional, and in some cases with a mental health therapist. I had also decided to recruit young people via high schools rather than secondary schools, partly as an ethical precaution. Despite numerous caveats regarding research on potentially vulnerable groups and sensitive issues, it is argued that excluding such groups from research participation with the aim to protect them may also have serious negative consequences for them, e.g. poorer knowledge of their lives and problems (Ruyter, 2003, p. 29). Participation in the project may also have benefitted some of them, for example in providing a reflexive space and/or tools for their own processes of meaning-making (cf. Rosenthal, 2003; Hutchinson et al., 1994). One important factor in working with sensitive issues that is emphasized by laws and guidelines is to de-identify information such as names of people and places (NESH 2006, pt. 14.) All participants have been given pseudonyms in the written accounts, key participants who are described in depth have been consulted, and personal information of little importance to the analysis have been altered in some descriptions of young people to enhance anonymization. The use of film added some ethical implications as it conflicts to a large extent with the ideal of participant anonymity and may reach a larger audience than ordinary research articles. To minimize harm, we advised the participants to keep in mind possible audiences for their films, especially with regard to the planned screening with invited local health professionals, family members and friends (Cox et al., 2014; Gubrium et al., 2014). This may have supported their conscious boundaries when working with visual presentation of self. Four of the five films made in the course of the project identify the young participant-director. These films remained in their possession exclusively, and our collaboration was not disclosed in the film credits. Two decided to screen their film only at their school, as they felt that the most relevant audience for the film was their peers. However, the fifth film, made by "Peter", was filmed in a style and manner that made it anonymous. With his permission, we kept it for academic use, and have presented and screened it for both academic and health professional audiences. These screenings made us aware of varied interpretations from audiences of different backgrounds, and the need to contextualize the presentation and discussion by the researchers according to the settings. For these reasons, the visual materials generated in the course of this project have not been published.

Another ethical "field of uncertainty" (Kvale & Brinkmann, 2009, p. 87) that needs to be accounted for as an ongoing concern is the role of the researcher in relation to her participants, as well as the resulting quality and usefulness of the knowledge following from it (Ruyter, 2003, cf. Clifford & Marcus, 1986). Ethical questions are embedded in each field encounter, as well as in the "macro-ethics" of the societal effects potentially caused by our research representations (Kvale & Brinkmann, 2009, p. 79). These questions are discussed in the following sub-chapters.

### 2.4.1 Initial role dilemmas and reflections on "problem- focused" approaches

Based on my experience as a social worker after completing my master in social anthropology, I was aware of several possible pitfalls in the understanding and management of challenges in youth, in research and in professional encounters. In the planning of fieldwork and analyzing and writing phases of this research study, I was for example concerned that my recent experience from being a social worker in the Norwegian welfare state could lead to confining, individualizing and "problem focused" (cf. Bucholtz 2002) fieldwork encounters and research accounts, due to acquired pre-understandings, role- inclinations and embodied communicative practices. In a report based on fieldwork in Norwegian outreach work services for youth, Henningsen et al. (2008) warn social workers and policy makers against observed changes in professional understanding and practice. Henningsen et al (ibid., p. 82) argue that recent demands upon the preventive field; of early intervention, documentation and collaboration, has de-politicized the social worker role, led to a tendency to individualize social problems, and amplified and/ or broadened a "gaze of concern" in relation to young people; in other words an increased sensitivity for signs in individuals and their lives and practices to be understood as "problematic". Sandberg and Pedersen (2011) and Sandberg (2009) similarly point to a tendency for street youth in the Norwegian capital to adopt this rhetoric and slip into a “victim and/or oppression discourse”. This is seen in their personal narratives about needs, adverse experiences and poor living conditions, in encounters with social workers. Finally, research on the application of MUS and related concepts (e.g. psychosomatics) has pointed to similar dilemmas in the medical framing of the phenomenon and the way it is presented and constituted in research as well as in health encounters (e.g. Jutel 2011).

Thus, during this thesis, sometimes explicit and sometimes more on the side with my supervisors and myself, I have had a continuous reflective stance towards several caveats or pitfalls regarding the understanding of, communication with and representation of young people experiencing persistent symptoms in the project group. A caveat that preoccupied me, especially in the early phases of planning, was the likelihood that I would reproduce communicative dynamics where the research participants felt *obliged* or compelled to present themselves as primarily sick and as patients according to a medical framing, as oppressed and/ or victimized potential service users in the welfare state, or in line with a vulnerability discourse concerning Norwegian youth (cf. later additions to the literature, e.g. Madsen 2018). This caveat went along with the ongoing concern about how to critically approach the central term MUS and its ramifications empirically and analytically. These concerns have been sought taken into account in initial choices and uses of research methods, and in choices of analytical tools, described below.

To avoid confining communication dynamics with young people in the field, I have applied methods that emphasize dialogical aspects, empowering the participants as subjects and their subjective experiences as valuable sources of knowledge. In the life mode interviews I worked to engage in a dialogue that directed attention and recognition towards them as subjects (Haavind, 2011), for example by asking about everyday experiences and activities in their worlds, and confirming their perspectives as competent and valuable. In the collaborative film dialogues, I worked to decentralize, or “share” authority over the film making process (cf. Lassiter, 2005, Rouch 2003 [1973]), to give some independence to my participants’ voices, and to enable us both to “advance (our) own goals” (Flores, 2007, pp. 221-223, cf. MacDougall, 1994). With both “Peter” and “Anne”, my main participants, it was evident that our project had to be useful and relevant for their own concerns, for them to gain trust in me and to engage in the process. This may have produced films that communicate less directly to a professional and academic audience than was expected of me. In return, however, I gained enhanced understanding and “thick descriptions” of their experiences and coping strategies (cf. Geertz, 1973). When Peter resisted pointing his camera to major aspects in his experience that he defined as "slack", for example (see paper I, Østbye et al 2018), I explored his engagement and allowed him to choose a topic and form of his film that allowed for numerous little discoveries about his understanding, illness experience and transition goals in the filmmaking process. In spite of intentions to share authority in the research process, however, imbalances inherent in the research encounter will always be present, especially in the writing phase (cf Clifford 1983). This topic will be elaborated in the last section on ethical considerations below.

Analytically, I have tried to resist contemporary moral panics and reification of "problem-focused" accounts of youth (cf. Bucholtz, 2002), and have instead sought to unpack "forms of problematization" and how young people's challenges are formed to become particular kinds of "problems" (cf. Foucault, 1984). Although MUS, and related concepts (e.g. psychosomatic symptoms, functional symptoms) are medically framed, I have not taken the phenomenon for granted to refer to medical facts or non facts, or as entities in young people´s minds or bodies. Rather, I have taken departure in MUS as a social situation where medicine and medical framing plays a part in how suffering is understood and managed (cf. Kirmayer 2000). Thus, I have explored how "problems" and solutions (i.e. responses) concerning persistent bodily complaints in youth take form, rather than investigating ´the predefined problem of MUS´ as an ontological fact. I applied anthropological theories on youth, subjectivity and suffering as tools in this process. Theories on youth for example, opened up for approaches to my participants as more than just ill, and to a more open-ended exploration of the place of illness in their everyday lives. Theories of suffering opened up for an existential exploration of challenging bodily, emotional and social experiences beyond a medical gaze (cf Hahn 1983). They also opened up to exploration of possible solutions as ways of responding to suffering, and to perspectives on care (Mol 2008). Subjectivity opened up for attention to agency that encompasses emotional, reflexive aspects of suffering and health, as well as the relationship of agency with structural constraints. In the sociocultural context of my field, the social organization of processes of transitioning to adulthood seem to intersect with medical framing of health and conceivable responses to suffering as well as other institutional logics concerning citizen productivity that contribute in shaping the social course of illness among my participants.

Concerning professional interlocutors and informants in the field, I have been concerned about a tendency in social scientific studies about health professionals, for example professionals encountering MUS patients, to present them as a generalized professional "other" representing medicine in polemical constructions against illness experience (cf. Greco, 2012). As an analytical lens, the "logic of care" (Mol 2008) instead opens up for exploration of care processes as situationally conditioned. I have therefore traced expressions of a logic of care among local professionals in high school settings, municipal services, and general practice, i.e. in an arena of primary care/first line health care system consisting of both medical professionals, health nurses and consultants with semi-medical/psychological training. These professionals constitute the easiest accessible and the least specialized line of care for young people with persistent physical symptoms. I have tried to show what care responses to suffering these professionals use and rely on in their meetings with young people, from their own perspective and not based on empirical observations of dialogues, as examples of challenges in the case of communication on MUS (cf. Mol, 2008).

### 2.4.2 A representational dilemma concerning responsibility, agency and constraints

An analytical predicament mentioned by Dalsgård (2014) and Dalsgård and Frederiksen (2013) resonates with one of the dilemmas emerging later, in the course of my own fieldwork and writing this thesis. Dalsgård and Fredriksen (2013, 56) describe how their young interlocutors in Brazil and Georgia sought to alter experiences of marginal circumstances and poor prospects through everyday forms of imaginative, "hopeful praxis" (cf. Flaherty 2011, Miyazaki 2006). Little acts (e.g. wearing significant pieces of clothing) to "stand apart" from societal backgrounds, past experiences and depressive atmospheres and keep future outcomes open seemed to change emotional experiences that could manifest physiologically in embodied attitudes of self-respect, composure or sense of energy with "real consequences" (ibid., pp. 55-56). Longitudinal fieldwork relationships revealed that conclusions the anthropologists had drawn in previous writing were often mistaken, as the lives of the young persons in the field had continued in unpredictable ways. However, this experience of potential, and the ability to stand emotionally and experientially apart from past and present limiting constraints among young people in their fields was coupled with "sincere doubts and risks". It also seemed dependent upon, and continuously maintained by, an availability of inter-subjective discernment and recognition by one or more significant others, in some instances the researchers themselves. These complexities posed an analytical and ethical dilemma; namely how to nourish hope and take young people’s insistence on openness and indeterminacy “at face value”, without “inflicting impossible responsibilities” on individual youth for structural and societal challenges by “indicating that it is possible for everyone” (Dalsgård et al., 2014 p. 17). Dalsgård (2014), Dalsgård and Frederiksen 2013) propose to meet this dilemma with an insistence on doubt and potential, in other words a flexible, open-ended understanding of youth that seems aligned with the practices of her young interlocutors in the field (Dalsgård & Frederiksen, 2013). They draw attention to the limitations in ethnographic writing that objectifies life as lived. For example, they point to a tendency in research to approach marginalized youth as either “victims of structural constraints” or “agents in their lives” (ibid., p.51), to make one’s own judgments about hopeful practices as either “prospective or deceptive” and to depict marginalization as an “endpoint” (ibid., p. 58). They argue a need to let the “time of the field”, in their case experiences of recurrence and potential, “be reflected” in analysis and text (ibid., p. 59).

Inspired by the thought-provoking and useful reflections by Dalsgaard et al., I believe that their ideas resonate with my methodological choices as well, i.e. the methods used in this thesis have helped me to produce an open-ended version of the young people’s lives, se above mention of the specific methods. Consequently, I saw that the young people I encountered in the course of fieldwork seemed to be working with hope, in the sense that they seemed preoccupied with efforts to imagine and enact future potential and possible open-ended, or subjunctive, scenarios despite their experiences of illness, constraints, doubts and risks. These efforts, or “hopeful practices” seemed vital in their everyday life coping with illness and limiting situations. Their emphasis affected my own interactions and responses to them in the field, for a few perhaps as a complementary, acknowledging other. Like the youth in Dalsgård and Frederiksen’s fields, my participants also faced doubts and risks however, based upon negative experiences of disregard, experiences of previous failures and personal weaknesses in relation to expectations to them as youth, and fragile hopes for their future prospects of growing up in recognizable and viable ways. Others might furthermore have been in worse conditions, and feeling even more alone or hopeless with their prospects. Finally, in the course of planning, fieldwork, analysis and writing, beginning in the autumn of 2014, discourses about health and illness in Norwegian youth have taken a turn towards increasing emphasis upon the abilities of stressed or psychologically ill young individuals to “master” life, even to the degree that a new, obligatory school subject on “life mastery” has been proposed (see Nordtug and Engelsrud 2016 ). These developments may to a certain extent converge with our own choices of methods that emphasize and affirm the young participant as an active subject. However, they may also inadvertently contribute to individualizing responsibility for societal and structural change (e.g. Madsen 2018), that mirror moral discourses about the psychosomatic subject to balance inner and outer states to stay productive and well (Greco 1993).

Thus, to pay attention to my young participants and collaborators´ open-ended character as human beings, we have tried to let their experiences of time, including not only hope, but also of temporal tensions, subjunctivity and doubt, be reflected in analysis and text. In the papers, I have sought to present my interpretations as among several possibilities and in dialogue with the participants' contextual understanding. This is perhaps most visible in paper I, where negotiations between interpretations and orientations are outlined between participant and researchers, and in the mood of Peter's resulting film. I have also attempted to keep my accounts of the participants as "open-ended" and hopeful as their own (cf. Dalsgård & Frederiksen, 2013). This is perhaps most visible in paper III, where the participants´ efforts and forward directed orientations, in the face of illness and social constraints are in focus. To avoid imposing impossible responsibilities on individual youth in the process, we have sought to point to how time "becomes objectified" in their lives (Dalsgård and Frederiksen 2014, 9) through narrow pathways to adulthood, institutional logics in the local context of care, and social imaginaries of youth that seem active in their lives among other things. We have tried to show these in all papers, without eliminating agency in our analysis. The analytical tools, theories of youth, subjectivity and suffering, have been helpful in this task, especially the simultaneous attention they afford for both agency and structural constraints.

Research studies on youth have had a tendency to reflect and reproduce public discourse as "children of their time" (Mørch, 2010; Hyggen & Stefansen, 2016, p. 6). In light of increasing debate and critique on the potentially adverse effects of objectifying research on the ill health of Norwegian youth (e.g. Madsen 2018, Hydle 2019, Shille-Rognmo et al. 2017), another PhD candidate (Lund 2020) recently posed relevant questions about her own work on minor mental health challenges among girls; Is my research project important? Is it harmful? Lund expresses concern that her own research may contribute to a discourse that views young girls´ mental health challenges through a therapeutic gaze and seeks therapeutic, individual solutions. She asks if one way out of our predicament as youth researchers is to work for better mental health and wellbeing in youth without necessarily *calling* it psychological, and/ or using the "psy-words" excessively. In what way may this thesis reproduce a discourse that frames young people's complex, persistent health complaints as a problem of internal, psychological vulnerability, with therapeutic, hence individual, solutions? I have leaned towards a language in the papers of this thesis that emphasizes social, cultural and structural aspects of suffering. For example, I have chosen personally *not* to use psy-words in my own analysis to describe and interpret emotional and bodily suffering that the professionals and/ or young people in the fields relate to experiences of relational hurt, bullying, abuse, parental divorce, institutional disregard or increased "pressure" in the schools. I have shown practices in the field seemingly oriented towards forms of self-care, that are partly "inward-looking" (cf Madsen 2018), but have attempted to show as well how these seem framed by logics and structures in the sociocultural context of care.

## 2.5 Strengths, limitations and trustworthiness

The criteria for assessing qualitative research is a much-debated topic, and closely tied to epistemological questions such as what knowledge is and what it is possible to know (Guba & Lincoln 1994). Arguing against the application of (post)positivist criteria to evaluate the validity of qualitative research studies resting on constructivist foundations, Guba and Lincoln (1994) propose four criteria, namely credibility, dependability, confirmability and transferability, for assessing their "trustworthiness". In the following, I will discuss some of the factors that have given me the most concern in relation to the quality and trustworthiness of this project, related to recruitment of participants, fieldwork methodology, analysis and presentation, and some steps taken to amend them.

Guba and Lincoln (ibid.) suggest that credibility may be assessed in constructivist research by examining how well the source material and methods are suited and able to provide answers to one's research questions. We initially planned to recruit young participants to our research project via health professionals, but struggled to reach the required number through these channels. Some of the professionals expressed that even if they had young patients who fit Peveller's criteria described in the recruitment section of this thesis (1997), they found the topic of MUS to be challenging in relation to young people in early phases of assessment where nothing had been established in terms of explanations despite their long-term debilitation. After some deliberation in the project group, I then used a parallel path for direct recruitment in purposively selected schools. Colleagues from a medical and quantitative tradition expressed concern as to how I could be sure that I had recruited “the right ones” through direct recruitment, in the sense that their MUS were not already established as medical “facts”. It can be argued that early phases of MUS are almost by definition challenging to clearly define and categorize. In my opinion, the young people who contacted me for additional information after I had presented my project in their class had a clear enough understanding of their experiences in terms of Peveller’s criteria as debilitating and not fully explained by their GP despite repeated consultations. This level of understanding by the young people I met may also have been strengthened by my choice of high school students rather than secondary school pupils.

Another topic of concern in this project has been the choice of fieldwork methodology. When George Marcus launched the idea of multi-sited fieldwork (1995), he foresaw some “methodological anxieties” it might spur, such as the way its differently configured objects of study seemed to “test” the limits of ethnography, the danger of spreading one’s attention “too thinly”, and the fear of losing sight of “the subaltern” (Marcus, 1995, pp. 99-102). The intangible character of MUS as an object of study and its associated communicative challenges tested to some extent my own limits and preconceptions as an ethnographer, by suspending at times my sense of “being there” (cf. Geertz, 1988) and requiring a degree of flexibility to follow its traces. In my experience from this project, however, multi-sited ethnography “conforms to (and often exceeds) the most exacting and substantive demands of traditional fieldwork” (Marcus, 1995, p. 101); the phenomenon under study is always an integral part of local situations, and some locations are always covered in more “depth” (ibid., p. 108). In this project my experience with participants with persistent symptoms was covered in most detail, particularly the extensive collaboration with key participants in reflexive film-making processes. While each process was related to a unique human being and often complex health and social situations, I found that the main themes emphasized by the key participants and observed by me were also emphasized by other participants and reflected across my overall material. This enhanced dependability, defined by Guba and Lincoln as the consistency of one’s findings (1994).

According to Guba and Lincoln (1994), dependability may also be strengthened what they call method triangulation (cf. Hammersley & Atkinson, 2007, p. 183). In this project, the use of different methods or alternative routes to knowledge has been vital to gain a better understanding of the field. The sensitive and somewhat contested nature of persistent symptoms for professional participants and gatekeepers as well as for most of the young participants affected my ability to participate and observe (how and where). Gaining access to health encounters proved harder than expected, and the young people experiencing MUS generally tried to contain and silently endure their persistent symptoms in school or other social settings. By adapting to these constraints, I gradually began to appreciate the absences and silences as data in their own right, reflecting central themes regarding the topic of this thesis. But most importantly, the use of multiple methods enabled me to perform additional participant observation in connection to researcher-constructed sites, and allowed me to approach the phenomena and explore my research questions and initial impressions from different angles. For example, the in-depth interviews provided a more extensive meaning context for seemingly minor non-verbal acts of containing symptoms observed in participant observation in the schools. Regarding young people living in isolation, we mainly gained insight into their relation to the context through their narratives. Initially, we thought of the low number of participants referred to our film workshop and the length of the filmmaking processes, in other words exceeding the structure of the method, primarily as a limitation. This also opened up for longer, more in-depth collaborative dialogues however, and more extensive adaptation of the visual method according to the young people's overall situations and states of health.

According to Guba and Lincoln (1994), insight into whether and how the findings of a study are shaped by the researcher's motivation, pre-understanding or interest may strengthen the confirmability of the research findings. This thesis rests on the assumption that our findings and representations are "situated" through intersubjective and performative knowledge-generating processes (cf. Haraway, 1991; Marcus & Clifford, 1986). One of the main motivations for me to return from social work to anthropology was the ability it might give me to explore young people's challenges with a broader perspective than I felt I had opportunity to do within my professional mandate. As a social worker, I usually had to focus my attention on the individual young person and/or family alone, on matters that seemed to repeat themselves in somewhat diffusely patterned ways across each "case" in the system. In this project, therefore, I expected to see patterns that expanded my perception of the body or mind of young individuals. From an anthropological perspective, the concept of subjectivity provided a fruitful lens to explore relations between such potential patterned constraints and the abilities, concerns, aspirations and experiences of the person, without ending up with either a too socially deterministic, or a too individualistic, analytical approach. Throughout the research process, I attended to my pre-understandings as a previous social worker, and anthropologist "at home" (cf. Wadel, 1991), by repeated discussions in the research group and writing fieldwork diaries including assumptions and embodied reactions. Most importantly, I worked to suspend any social worker-based "answers" I might have to the challenges my participants presented me with, cultivating as much as possible the role and attitude of a naïve student in the field to learn. However, encounters with any other fieldworker would undoubtedly have evolved differently. With these limitations in mind, the contrast between more "naturalistic" sites and the sites I myself arranged should not be exaggerated (Hammersley & Atkinson, 2007, e.g. p. 120). I paid attention to the particular context and my own role when interpreting all events and accounts, and have presented a few of the collaborative processes with emphasis on the co-constructive character of events and narratives in relative detail in papers I and III. The confirmability of our analysis may also have been strengthened by regular debriefing by the three supervisors as a form of researcher triangulation (Holstein, 1996). We involved a renowned researcher external to the overall project in engaged research meetings every month, where we discussed our progress and where the data generated by the film workshop method and life mode interviews with potential interpretations and approaches were scrutinized, leading up to the writing of the first paper.

One final concern has been my ability to provide "thick" enough descriptions (cf. Geertz, 1973) from my field. According to Guba and Lincoln (1994), thick descriptions support the transferability of one's findings. To enhance ethnographic validity, I have sought methodological transparency and to provide a simplified "road map" of my "ethnographic path" to the reader of this thesis (Sanjek, 1999). The article-based format with its imposed word limits and journal style preferences entailed certain limitations to the scope and depth of field descriptions related to the findings. To provide contextualized interpretations in the form of "thick" descriptions (cf. Geetz, 1973) in the presentation of findings related especially to our experiences with young participants, one key participant was prioritized and covered in depth in both Paper I and Paper III. In the latter paper, I have tried to analyse and clarify the ways in which the experiences of the key protagonist in my narrative illustrate recurring themes across my material. These steps may support the transferability of our findings to other settings, especially where young sufferers of persistent symptoms are concerned. As such, the resulting products (papers I-III) have perhaps reached audiences beyond anthropology by being published in journals that do not mainly target anthropologically scholared readers but also an interdisciplinary audience and first-line care providers.. This may for example allow the results to more easily form part of a dialogue with the interdisciplinary research field of MUS and communication, where anthropological perspectives have proven useful and relevant (Fink & Rosendal, 2015).

# 3 Findings

## 3.1 Social processes in the field

In the following, I describe and analyse the social context and social processes in the field, including significant parts of my interaction with participants from municipality, school- and film workshop sites. In 3.1.1 below, I begin by describing my encounters with town hall administrative counsellors and health and social care heads of service involved with local processes of service development and administration of care provided by the municipality to young people. In 3.1.2 - 3.1.4 below, I describe encounters with multi professional teams, professionals and students in the schools, involved from different angles and positions in work-intensive efforts to harmonise participation, documentation- and performance demands with particular resources and needs. Finally, in 3.1.5 – 3.1.6, I describe communicative dynamics and meaning making processes in sites generated through the collaborative film methodology.. The chapter presents a context and departure for the road towards the analytic focus of the three studies presented in papers I-III (chapter 3.2)

### 3.1.1 *“Cases in the grey-zone”:* Rigid conceptualisations in the local context of care

In the course of initial conversations with health and social care professionals and heads of service in the community, several of them related the topic of my study to local, ongoing efforts to improve health and social care service provision for young citizens with complex and/ or *“diffuse”* challenges. I contacted administrative councillors in the municipality who were engaged in the administration of service provision, and asked for an informal meeting to explore their understanding of the local context of care and the place of persistent bodily symptoms in the service system. Two councillors were very willing to explain how care responses to health related problems in youth were organised and evaluated from an administrative perspective and to inform me about ongoing service development plans and interventions. They scheduled a meeting in the city hall, where I was offered a cup of coffee, and was seated in a small, naked office with four chairs and no windows. The councillors explained that all municipalities were obliged by national law to *“keep an overview”* of health and social care needs in the population and to adapt their services accordingly. The Youth Data database was a sought after and free of charge tool where one could fulfil this obligation and *“get an overview at once”*. The local response rates for the latest Youth Data survey had been *“excellent”*, especially among the youngest respondents (over 90%), but the results had been interpreted by the city council (byrådet) as a worrying sign that too many young municipality citizens had unmet needs, especially regarding wellbeing and mental health challenges. Furthermore, the municipality had received poor evaluation ratings in a recent county governor report, for its insufficient ability to provide coordinated and timely health and social care services in line with national coordination reform directives. Based upon these research reports several ideas and projects had been proposed to investigate and/ or prepare potential re-organization of municipality services for children and young people in new and ideally more resource efficient, *"coordinated",* " *"unified"* and *"operative"* ways. Among other things, a panel meeting regularly at the city hall had been established by the city council with this goal in mind, constituted of heads of service and/ or professional representatives from schools, child welfare - and several health and social services. The councillors kindly put me into contact with the panel, where I was allowed to visit one of the prescheduled panel meetings and eventually performed a taped semi structured group discussion with them (see 2.2.5 for more information on group interviewing).

The panel discussion provided an interesting view into existing conceptualisation practices and tensions in the local service system regarding health and illness in youth, including persistent bodily health complaints. Especially, the group discussed the perceived complexity of young people's health related problems and some of the challenges in the local service system to respond and provide care. On the one hand, the panel members presented a front in my presence, expressing shared ideals and using public policy terminology; arguing that *"early intervention"* depended upon *"coordinated services"* where ideally, prevention began *"before birth"*. A main theme emerging in the panel that echoed the panel's official mandate was for example the contrast between a politically sanctioned ideal of coordinated efforts for young people with complex and/ or unexplained challenges and the practical reality in the municipality to date. Several expressed frustration about the barriers they experienced towards implementing change in a rigid service system. However, they also referred to individual experiences from previous professional roles in direct health and/ or social care work with young people in the community. Several recalled concrete examples they had encountered in different roles of the health and care system, where it turned out that a young person had been left to him/ herself and/ or shifted from service to service for years. The group differentiated between "*the health world", "the school world"*, the worlds of "*social services"*, and of *"leisuretime (fritid)"*. Separate and delineated professional law regulations, mandates, budgets and cultures, one of the panel members argued, followed by supporting nods around the table, could lead to long-term forms of professional withdrawal of responsibility and neglect from the service system in complex and/ or *"diffuse" "cases in the grey-zone"* that were harder to categorize. A shared understanding and goal in the panel was that this had to change in order to improve public responses to unmet needs among children and young people, as expressed by one of the panel members;

> *"As an organization and as professional actors, taking care of "the diffuse" needs to be valued (several others hummed in agreement). You know that if you take care of "the diffuse", there is going to be a lot of work and that makes people hold back. But we need to get to the point where people know that if I take care of it I will be supported by the others around that table. That culture change needs to take place. To take care of that which what most of us can see. Which does not fit in." (Panel member)*

Most examples of a "*diffuse*", or *"grey-zone case"*, discussed in the group concerned young girls and boys who had quit, or had poorly understood absences from school, some of which presented physical symptoms. Several of these cases passed in the municipality system under the informal term *"school refusal", or the* new and more politically *"correct"* label *"youngsters having a concerning high absence from school"*. Neither category label seemed to provide explanations and/ or directions for allocation and management and care. Was it a school problem, one panel member rhetorically asked. Several panel members mentioned examples of *"pressure"* and stress affecting young people for example, drawing from the national media, multidisciplinary meetings in the schools and relationships with young people in their personal lives. Or could it be a care problem in the family requiring the involvement of the children´s care unit instead? The young adult user representative confirmed that psychosomatic complaints were *"almost everywhere"* in her organisation for children of drug abusing parents. Was it a psychological problem? After all, the youth data survey had shown increasing mental health challenges among young citizens. From the perspective expressed in the panel group discussion, complex *"grey-zone"* cases, including young people suffering from persistent bodily health complaints, often fit into several categories at once. Existing interventions and practices in the community however often focused on getting the young person to school without really having done a *"proper"* assessment required to arrive at a holistic problem definition with the young person at the centre.

Ultimately, encounters in the city hall in early phases of fieldwork illustrated overlapping national, administrative and professional ideals in line with a biopsychosocial framework and/ or holistic understanding of health and illness in youth in the community. They also illustrated ingrained conceptual and structural limitations that seemed to affect professional response-ability for *"diffuse*" and/ or *"grey-zone cases"*, including persistent bodily health complaints.

### 3.1.2 Managing *"pressure"* and individual capacities in the schools

In initial phases of fieldwork in the school sites, I attended multi-professional team meetings, mingled with different groups of teachers and other professionals in their lunchrooms and by informal visits to their offices, to present myself and my study and to get an impression of their understandings and approaches in relation to persistent bodily health complaints among their students. I first initiated fieldwork in one of the schools offering vocational curricula. These also offered a combination of practical and theoretical subjects and/ or an additional theoretical year to qualify and prepare for higher education. I then added one school at a time while keeping in touch with the contacts and arenas I had engaged with in the first. I encountered eight of the participants included in study 3 in this thesis directly in ensuing fieldwork in the schools. Additional five of the participants had been a student at the same schools, but were on long-term sick leaves due to health-related challenges.

The three school buildings were relatively modern, with large windows, open spaces and colourful pieces of furniture. A large TV screen was mounted on a wall in each school where short messages directed to the students shifted; for example, reminders to apply for a student loan before the upcoming deadline, where to get IT support in the school, an invitation to see the school health nurse and school advisor. The school health nurse's offices were discretely located in remote corridors of the schools, together with the school advisor's offices. All the school health nurses were women. Some of the school advisors were men. For anonymity hensyn, all are referred to here as women. I visited these corridors from time to time, to have a chat with the school health nurses and school advisors if possible. These corridors were normally very silent parts of the school. On my first visit to this corridor at the second school offering vocational curricula, two skinny looking girls wearing makeup waited smilingly by the school health nurse's office door. The door opened, the nurse stuck her head out, told the girls she had half an hour available later in the day and handed them a yellow post it note with their consultation time on it. One of the school advisor's doors was open. The school advisor said she kept the door open when she was not too busy, to make it easier for students to make contact. She had the impression that many students, particularly the boys, appreciated that the offices were so far away from the classrooms and canteen, so that other students could not see them entering. Upon presentation of my study, she replied that she was not surprised that so many students struggled to stay in school after the many educational reforms that had been passed that forced all young people regardless of their social backgrounds through educational paths with a reduced number of practical learning options, and more challenging theoretical demands on all students. She disagreed with the term *“dropout”* for this problem. –*“When I grew up, less than half went to high school. Now everyone shall enter”*. Some entered on special conditions because they were sick, she explained, and some did not even have full diplomas from secondary school, but there was no automatic follow up of everyone’s needs. In the worst cases, she felt that it was better for them to be allowed to have a legitimate time out, and she helped some of the most ill students to apply for a sick leave as it would look better on their resulting diplomas than a failed school year. She advised me to check out one of the vocational curricula where many students receiving individual follow up and school advising on several health related problem-areas were attending.

### 3.1.3 Health communication in the classrooms

I presented my study in altogether 10 classes in the three schools. Health related challenges affected school participation and performance for individual students in all ten classes, but the number of students who seemed affected, the complexity of challenges and the extent to which *“diffuse”* and/ or mental health challenges were expressed to teachers/ and/ or other students varied according to my own observations, information from professionals, and life mode interviewing with ill students.

I selected the classes in dialogue with teachers, based on the relevance of their overall student group, and/ or the interest by the teacher for my topic. I first contacted the department leader in one of the vocational departments that had been suggested by several professionals in the schools, and was offered an opportunity to make a short presentation at one of their internal department meetings. About ten experienced, female teachers attended the meeting. Reluctant to define certain student’s symptoms as more or less explained, and/ or more or less important for research purposes than others, they suggested presentations directly to full classes, to allow the students to make the choice themselves. They directed me to the first year classes, as several of the ones with the most severe health complaints typically quit after the first year. When I presented my project to classes, it was my impression that there was a relaxed atmosphere with little tension in these classes. All the students appeared to pay attention and keep eye contact, and several dared to comment and respond to my presentation. I told the classes that I was interested to learn about their experiences with bodily health complaints that had been presented to their GP and that had affected their everyday life for more than six months but the complaints had been challenging to fully understand and manage. I then drew a stick figure on the whiteboard and asked the class to suggest possible complaints they thought fit this description, using recurrent headaches as an example. In the first class I presented to, a boy mentioned problems with sleeping as a general example. One girl mentioned fatigue. Another said she was troubled with her stomach and had had a tube down her tummy and the doctors had concluded that it had to be caused by stress. Several others shared experiences with physical reactions to stress. I asked what the school did in relation to these kinds of complaints. –*"They send us to the school health nurse"*, another girl added.

During two of these presentations, a student got up with their things to attend private appointments, saying something like *"you know what it is"* in the direction of their teacher. The teachers nodded in return and/ said that her absence would be reported as valid. I later learned that they had been to see the school health nurse and/ or another health appointment. None of the other students seemed to react in any way as it happened almost daily. I invited students to contact me if they wanted more information about my study, and asked if it was ok that I stayed in their classroom the remaining day, and/ or if I dropped by from time to time to see what a school day was like nowadays. I encouraged them to tell their teacher anonymously if they would prefer that I refrained from visiting their specific class again. No one objected to my visits, but some of the students seemed more open and/ or interested than others within each class. Several of the students left the classroom in breaks, and had their lunches in the large school canteen with students from other departments, while other groups of students regularly stayed in the classroom throughout the day, making it more easy for me to keep in touch from visit to visit.

I observed differences in how students seemed to communicate about health and illness related topics, from school to school, but also from class to class within the same department. With some exceptions, more students in each of the classes in the vocational curricula presented health related challenges in negotiations with their teachers about school participation and performance demands, than in university-preparatory classes. Their challenges were complex and many carried what one of the teachers called a heavy *"backpack"* of adverse social background experiences in addition to school related demands and their more openly presented bodily symptoms. Out of the eight students who were recruited directly in the schools, and five who had quit these schools due to complex health related challenges, three presented previous experiences of bullying, two presented experiences of violence in the family, one presented experiences of abuse, and five presented various levels of conflicts in the family that they tied to their present overall health. After one of the initial presentations, for example, I sat down with a group who openly told me that they had a lot of illness related absence from school, including persistent bodily symptoms. Eleven out of thirteen had previous or present contact with a psychologist. Six out of thirteen still lived with their parents. In the course of ensuing participant observation in their classroom corner, they were often absent or late, openly resisted new assignments on several occasions. A problem in this class according to the teachers, was that *"being good"* was not considered cool. The same group of students also enthusiastically described ambitious career dreams however, such as becoming a psychologist or lawyer, all of which would require good grades and diplomas from high school. One of these students (included among the participants in study three and paper III) agreed to receive more information about my study in a school meeting room, and later participated in a life mode interview where I was able to get a deeper understanding of the meaning of these observations, for her. Here, she described previous experiences with violence in her family and a need for professional understanding and time to talk about, and manage, her life experiences and circumstances to be able to move on in life.

Furthermore, students with explicit health related challenges expressed and shared these with their classmates in a higher or lower degree.. In one class, for example, a few of the students told me right away that *"everyone"* there had different health related challenges. Several pupils had often not done their homework, and often negotiated with teachers about school assignments; seating arrangements and tests with reference to their health related challenges and situations. All high school students received public funding to buy a school laptop, and theirs were always up on the desks. Many seemed to spend their days on soci ms al media and in class simultaneously. The students often kept several Facebook chats up on their desktops for example, to seek peer advice on relational problems and complain about teachers among other things. According to some of the teachers, a problem in this class was the extent to which the students brought their health challenges *"into the classroom*". Other classes in the same department differed, according to the teachers, in the sense that the students seemed intent that they were in school to learn. In subsequent interviewing with one of these students, who is included in study III and paper III, she spoke very warmly about this aspect of their class community however, as a prerequisite that enabled her to *“be herself”* in class, and to manage educational demands rather than *“dropping out”*, given her conflicted background.

Finally, illness related challenges that affected school participation and performance demands also existed in the school offering university-preparatory curricula, but these were less widespread and less openly expresses in the classes I visited. All participants in my study who were recruited from or had quit from the school offering university-preparatory curricula still lived with their parents. They presented mental health challenges in addition to their bodily symptoms, they tied experiences of parental divorce, bullying, and pressure to school performance, pressure to wear expensive clothes, fitness pressure and/ or stress respectively that posed real challenges in their everyday lives, often worse that their bodily symptoms.

In contrast to the atmosphere and responses in abovementioned class presentations, one of my class presentations in the school offering university preparatory curricula was very silent. I was a little surprised at this, especially since a few of the other classes where I had presented the previous day in the same school had a much lighter atmosphere in the sense that several girls had been laughing lightly, and it had been possible to send a question or two to the class and get some answers in return. In this class, only one girl smiled interestedly while all the others fiddled with other things. No one responded to my questions or stick figure drawing on the blackboard, but a boy smirked teasingly to his classmate when I mentioned recurrent headaches as an example. According to some of the teachers, a problem with this class was that it was typically very silent, and that more openness was needed among students and towards the teachers in the school about “diffuse” and/ or psychological challenges, to allow for individual adaptation in the school and achieve a better understanding from and integration with healthy peers. Later the same day, one of these students sent me a text message, asking for a confidential information meeting, and was later included in study III and paperIII. Some of her classmates, she said, had complained about her *“absences from class with no good reason”*, but she felt it was too embarrassing to say anything to anyone but her best friend in school about her bodily symptoms and emotional challenges. She felt increasingly lonely. In a group discussion with quite popular, outspoken girls from one of the classes at the elite sports department in this school, they confirmed the impression that *“hidden”*, in other words un-expressed but noticeable health related challenges were typical in their school and that it could lead to irritation and the formation of speculation among other students about whether the ones who were often absent from class assignments were just lazy or really ill. They also discussed a wish to achieve a more open communication and better understanding to be able to support suffering peers however.

Thus, several students experienced complex health -and life related challenges that affected their abilities to participate and perform according to school related demands.  They expressed bodily health complaints in response to experiences of “pressure”, not primarily or necessarily to withdraw from expectations but also to be able to participate on their own terms.

### 3.1.4 Professional rationales and routines

All the schools had multidisciplinary teams composed of the school advisors, school health nurses, representatives of the school leadership and varying invited professionals from services. These were the Child Welfare Authorities, the Norwegian Labour and Welfare administration (NAV), social workers, Adolescents' Psychiatric Polyclinic Services (BUP), the Follow-Up service (OT), The Educational and Psychological Counselling Service (PPT) and more, depending on the topic at hand. Representatives of the teams at the schools offering vocational curricula showed the most interest in my topic. One of the teams agreed to let me use one of their regular meetings to perform a semi-structured group interview with them, to explore their thoughts and experiences of persistent bodily health complaints among their students more in depth. I brought fruit and sandwiches to the team members, and the mood was cheerful. Some of the professionals were familiar from my previous position as a youth worker in the community. They questioned the focus on medical explanations in the line of care, and I felt the need to explain my use of the concept of MUS in initial information letters, as a *social situation* where the meaning of symptoms was subject to interpretation, contestation and negotiation. I also underlined the need to ask naïve questions, to avoid taking familiar explanatory models for granted due to home-blindness, and to get their good descriptions “on tape”. I asked the team group to discuss among themselves the extent and kinds of persistent bodily health complaints they encountered in the school. One of the school advisors said she saw many very tired students, and other team members agreed that many students presented tiredness and stress, and feeling a sense of *“pressure”* affecting their bodies. Headaches, muscular -and skeletal complaints and sleeping -and concentration problems were the most typical symptom presentations. The team agreed that these were not necessarily signs of disease but rather signs that these students were living in a way that made their body say stop and that they may need to be helped to listen to their bodies in time. Quite often, other explanations turned up in conversations with the students, like experiences of abuse or an ongoing parental divorce or worry about their grades or an unhealthy relationship that the team agreed could *"take root"* in physical symptoms. However, these were not as easy for the young person to express as physical illness.

Communication in multi-professional collaboration in the community, such as the teams in the schools, was partially restricted by differing regulations of confidentiality.  For example, the school advisors and school health nurses were adhering to differing social -and health service laws in relation to the knowledge each had acquired in contact with individual students, and they were not at liberty to discuss sensitive health topics regarding named cases in each other's or my presence without permission from the student and/ or parents. Although the team members participating in the group interview acknowledged the need and right for student's privacy, they also experienced limitations in their own ability to effect timely changes that required multi-professional collaboration in cases where the student held back permission to share information about their situations. Many students resisted involving their parents as well. To ease anonymization in practice-near descriptions and reflections, they therefore advised me to invite professionals to individual interviews. The group discussed, however, on a more general level in the course of the group interview, the health related challenges they observed in the school and their management routines and rationales. An initial team goal according to the leader representative was to clarify the nature of a student's health challenges and their consequences for his or her learning as quickly as possible.  Some students came with quite specific documentation and *"preferential rights"* to have their school days and learning plans adapted with the use of additional resources. Others brought a written form that described undiagnosed challenges that did not trigger the same rights, but that were likely to affect their learning outcomes. The school health nurse held an important role in assessment and care of unclear health related challenges that seemed to affect a student's school days. She shared that many of the students who came to her office presented with *"aches"*. If they came with a complaint, she said, she tended to ask more openly, how they were, to see if she could *"get a bigger picture"*. The group agreed that the school health nurse should ideally have been present much more than the two days she had allocated in their school. Three other schools in the urban community were involved in an ongoing nationally funded project aiming to prevent students from *"dropping* *out"* from school that involved seven extra school health nurse positions. It allowed *all* the first year students at these other schools, including the boys who were known to make less use of the school health nurses, to be called in to have a primary consultation. The group also agreed that too many students came into contact with some of the *other* services outside of the school too late. The few times they had had a psychologist visiting the school had been *"fantastic"*, because more students had been motivated to drop by for a consultation. All agreed that they missed more open communication channels with the student's GPs, that *"a little bridge"* was lacking, to be able to inform the GP if a student seemed to be struggling, and to ask the GP to call him or her in for a clarifying consultation, preferably a long one to get to the bottom of things. The team also described however, using several anonymous examples, how they experimented in cases where a pupil with *"diffuse"*, and persistently undiagnosed bodily complaints *«struggled to keep a full progression"*. They recalled how they attempted to adjust a girl's school week, to make it less theoretically demanding and more flexible for example, with half of the time spent in the classroom and half at a relevant work placement. The girl had quite a lot of absences from the work placement too, and told her teacher that she found it challenging to return after that. The team then decided to expand the school year over two calendar years. That went fine for a while, and the teachers *"stretched"* their own time-schedules and teaching plans quite far to utilize the remaining hours with her as well as possible. Even if the professionals went to great lengths to adapt individual students' learning processes, it could still be challenging for the student to keep up with and/ or to *"hook… off and back on»* the school year learning plan, that the rest of the class was following. These objectives and rationales seemed to reflect an emphasis on and need for documentation practices in the schools, i.e. seeking somatic and/ or psychiatric medical explanations and/ or diagnoses for challenges understood as complex. They also illustrated however, efforts to experiment and adapt the learning experience to the capabilities, conditions and needs of individual students in an increasingly differentiated student group, with and beyond available resources.

I later observed similar emphases and efforts in some of the teacher's routine approaches regarding students with persistent symptoms. Quite a few of the teachers had special educations with relevance for taking care of special needs, but several also described experience based routines to help students thrive and the need to be a *"fellow human being"* in addition to their role as pedagogue. Informal encounters with professionals in the school offering higher education and elite sports curricula confirmed the impression expressed by several professionals and teachers in the community that they had fewer students with established and/ or complex health complaints that affected school performances in comparison with the ones offering vocational curricula, but illness related absences did occur. In a group discussion I arranged with four main tutors from the school, they described how bodily health complaints presented by their students often turned out to reflect a *"total sum"* of bodily, emotional and social *"burdens"*. In their experience, some of the students seemed to hide their challenges from them, but many of the *"aches"* they presented to explain their absences from class seemed to emerge in relation to tests or other typical evaluation situations. Especially the last year of high school they saw an *"insane level of pressure"* upon the students, and several contacted them to express concern about how they could manage the stress they were experiencing. The teachers in the group discussion expressed feelings of ambivalence about their roles, especially their duty to evaluate individual students on a scale when each student seemed to have progressed equally well depending on their differing starting point. They agreed that an important part of their role was to help students reduce the "*pressure*" to prevent overload, for example by, reminding the students to eat nourishing food and get enough sleep. They consequently spoke of school as the student's "job", and advised them to reduce or quit their job on the side. They also described routine attention to individual students to capture eventual changes in their wellbeing.

Caring roles and parallel efforts to document and adapt were especially evident however in one of the vocational departments that had been mentioned most often by different professionals in the school as relevant for my study, due to the amount of students requiring follow up from several challenges, including "*diffuse*" bodily complaints. Here, teachers regularly took individual students aside for eye to eye conversations, and were told by both students and teachers that these were mainly about their absences and health -and wellbeing related challenges that interfered with their everyday performance at school. I never established a natural role as a teacher and/ or health professional in the schools that allowed me to be present in these conversations, but spent time with teachers in their designated lunch areas where I engaged in ethnographic conversations about their everyday tasks, communicative practices and ongoing processes in the department. I also asked some of the teachers who seemed most experienced for an individual interview, to explore their routines more in depth. To help as many as possible through their first year of high school within the present regime, the teachers explained in these conversations, they regularly asked for a talk with individual students to get to know them, maintain a good relationship and reflect with them on their absence patterns. In some instances, a teacher also called individual students in the morning to motivate them to get to school. They also sent the ones who presented *"diffuse"* health related problems to see the school health nurse for a consultation, to the school advisor to look at their absence levels, and/ or their GPs to seek documentation that might legitimate their absences and result in interventions. Several of the students had had to move away from their families to the urban center. According to the teachers, many of the parents who lived nearby had also partially *"abdicated"* from their parenting roles, in the sense that the teachers struggled to engage their participation in care and/ or follow-up tasks. Their efforts to support individual students were especially visible at the end of each term, when term grades were due and several students with complex health related challenges were in danger of failing in several subjects because they had been absent for too many hours and had handed into few assignments and/ or tests according to regulations. All the main tutors moved a little faster between classrooms and offices in these periods, carrying and photocopying files and papers holding additional conversations and arranging additional tests and presentation opportunities, with students in danger of failing the term. They also held numerous meetings with the student and their parents and/ or health professionals to see what could and needed to be done to get them over the finish line.

Overall, various professionals in the schools acknowledged the need to adapt and adjust standardized educational pathways to an increasing number of high school students. Adaptation needs were commonly seen as understandable, given the wider inclusion of young people in the schools and the *"total burden"* of constraining life conditions, stressors and health related symptoms, especially manifesting among students in practical and vocational departments. To respond to the needs of these students and take into account social consequences, their communication and management practices adapt to an ever tightening documentation regime but also work to produce "work arounds" (cf Rasmussen 20??) to support unique situations and forms of suffering that may be more challenging to acknowledge/avklare within existing, medically oriented frameworks. These work arounds seem founded upon close relationships between professional, for example experienced main tutors, and student, and resulting understanding of each individual, their constraints and resources, and a balancing of care with societal demands. Students, on their part, seemed to adapt to societal "pressures" to participate and perform according to expectations to them as youth through, holding high career expectations to themselves, but also communicated health related challenges through illness presentations and forms of resistance. These social processes and practices in the schools were everyday and mundane, confidential, sensitive and under communicated in many situations. Their underlying meaning were not always evident form their social context. Individual interviewing with professionals and students were therefore done to explore emerging themes more in depth.

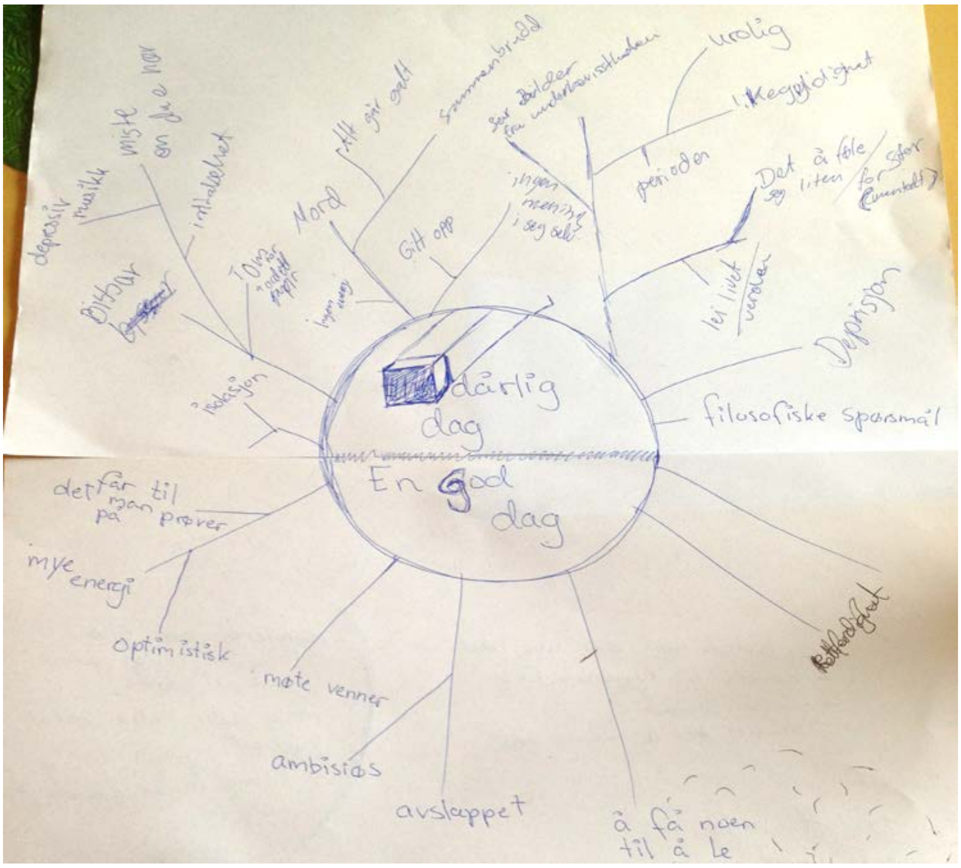
### 3.1.5 Visualizing good and bad days; negotiations among film workshop participants

I ran the main part of the film workshop group with two other adults. One of the other adults was the second female PhD candidate employed on the COCHA project with experience and training as a clinical psychologist but with no previous experience in filmmaking or film methodology (Silje). Silje and I presented our relationship to film, clinical psychology and social work respectively, to the participants in information meetings prior to their decision to take part, emphasizing however our present roles as researchers who were interested to learn from their everyday life experiences and points of view. A younger local filmmaker with experience from previous Youth Gaze film workshops at the outreach youth service center in 2005-2007 was also hired as technical support in some of the sessions. Although four young people aged 16-20 who had been recruited to the project by professionals took part in the group workshop, the actual number attending each session varied between 4 and 2 due to illness related absences. All the young participants had been fully or partially out of their first year of high school for more than 6 months due to their complex challenges, including mental health challenges, that they related to their overall situations. In encounters and group assignments, their absences from ordinary activities with their peers, and what they understood as *"good"* approaches to everyday life with their bodily, emotional and social challenges, emerged as implicit and explicit themes.

A short description of the first workshop sessions may illustrate communicative processes and dynamics, framed by our organization and facilitation as researchers, by interactions among the young participants, and in seeming dialogue with dominating ideas about youth and illness in the broader social context. Group sessions were arranged in an educational institution, in university campus film and meeting rooms, seated around a big oval table in front of a whiteboard and projector. Upon arrival, the participants shortly greeted each other and made light jokes about how the place *"smelled like school"*. 20 year old Kim (all names are pseudonyms), was the first young participant to present himself informally around pizzas, and he shared his lacking participation in education or employment to the group in an apologetic tone:

> -*“I don’t do anything nowadays, no school and no work, so that’s me now”.*

Looking rather uncomfortable while she waited for her turn, 17 year old Renate hastily shared the name of her school and that she had nothing more to add. 17 year old Peter told the others that he had to take a long break from high school because it had been too hard, but emphasized his solitary engagements at home as a meaningful alternative. He leaned forward, and told the group that he had seen on average three films a week the during the last half year. He had begun by watching a documentary on the history of film, then a few Chaplin films, and the ball had just started rolling. He referred to a lot of directors whom none of the others, or most youth in Norway probably, had ever heard of, lighting up while he talked about it (see paper I, Østbye et al 2018, for more detailed descriptions on Peter´s meaning making process). During an introductory group assignment (part of the Youth Gaze methodology) to make a short film together about a good or a bad day, Peter´s interpretations of productive and meaningful isolation were challenged by the other two. This assignment aims to allow young participants to get to know each other better for the following film reflections and to facilitate an experience of mastery through the completion of a full filmmaking process from beginning to end. They also open up for social situations wherein the young participants negotiate what is important and right, thereby providing relevant data for adults seeking a better understanding of how they define and experience their everyday lives. We handed a large piece of blank paper to the group, instructed them to draw a circle in the middle, and to add themes and/ or scenes that a film about such a day could include from their perspectives. Renate added *“energy”*, *“feeling relaxed”*, *“optimism”*, *“meeting friends”*, *“ambition”*, and *“accomplishing what one is trying to do”* to the side of the circle symbolizing a good day.



Peter argued that no days are *"all good"*, considering all the suffering and political injustice taking place, for example in other parts of the world. Following from this logic, Peter claimed, a film about a good day should at least involve some social and/ or political *"justice"*. The others agreed that the distinction between good and bad days was not a given, but argued that smaller things in everyday life, and one´s own reactions in relation to circumstance made a big difference in this regard:

Renate: *Like if something happens, if you don´t manage to do something right, or run out of something. If you´re having a bad day, all that can get so big and overwhelming. Like all the little things turn into disasters.*

Kim: *I´m also thinking about it like that. Lately I have been very occupied by thoughts and emotions. I think, personally, that it matters a lot if a day turns out good or bad. Right? (Renate: yes) It also makes a difference when it comes to the person, how he or she is going to be and act for the rest of the day towards others.*

Renate also added *”isolation”* to their mind map, as something that could typically bring about the kinds of thinking that constituted bad days in this way. Peter, who had kept silent up until then, strongly argued that he needed balance between *”being social all the time”* and being alone and able to relax. The others agreed that some time to relax and*”be oneself”* alone was important, as long as one did not allow it to lead into unproductive ways of thinking. Over the two next days, the group made an approximately three minute long film about a bad day together based upon their ideas thus far, shooting all scenes at different locations in the campus building. The fourth participant, a 16-year-old girl, arrived on the third day, and took part as an editing assistant. The first part of the film presented a young person looking troubled while his distressed reactions to a recent event were played on a voiceover track. In editing, Peter eagerly added several exaggerated images for example a shot of an exploding atom bomb gleaned from his favourite films to this part, to symbolize the young person’s emotional suffering. Kim then came up with the idea that they should film the character going to his psychologist to *“deal with”* the experience, and asked Silje to play the listening psychologist in a silent dialogue scene with the main protagonist. In the final scene, we are shown what the troubled young man is sharing with his psychologist: he had merely run out of toilet paper. Made with the wink of an eye, the film was on the one hand a humorous result of various compromises between Kim, Renate and Peter´s ideas. Conceptualized as an illustration of *”first world problems”* compared to *“real”* problems that exist in the world, and as an exaggerated reaction to life´s *”little”* obstacles however, the film also seemed to satisfy all the young participant´s understanding of good and bad days - as relative to political context and personal ways of thinking in more or less healthy and/ or productive ways.

### 3.1.6 ´Cine-thinking´- on social relationships, embodied experiences and possible selves

At the end of day three of the film workshop, we handed out a small HD video camera to each participant with an assignment to film a self-portrait or a place where they spent a lot of time and told them to bring it to the group in one week. Peter had already received a camera from Silje on their initial information meeting. He said that he had filmed some shots at a place he really liked, and asked if he could bring these instead. I told him we would love to see what he had filmed, but asked if he could film a place where he used to spend some time as well. I told him that it was possible to solve the assignment in a creative or personal way, for example by selecting the parts and/ or angles he wanted to show and not. Peter said he spent almost all his time in bed where he looked *”slack”* and that he thought it would be a boring thing to film. Hanne asked if she could animate an image of herself on top of an image of a beach: *”That´s where I would like to be the most”*. I hesitated, as these responses were new to me. All participants in previous workshops for young people I had been involved in had accepted this assignment no questions asked, and I was a little concerned that filmed material focused on ideal or imagined places would not be as experience-near as I was hoping for. Furthermore it made me realize that I had partially expected them to be more preoccupied with everyday life limitations and experiences with health service communication despite our initial efforts to avoid a problem-focused approach. I asked her if maybe she had a picture of herself on a beach that meant something to her, or a place where she used to spend some time in her everyday life. She replied that she spent a lot of time in front of her computer, but didn´t seem very enthusiastic about the idea and called in sick on our next workshop day. This task and the following process of establishing a topic for their individual films seemed to trigger an emotional engagement in the participants. With one exception, none wanted to make a film with explicit departure in and focus on their everyday matter-of-factly experiences of illness, manifest in the places where they spent the most time in the situation they were in now. To explore the meaning of these ideas, we (the researchers and film assistant) eventually tried to establish a dialogic space for collaborative imagination and narrative openness (cf. Rouch 2003 [1973], Jørgensen 2007). We chose a flexible, partly open-ended approach within certain workshop frames, and engaged in ongoing reflection with the group and with each participant regarding their individual film ideas.

Some discussions took part during transportation and giving participants a lift in the car often lead to long ethnographic conversations about our film processes, but also about their experiences and perspectives in life more broadly. The week after, I picked up Peter by car on my way to some of the other participants. Peter lived in a small apartment building with his parents and brother. The male members of his family shared a strong interest in sports, and Peter had attended an elite sports high school curriculum at the time he got ill. Attempts to go back to school had so far been *“disastrous”* according to Peter, who had been unable to stay calm and focused and had had to stay at home. Peter recalled his father’s worried comments that Peter’s life would be *“ruined”* unless he managed to return within the year. His everyday life was now spent mainly in his sofa-bed at home, where he felt isolated. He missed a closer contact with his family, and with his friends who were mostly connected to his sports team. Peter wore jogging pants at home, but felt embarrassed to be seen in them by other people his age. When he came out to the car, he had changed to denim jeans. Peter emphasized that fashion was not one of his interests, but he planned to buy a long woolen coat, like the ones he had seen the famous film directors wearing. I asked him how he was, and although his body spoke out volumes of his symptoms (heavy sighs, stretching, neck bent, slow pace), he always based his answers to this question on how many interesting films he had managed to see instead on *"just"* computer gaming, and eagerly detailed what he had liked about each new film. I told him that he had an impressive knowledge about films and directors, and that I had seen only a few of the films he was talking about as a student on Visual Cultural Studies. Thinking out loud I mentioned Tarkowskij, Vertov and Eisenstein, trying to remember what I had learned some fifteen or more years ago. Peter added that Eisenstein was known for making Russian propaganda films. When I asked if he had made *"the one with the baby carriage in the long stairs"*, for example, Peter confirmed with a gleeful *"Yes!"*. As we drove to pick up the next participant, we continued to recall and make inside jokes about some of the films that were listed in the documentary series by Cousins (2011) on film history that had triggered Peter's new interest in surprisingly old and sophisticated films for his age. –*"It is nice to have someone to talk with about film"*, he solemnly said when we arrived at Kim's place.

Two of the workshop group participants lived with their parents (middle class family), and two had recently moved into their first independent small rental apartments. Kim, the fifth participant, had sought refuge in a safe house apartment to rest from his angry and non-accepting parents recover from his bodily and emotional symptoms and make sense of his transgender experience. He wore baggy, street-style clothes to hide his female shapes and express his new identity. He never talked about his emotional or bodily symptoms (sadness, headaches, back pain) much with me, but often shared frustrating experiences of ongoing conflicts with his parents and with the medical specialists in the hospital clinic where his transgender status was being assessed and judged. One of the new participants, who had reported ill on the first few workshop days, lived in a small but new apartment in a relatively posh neighborhood. Her mother suffered a long-term sick leave due to similar symptoms as her, but the family was relatively well off. She spent a long time getting ready with hair and makeup. In the car on our way to her first workshop session, she described a melancholic feeling of loneliness and being on the sideline from her peers before and after she quit school due to debilitating fatigue. She tried to meet friends on their spare time, but in her experience, most girls in this town were all about *“drama”*, and most boys were only after *“one thing”*. Thus, she was both eager and anxious to see whom she would meet in the group.

We screened their new footage on the university meeting room projector. In the first screening and feedback sessions in the film workshop, the group members seemed to support each other’s self-presentations to a certain degree. The new girl had filmed three minutes of video on her camera, showing her tidy apartment and saying to the camera that if others could, she too could dare to film something. The others told her she had a nice apartment, and applauded the fact that she had the same gaming console as them. All agreed that first person shooter games were excellent for calming their bodies down. She complained about her odd voice, but smiled shyly at their compliments. Kim shared filmed footage of himself gaming ( a first person shooter game) and smoking cigarettes alone, and having a few guests from the safe-house in his safe-house apartment. He was commended by the others for being brave and *“real”* on his images, by showing what he was actually doing, and seemed pleased with their feedback. Peter first brought and shared some of the material he had already filmed from an urban playground in his neighborhood that he *”really liked*”, in addition to some new shots he had taken from inside of his family kitchen and living-room, facing out from windows and doors. These were shots of trees, leaves, running water, confined spaces underneath a staircase for example, and several run-down jungle gyms and outdoor toys. All were filmed by Peter alone at night. His images were very calm and there was no dialogue or sound except for a clock ticking in the kitchen and the odd seagull. Only a few of his shots revealed parts of, or reflections of himself. The other participants commented that his images were *“mystical”* and *“scary”* in a cool way, almost *“alien-like”*. Peter, who was not at all pleased with these interpretations, tried to explain that he

*Screenshot from" Peter's" first film footage alone at night*

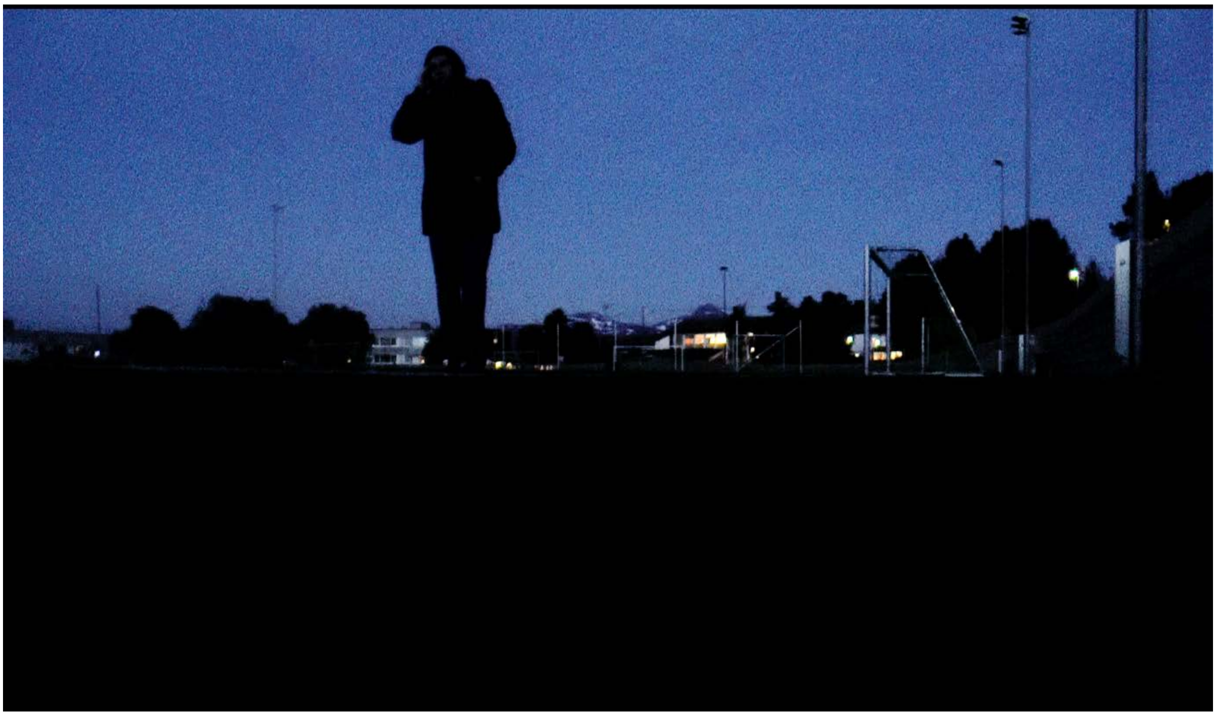
had filmed this footage to evoke particular emotions in himself. Through watching old classic films, he explained, he had discovered that some atmospheres could actually make his debilitating tensions momentarily go away. With the camera available, he had found that he could also achieve some of the same effect by filming particular scenes, especially calm atmospheres in nature and scenes that were inspired by his favorite directors so far who he felt had a similar temperament as himself, mainly Bergman and Tarkowskij. The others had no knowledge of these directors, and had nothing more to say. I asked Peter if he had considered filming any of his family members, but he scoffed to this, and said that his family would most likely ridicule his attempts. As we packed all our camera gear and got ready to leave for the day, the new girl exclaimed lightly: *"This was fun, now I'm really motivated to film!"* We later used the same brainstorming method as we had used in the shared group assignment, to help the participant develop ideas for topics and scenes in their films, and the participants took these ideas back to their everyday lives with their cameras. I now focus on my two main participants, Peter and Anne, and our collaborations with film.

*Screenshot from Peter´s first long walk to the oceanfront, later arranged in the chapter called "Out"*

After this feedback session, Peter was inspired to take a much longer nightly walk than he had done since he got ill to film the ocean front. Peter said he had gotten a bad backache to and had been tired for a few days, but it had been worth it. This time he seemed motivated not only evoke atmospheric sensations in himself, but also to try to express them to the group and a broader imagined audience. These were nighttime images of a more open landscape than he had filmed closer to his home. Peter told the group that he was trying to share a feeling, close to the feeling of *"isolation"* but not entirely the same, that he was not entirely "aware of", in the sense that he struggled to find good enough words to express and experience it as well as in images and sounds. When he shared these images to the group, he was visibly disappointed by the shivering images resulting from his handheld camera and bodily symptoms. We discussed the option for Peter to try again using a tripod, but Peter argued that it was physically straining enough for him to walk the distance even without anything heavy to carry. Afraid that he would be tempted to give up, I offered to take Peter for a drive the following week, to any locations he would like in reasonable proximity to the urban community. Peter asked if I could pick him up at eleven pm, to get the "interesting" light and atmospheres he was after, which I did. He wanted to film other parks and ocean fronts, but also asked me to drive to more populated locations in the city center. In these locations, Peter put his headphones on, and played music to himself from his favorite films to evoke some of the same *"feel"*, or atmospheric expression, in his own filming. Once in a while he directed me as his assistant, to carry and move the tripod to another position, and to press play on shots when he wanted to pass the camera himself. The shots he was most pleased with was one of the church tower with a bus passing in the moonlit city center, and one of a well-lit cruise ship that passed beneath a darkened city bridge. After I had asked several times if he was getting tired and ready to be taken home, Peter reluctantly finished filming when his camera was out of battery power. It was then 03 at night, but he was in a spirited mood.

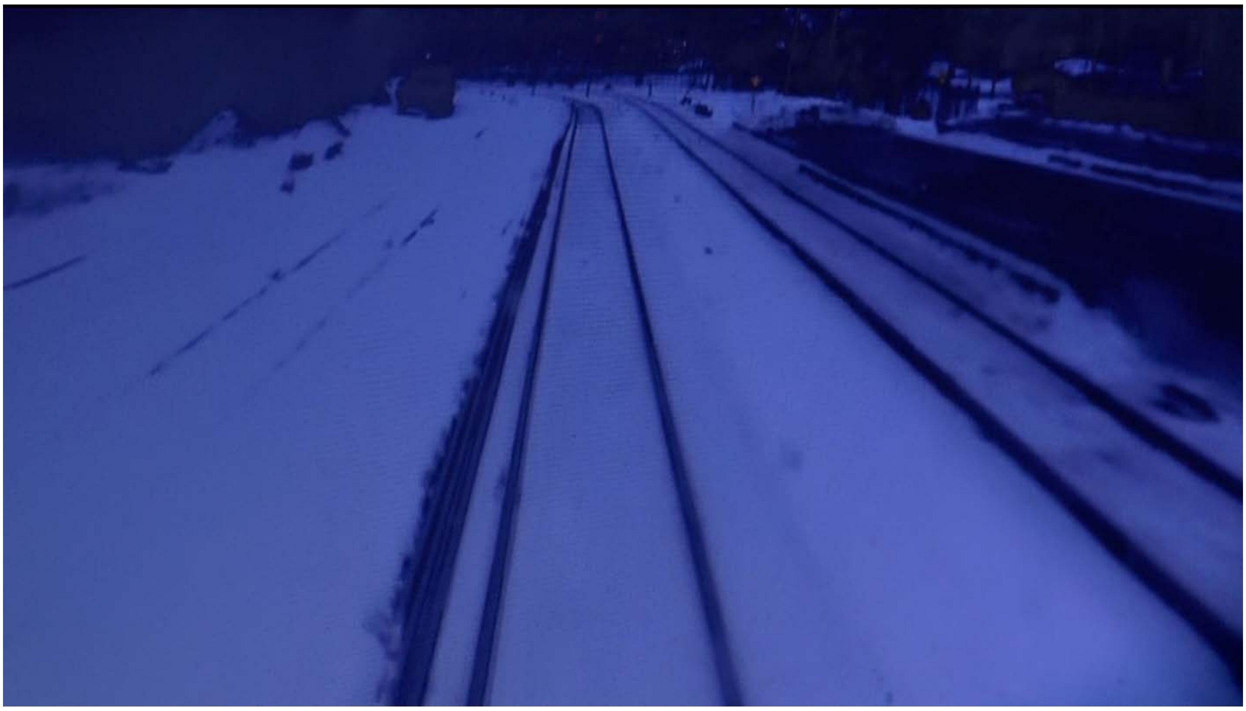
The meaning of this material seemed to evolve in the course of the workshop and editing period, for both us as researchers and for Peter himself. When the time had come for the participants to begin editing their films, Peter first sat down with the technical assistant who taught him to import his images to the editing software on one of the project´s portable mac book pro´s. The different participants worked more independently in this phase, and the researchers and film technician shifted between them to support and explore their progress. By the time I approached him, Peter had imported and begun going through well over 200 items in his iMovie library, of more than two hours duration totally. I told him that it could be wise to make up one´s mind about what clips would work the best for the story he wanted to tell with this particular film, that was going to be 15 minutes at the most, and then save some of his plentiful material for other short films that he could make whenever he liked. My suggestions to make a storyboard, a list to make his rushes more manageable beforehand and/ or import some of it on his own computer at home for other uses were turned down. Instead, he continued in his own pace by looking through clip by clip, sort of sensing if it should be selected for the timeline or not. Seemingly unaffected by me, he opened and started playing a clip where he is filming outwards from an open veranda door at home. One could hear birdsong from the outside, and the midnight sun was shining. The door closed and opened a little. He moved the clip to the timeline, saying that he *"kind of liked"* it. All his clips were ordered chronologically after the time they were filmed. I asked him if he felt that there was something that seemed to stand out across his material. He sat in silent thought for a minute and said there was quite a lot of experimentation. To illustrate this, he showed me a moonlit clip from his first long walk to the waterfront where he zoomed very slowly, saying he was inspired by a particular atmosphere in a film. He then showed me a scene from the film Nostalgia on YouTube with a somewhat similar *"feel"* and zooming movement. I asked about individual clips to explore their meaning for him and he said there was a certain feeling of being *"closed in"* in some of his first footage. –*"And here is what*

*I am longing for when I am locked in"* in, he then said, pointing to a clip of an empty rowing boat on calm waters from his first walk to the water front. He said he wanted his film to follow his body, like Bergman, rather than his thoughts, and to communicate a feeling inside of him, a certain feeling about who he was as a person, and what it was like to be in his situation. To express a phase he was in. To illustrate his point, he looked up a scene from a Bergman film (Fanny and Alexander), and said he liked the way it seemed to follow the body rather than conscious thought. When we packed out things, he smilingly said that even though we had not done a lot of editing that day, we had done quite a lot of *"thinking work."* It seemed as if he made sense of his own experience using new role models, the camera as tool, and our mutual reflective efforts to achieve a mutual understanding (see paper I, Østbye et al 2018, for more on this topic).



*Screenshot from Peter´s latest filming, later arranged in the chapter called "Free"*

On the next workshop session, I told Peter to reduce his selection, and to begin planning a structure for his film. Supported by the technical assistant, Peter reduced the number of clips based on the aesthetic and atmospheric strength he felt them having. Reluctant to make a script for an explicit story, the remaining clips in chronological order of filming gradually seemed to form a structure of their own. The film technician suggested that Peter could try to use time as a structuring element in the lack of a plot or explicit message. We commented that as time passed, Peter's scope of filming seemed to expand to wider and wider shots, and he seemed to move further and further away from his house into increasingly dynamic scenes. Pressed to make a structure and support our understanding, he then split the material into three chapters based on these differences, and begun identifying them as part-phases he had been in since receiving a camera. Peter regarded titles a little superfluous and cheesy, but added the titles *"In", Out"* and *"Free"* to his sub chapters, and/ or experiential phases. He then tested out and chose three different music scores from his favorite films, to accompany his film. He took especially long time searching for a perfect score for the last phase now titled "Free". When I asked if a new score he was testing out was meant to express a lighter mood, he scoffed with an irritated facial expression, like he sometimes did when my interpretations missed. I explored his irritation, and found that the sub-title *"Free"* came with an implicit question mark and sense of ambivalence for Peter. Coming back out from his *"comfort zone"* he said, although he felt that he *"should"* come out, held feelings of hope for new, and slightly different youth role but also held a strong sense of insecurity about whether he could succeed and be acknowledged for it by others. While I continued to explore Peter's film clips in our encounters to achieve a better understanding, new and/ or embodied meaning was gradually put into words. Our dialogue when I am asking about one of the first images he filmed of an abandoned playground swing well into the editing phase for example, is included verbatim it paper I.



*Screenshot, from Peter’s film: forward moving train on it’s tracks between chapters*

Peter’s process was belated by a month long stay at a national assessment and treatment center for young people with medically unexplained fatigue. He planned to return to his high school little by little, with adapted, individual teaching in one or two subjects at first. When it was time to find a title for his film, Peter was inspired yet again by a Bergman film, where the protagonist had complained about life being like a long wait by the railway station. He found readymade moving train footage on YouTube, that he added between his chapters, and suggested to call his film “*derailment*”. (See paper I, Østbye et al 2018, for a detailed description and analysis of the process leading up to the title derailment for his film.).

After the group-based workshop had finished, 14 year old Anne was referred by the pedagogical –psychological services who were assessing her special needs for adaptation in school. Anne had been referred on the basis that she struggled with verbal expression, in addition to long-term “psychosomatic” illness absences, also termed a form of “school refusal”. As we had not received enough referrals for the film workshop to run another group, I asked Anne if she would like to make a film with me alone, and she accepted. (Anne is the main participant in paper III) Anne’s had grown up in what her mother called a “war-zone” between her now divorced parents, and had endured long-term bullying in school. It was clear that an interview with Anne by herself would be virtually impossible, but we also struggled to get started with the first film assignments due to communicative challenges that also made their imprint on our initial individual workshop sessions. Through repeated visits in their home, and a few walks alone with Anne with a camera alone, I gradually gained insight into their partly overlapping processes of sense making, and into social processes in her school where I did not have access.

We ran the collaborative film process in hers and her mother's small rental apartment, in a mixed part of town with working class and middle class housing. On the first visit, I was seated in their small living room sofa, next to Anne. Her mother brought little ceramic cups and pronounced that they had bought them recently on a flea market for Anne, and produced a chocolate cake. If I asked Anne a question that she did not want to, or know how to answer, it was easily detectable on her eyes and facial expression. Her mother was present in the first sessions, which I found a little odd at first, but I soon discovered that she played a central role in managing Anne's communicative challenges in encounters with other adults. When asked about almost anything at first, Anne would smile like Mona Lisa, whisper an *"I don't know,* then look hopefully to her mother's aid for an answer. It was clear that Anne was less alone in her sense-making process and management of everyday life with symptoms, than most of the others in the group workshop. They were pleased with both their GP and Anne's psychologist. Anne's mother recalled how the new child- and adolescence psychologist was the first who had redefined Anne's mother from problem to resource, and she had translated everyday life events that the psychologist could them build upon in the consultation to get beyond Anne's "I don't know's". the pscyhologsit had then , according to Anne's mother, helped to put words on connections that made her experiences and symptoms understandable to them all. I wondered what lit Anne's own engagement, and what would be the best approach to get an understanding of her value evaluations and goals. What had meaning for her, and how this meaning was separate from her mother'? While Anne had a lot of support at home, the film process seemed to provide a tool whereby she could begin to express herself in new ways out in the world, by herself among peers. As in the process with Peter and Kim, Anne refused (in silence) to make a film about her health challenges and problems. Anne chose the assignment "to film a good day". The camera angle in her film gave me a feeling of seeing the city with her eyes, maybe because she was not in the frame, but the viewer sees with her when she is filming as she and her mother move exit from a bus, move along shopping streets and look at something on display. You could tell that her mother was in the scene, but controlled the camera herself. She had learned some editing in school, and had already edited the assignment film into a 6 minute long short film with no sound.

*"-There is no sound because I couldn't find anything I liked",* she said excusingly.

I asked what kind of music she liked. After a short "I don't know", she continued to say that she used to listen to a lot of music before, but now she used her time to do other things, since she used to listen to  the kind of thing that other's liked. She looked down, but her little act of subjective judgement made me curious, and I started to explore her experiences in school since I had last visited her. Anne's film project stood still, but each session she shared more about her little likes and dislikes, and a lot about social processes going on in her school that irritated her. Anne was frustrated about some of the other girls, who seemed to do exactly as everyone else, and some of the boys, who put other people down for standing out, for example her immigrant friend who had to endure racist and sexist comments in school. Anne could relate to other's experiences of bullying by peers, and could express long, engaged sentences on camera about other young people who seemed to suffer in some way or other in school. When it came down to questions about her own film (implicitly about herself and her perceived weaknesses it turned out), she clammed up however and turned silent again for a little while. Our breakthrough was when Anne's mother suggested that Ann could make a film about her immigrant friends, as it might be a little less intimidating and less *"close"* to her emotional pain. I agreed, and Anne began planning her film right away. She made the film for other pupils in her school *"to make a difference"*, and to make it easier to stand out than it had been for herself. Now she ws not afraid to speak, and she definitely *"knew"* what she wanted to say. Each encounter, she shared more episodes from school, and now increasingly positive experiences of her own changing self. She edited most of the film by herself on her own PC, and showed it in her school. All her teachers praised her greatly.

Ultimately. The film methodology opened up for cross-cultural understanding across communicative barriers in Anne's case, and allowed shared understanding to develop between us and Peter about his embodied, preverbal experiences in Peter's case.  Kim eventually decided to make a film with his mother as a primary audience, to show her who he *"really"* was and ask for her understanding and permission to grow up as a man. He added a music score by Malvina Reynolds (1967) to his film that expressed a shared theme across all the film processes; who they could be with their challenges and how they could relate to narrow spaces of normalcy and other people's expectations:

*Little boxes on the hillside*
*Little boxes made of ticky-tacky*
*Little boxes on the hillside*
*Little boxes all the same*

*There's a green one and a pink one*
*And a blue one and a yellow one*
*And they're all made out of ticky-tacky*
*And they all look just the same*

*And the people in the houses*
*All went to the university*
*Where they were put in boxes*
*And they came out all the same*

*And there's doctors and lawyers*
*And business executives*
*And they're all made out of ticky-tacky*
*And they all look just the same*

*And they all play on the golf course*
*And drink their martinis dry*
*And they all have pretty children*
*And the children go to school*
*And the children go to summer camp*
*And then to the university*
*Where they are…*

As the only one, Berit decided that she wanted to make a film about her challenging situation and the process that had lead up to it. She planned to begin by filming herself while she visited her secondary school where she had been bullied for several years. She never did film these shots however, and later expressed that this theme had been *"too depressing"* to delve into. After a while she decided that she was too sick to continue. It seemed as if the films had to be able to enact a sense of hope or open-endedness  to feel useful and sometimes even healing to make, as in the case of Peter who explicitly felt better be delving into his filming. Thus, their films did not become easily disseminated "patient" stories, but the process of improvisatory and narrative openness provided many opportunities to ethno-think and reflect together and develop our understanding about life with MUS in youth.

## 3.2 Presentation of the papers

The three papers in this thesis address the understanding and management of MUS in a Northern Norwegian town and how it is shaped from different angles and perspectives. More specifically, they provide knowledge of ongoing concerns and management strategies, including meaning-making processes and health-seeking practices of young people experiencing persistent MUS. These are characterized by reflexive navigation of social and moral expectations to act on their illness, participate among peers, and qualify to achieve acknowledgeable transitions to adulthood. They also provide knowledge of some of the ways MUS in youth is understood in a local care context and the communicative care responses that are conceivable and available from the perspectives of professionals in school and the primary health and social care sectors.

In the first paper, titled "Not a film about my slackness': making sense of medically unexplained illness in youth using visual collaborative methods" (Østbye et al., 2018), we explore how a key participant, "Peter", attempts to make sense of and cope with embodied and social aspects of his illness experience, and how the use of collaborative, reflexive filmmaking may facilitate understanding across communicative barriers and support efforts at meaning making. It is based on our collaboration with "Peter" the year he turns 17, when he has been isolated from school, sports activities and friends for more than six months due to debilitating, undiagnosed fatigue, dizziness and concentration difficulties. A primarily narrative analysis reveals that Peter is working intensively on an existential project of reorientation, now that his school path and sports-related identity have come to a halt. "Peter" is interested in our study due to our visual methods and actively engages in our film workshop, negotiating the tasks to allow them to support his own process of meaning making. Through the film making process and the engagement it evokes, we gradually gain more insight into embodied aspects, what is at stake for Peter and what he is trying to accomplish. Not only in the film workshop but also in his room at home, namely to create new meaning and spaces of opportunity through what he calls his "derailment" from his own and others' expectations of him as a young boy. Two meanings of his illness experience, as an illegitimate failure to perform and participate and as a space of opportunity to find "new rails" perhaps more adapted to his perceived personal strengths and weaknesses, constitute the two main themes of our findings, "Derailment" 1 and 2. The title of the paper illustrates how the process and negotiation in filmmaking brings forth Peter as a subject and the moral, illegitimate meaning he connects to his illness in addition to the bodily aspect. In his film, "Peter" maintains an open-endedness in the hope to succeed, but also wishes to convey a deep emotional insecurity about whether he could become an Acknowledged young man, in his particular time and place, and given the personal “weaknesses” he identifies in himself.

In the second paper, titled “Careful expressions of social suffering: How local professionals in high school settings, municipal services and general practice care for youth presenting persistent bodily complaints” (Kvamme et al., 2019), we explore the communicative dilemmas and solutions from the perspectives of professionals who regularly encounter young people presenting persistent bodily complaints in high school settings, municipal services, and general practice. We especially noticed the restrictions as well as the performative role of language in their reflections on encounters with young people who present with persistent bodily complaints. Our study identifies and adds insights to perspectives of previously understudied professionals involved in interpretation of persistent complaints in youth, their explanatory models, experiences of communicative dilemmas and experience- based solutions to these. All the professionals emphasize the social aspects of persistent bodily complaints in youth, and the need for an appreciative and trusting approach to recognize social suffering and achieve a shared understanding. The dilemmas they share point to difficulties of bringing up social or psychosocial dimensions of health due to limitations on available language in the institutional setting. Building on Annemarie Mol’s notion of a logic of care, the study identifies two modalities of “careful expression” whereby the professionals “tinker” with logics of care to counteract dilemmas connected to a medical and psychological institutional logic and language of disease and treatment. We define “careful expressions” as communicative care responses that involve careful attitudes towards young people through pragmatic uses of the power of language. This, in a more precise way, involves how to try out, test, and be creative about the use of certain terms, metaphors, experiences and own knowledge basis, while at the same time responding to and accommodating to the young person’s situation and social predicaments. Eventually, while an initial modality involves pragmatic and cautious adaptation to institutional logics, a second modality involves person-centred dialogue to provide new frames and express explanations with an emphasis upon the young individual’s self-care, seeking to support the constitution of empowered subjects.

In the third paper, titled “‘Fixing my life’: Young people’s everyday efforts towards recovery from persistent bodily complaints (Kvamme et al., forthcoming), we use a thematic analytic approach to explore the everyday strategies of young people with persistent and medically unexplained bodily complaints. More specifically, we explore the constraints they experience and how they counter them, what they hope to achieve and what they consider ‘good’ in relation to others in this process. The paper illustrates the emphasis demonstrated by the participants on a broad and expanded understanding of health beyond bodily determined symptoms. A central theme is their active efforts to “fix” aspects of their lives, in other words to get their lives “in order”, to overcome their suffering. The paper identifies two modalities of self-care in these efforts that involve reflexively navigating temporal and relational aspects of their social environments. In the first modality, they imagine and enact possible selves and who they can become as persons with their challenges, through a form of time work that involves future-oriented practices and processes of interpretation. In the second modality of self-care, they navigate sociocultural expectations, experiences of “pressure”, delimiting positions and social relationships to participate in peer contexts while at the same time taking their own needs, preferences and constraints into consideration. The paper shows how their understanding and management of their symptoms is informed by social and moral expectations of them as sick youth and the quest for alternative qualifying subject positions, while also reflecting subjectivities in the making, ordinary ethical sensibilities and forms of creative cultural critique and production.

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

### 3.2.2 Paper II: Careful expressions of social aspects: How local professionals in high school settings, municipal services and general practice communicate care to youth presenting persistent bodily complaints

### 3.2.3 Paper III: ‘Fixing my Life’: Young People’s Everyday Efforts towards Recovery from Persistent Bodily Complaints

Article

health:

Health
1–21
© The Author(s) 2018
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1363459318785696
journals.sagepub.com/home/hea
SAGE

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

**Silje Vagli Østbye and Maria Fredriksen Kvamme**
UiT The Arctic University of Norway, Norway

**Catharina Elisabeth Arfwedson Wang**
UiT The Arctic University of Norway, Norway; University Hospital of North Norway, Norway

**Hanne Haavind**
University of Oslo, Norway

**Trond Waage**
UiT The Arctic University of Norway, Norway

**Mette Bech Risør**
UiT The Arctic University of Norway, Norway

## 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

---

**Corresponding author:**
Maria Fredriksen Kvamme, General Practice Research Unit, Department of Community Medicine, Faculty of Health Sciences, UiT The Arctic University of Norway, 9037 Tromsø, Norway.
Email: maria.f.kvamme@uit.no

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.

### Acknowledgements

S.V.Ø. and M.F.K. have contributed equally and share first authorship. We would like to sincerely thank the participant for sharing his time and experience with us.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

### 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.

## Author biographies

**Silje Vagli Østbye** is a PhD student in the Clinical Research Group at the Department of Psychology at UiT The Arctic University of Norway. Her PhD is about communicative challenges in the understanding and treatment of medically unexplained symptoms in youth. She is also a clinical psychologist with an interest in relational psychoanalysis. Research interests are therapeutic processes of change and development, cultural psychological perspectives on health and illness, qualitative methods and the role of language and narrative in the construction of self and identity.

**Maria Fredriksen Kvamme** is a PhD student at the General Practice Research Unit at UiT the Arctic University of Norway. Her PhD is based upon an anthropological fieldwork on communicative challenges in the understanding and treatment of medically unexplained symptoms in youth. She has a Master's in Social Anthropology withVisual Cultural Studies and experience in public service outreach work with youth in Norway. Her main fields of interest are social aspects of health, youth, marginalisation and inclusion processes and the use of ethnographic and collaborative film.

**Catharina Elisabeth Arfwedson Wang** is a professor, a specialist in clinical psychology and the head of the Clinical Research Group at the Department of Psychology at UiT The Arctic University of Norway. Her scientific work includes research activities within the fields of depression, prevention of mental health problems, low-threshold and self-help, and evidence-based and alternative treatment approaches. She has worked with different research methods and designs including quantitative and qualitative methods, experimental designs, clinical trials, projective tests, user surveys and the development of new healthcare.

**Hanne Haavind** is a professor in the Department of Psychology at the University of Oslo. She has directed her research work at interpersonal relationships and developmental change, that is, children and young people growing up in the context of their families, the exchange of love and power in intimate relationships between men and women, and processes of change during psychotherapy. She has extensive experiences from developing and applying interpretational qualitative methods within psychology and related fields.

**Trond Waage** is an associated professor at Visual Cultural Studies in Tromsø, Norway and holds a PhD in Social Anthropology with specialisation in Visual Anthropology. He has done research in Northern Norway and Northern Cameroon, where he has explored the themes of youth, urbanisation, ethnicity, gender, religion and visual anthropology. He has worked at the Department of Social Anthropology and been connected to Visual Cultural Studies since 1994. Since 2006, he also has teaching experience in Visual Anthropology from University of Bamako, Mali. His interests include inclusive visual methods and local community dialogue.

**Mette Bech Risør** is a professor in medical anthropology. She has a long-standing research interest in the negotiation of symptoms and sensations in clinical encounters, linked to illness experiences and healthcare seeking practices. In particular, this has been applied to studies on functional disorders, cancer and lifestyle diseases with an emphasis on the interface between knowledge production and the crafting of relationality, bodies and subjectivities. Her position at the General Practice Research Unit of UiT creates the basis for an interdisciplinary approach to both her research and teaching.

Received: 7 August 2018 | Revised: 21 February 2019 | Accepted: 13 March 2019

DOI: 10.1111/hsc.12762

Health and Social Care in the community

WILEY

ORIGINAL ARTICLE

# Careful expressions of social aspects: How local professionals in high school settings, municipal services, and general practice communicate care to youth presenting persistent bodily complaints

Maria F. Kvamme[1] | Catharina E. A. Wang[2] | Trond Waage[3] | Mette B. Risør[1]

[1]Department of Community Medicine, General Practice Research Unit, Faculty of Health Sciences, UiT The Arctic University of Norway, Tromsø, Norway

[2]Department of Psychology, Faculty of Health Sciences, UiT The Arctic University of Norway, Tromsø, Norway

[3]Department of Social Sciences, Visual Cultural Studies, UiT The Arctic University of Norway, Tromsø, Norway

**Correspondence:**
Maria F. Kvamme, Department of Community Medicine, General Practice Research Unit, Faculty of Health Sciences, UiT The Arctic University of Norway, Tromsø, Norway.
Email: maria.f.kvamme@uit.no.

**Funding information**
This work was supported by the Faculty of Health Sciences, UiT The Arctic University of Norway, grant number A215090.

## Abstract

Persistent health complaints pose communicative dilemmas in care encounters, adversely affecting patient experiences and pathways. Little is known about the impact and role of professionals in encounters with young people with incipient, debilitating, and persistent symptoms. This study aims to explore communicative dilemmas and the role of language in care provided by local professionals in high school settings, municipal services, and general practice to young people presenting persistent bodily complaints. The study is based on in-depth individual interviews conducted from April to July 2016 with 12 professionals identified and selected during anthropological multi-sited fieldwork in a Norwegian community. We identify two modalities of what we have chosen to call 'careful expression', used as strategies across professions to overcome communicative dilemmas. Professionals reflexively and pragmatically negotiated with the powers of language to influence illness experience and to enact empowered young subjects. These insights may prove relevant for future studies of care encounters while also indicating a critical attitude to institutional logics that affect care responses.

KEYWORDS

care, communication, explanatory models/frameworks, medically unexplained symptoms, performative language, professionals, social suffering, young people

## 1 | INTRODUCTION

Persistent bodily complaints with unknown aetiology have been shown to cause communicative challenges in clinical and everyday encounters (Nettleton, 2006; Salmon, 2007; Ware, 1999). Although considerable variation exists in terminology and classification procedures (Rosendal et al., 2017), it has been estimated that 10%–15% of patients in primary care (Rosendal, Toft, Fink, Christensen, & Olesen, 2003) 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 do not receive a full medical explanation despite medical consultations for more than 6 months they are often referred to in the research literature as medically unexplained symptoms (MUS) (Peveler, Kilkenny, & Kinmonth, 1997). The term MUS is however not often used clinically, and its application by patients is disputed (e.g. Stone, 2002) as are other alternative terms. Here, we refer to persistent bodily complaints as a more open term than MUS (Marks & Hunter, 2015), to encapsulate possible understandings and management of the phenomenon in a broad scope of educational, primary health and social care community contexts.

A recurring theme in both medical and social research is clinicians' dilemmas when attempting to understand, explain, and recognise suffering that is poorly expressed within a dominant reductionist biomedical framework and language (Jutel, 2011; Kirmayer, 2004). These dilemmas are illuminated in research on general practitioners (GPs) struggling to express psychosocial aspects and reconcile incongruent explanatory models with adult patients (Johansen & Risør, 2017; Van Ravenzwaaij et al., 2010). They are also reflected in research on clinical communication with youth (Buchbinder, 2015; Geist, Weinstein, Walker, & Campo, 2008; Hareide, Finset, & Wyller, 2011) showing negative perceptions attributed to psychosocial explanations. Studies focusing upon primary care consultations with adults have demonstrated how communicative practices influence the subsequent development of aspects of the illness and healthcare (Olde Hartman, Hassink-Franke, Lucassen, Spaendonck, & Weel, 2009; Ring, Dowrick, Humphris, & Salmon, 2004; Risør, 2009; Salmon, 2007; Salmon, Dowrick, Ring, & Humphris, 2004). Systematic reviews rate cognitive behavioural therapy interventions as effective in cases of MUS but the evidence base for such interventions in routine encounters in more complex primary care settings is still lacking (Olde Hartman et al., 2017, see Nijhof, Bleijenberg, Uiterwaal, Kimpen, & van de Putte, 2012 for an exception). Good communication may also have therapeutic value in the management of common symptoms and MUS (Kroenke, 2014). Guidelines for MUS in primary care (e.g. Olde Hartman, 2013, IAPT, 2014, Rosendal, Christensen, Agersnap, Fink, & Nielsen, 2013) emphasise the central role of communication skills to ensure a care alliance, provide targeted explanations that make sense to the ill person and advice on self-management strategies. However, more knowledge on how remaining communicative challenges may be overcome by experienced frontline professionals is still needed (Olde Hartman et al., 2017). As most research on professionals' perspectives on young people presenting MUS has focused on encounters in specialist institutions, knowledge of communication with youth in other settings and often with early symptom presentations is limited (Hinton & Kirk, 2016).

## 1.1 | Communication through a care lens

In her analysis based on ethnographic fieldwork in an American pain clinic for adolescents, Buchbinder (2010, 2015) finds that the professionals apply a specific ethic of self-care and caregiving by using new expressions and explanatory frames of how to understand diffuse pain. Their responses to bodily distress work to produce certain kinds of stories and socialise certain kinds of patients. Here, we explore responses to diffuse bodily complaints in youth with an emphasis on care, referring to anthropological perspectives that understand care as 'both a culturally situated moral value and a grounded social practice' (Buchbinder, 2010, p. xiv). Medical anthropologists have long emphasised the situated nature of care practices and critically explored the ability for care paradigms and care providers to respond to suffering (Smith Morris, 2018). Care interventions may be 'imbued with institutional logics' (Buchbinder, 2011, p. 460) that place personal and moral responsibility upon the individual ill person for example (cf. Greco, 1993). Institutional logics may be defined as 'the socially constructed, historical patterns of material practices, assumptions, values, beliefs and rules by which individuals produce and reproduce their material subsistence, organise time and space, and provide meaning to their social reality' (Thornton & Ocasio, 1999, p. 804). Prevailing and conflicting logics of different institutional orders such as the market, state, and medicine may be reflected in the vocabulary used (e.g. Scott, Ruef, Mendel, & Caronna, 2000). An anthropological turn to care (cf. Smith Morris, 2018) seeks to highlight the on-going efforts by caregivers to keep together different values or versions of 'good' care (e.g. Pols, 2003). Mol, Moser, and Pols (2010, p. 14) define care as 'persistent tinkering in a world full of complex ambivalence and shifting tensions', taking account of the dilemmas professionals are facing. Collaborative consultation may be conceptualised as one modality of tinkering (Mol et al., 2010) and through good communication, a foundation of mutual understanding of what good care can be may be consecutively established and adjusted (Mol, 2008). However, Mol identifies both a logic of choice and a logic of care, where the former establishes neutral facts based upon scientific rationalist repertoires to facilitate equal opportunities, individual autonomy, and self-management. Conversely, a logic of care considers no facts as value-free and expects professionals to 'carefully experiment' (2008, p. 53) with the categories they use, and adapt medical and other technologies to everyday lives. In this study, we respond to an encouragement to 'translate' Mol's notion of a logic of care (2008, p. 90).

### What is known about this topic

- Health professionals struggle to achieve shared explanations with adult patients presenting MUS
- A reframing of the clinical setting may solve conceptual incongruences tied to biomedical frameworks and account for the concerns of the ill person

### What this study adds

- Experimenting with language, frontline professionals apply two modalities of care to overcome communicative challenges with young people with MUS.
- While an initial modality involves pragmatic and cautious adaptation to framing, a second modality involves person-centred dialogue to provide new frames and express empowering explanations
- These modalities seem most effective at an individual level, and reframing at higher levels of institutional and societal policy is still needed

## 1.2 | The role of language in response to persistent bodily complaints

To capture the care practices of professionals, we are especially interested in the performative functions of language. Critical approaches have focused on the limitations of representing subjective illness experiences and achieving a common understanding through language. According to Kirmayer (2000), the assumption often made of a coherent narrative does not reflect the nature of everyday and clinical conversations. Rather, he claims, encounters between health professionals and ill people are social sites where different interpretations of meaning are negotiated, drawing upon rhetoric, elements of discourse, and poetic or evocative use of language. Language has functions that can be traced both ‘inward to its physical embodiment and potential relief and outward into the world where it confers social power’ (Kirmayer, 2000, p. 32).

Das (1996) and Kleinmann, Das and Lock (1997) similarly emphasise cultural processes, whereby certain experiences of suffering are recognised or not. Pointing to the central role of language as social action, and using Wittgenstein's concept of language games, Das (1996) shows how presentations of pain constitute often unanswered invitations to understanding and social recognition. When the language available to express suffering is frozen into limiting sociocultural positions, responding to this plea may require new vocabularies (Das, 1996). Recent anthropological studies on GPs and specialist clinicians show that their language use in encounters with persistent bodily complaints simultaneously reflects and reacts to elements of sociocultural framing. In performing care, they act as moral entrepreneurs negotiating and adapting diagnoses, explanatory models, and metaphors to experience-based knowledge, to the particulars of each person and to anticipated consequences and governing ideals in the sociocultural context (Buchbinder, 2015; Mik-Meyer & Obling, 2012).

Based on the above, we aim to explore communicative dilemmas and the performative role of language in care encounters between professionals and youth presenting persistent bodily complaints in high school settings, municipality services, and general practice.

# 2 | METHODOLOGY

The study is based on ethnographic multi-sited fieldwork (Marcus, 1995) on communicative challenges in the understanding and treatment of medically unexplained symptoms (MUS) in Norwegian youth. This enabled us to identify and observe professionals playing a care role for young people between 14 and 23 years of age in the local community and to explore the social context of young Norwegians (Emerson, Fretz, & Shaw, 2011; Hammersley & Atkinson, 2007). To further explore situated professionals' understanding and their performative approach to care, the first author interviewed professionals from local primary health and social care and school services, including teachers, school advisors, school nurses, social workers, and GPs. We defined MUS as persistent and debilitating bodily complaints that the young person has experienced for more than 6 months and that had proved challenging for health professionals to understand and treat (Peveler, 1997). While these criteria guided the professional's selection of cases to talk about with us, the MUS term was new to them and they applied more explanations than the medical in encounters with young people.

## 2.1 | Health services

When persistent bodily complaints affect young people's lives in Norway, and most notably when they cause long-term absence from school, multiple actors besides family and clinical specialists are involved in rendering care. The GP plays a key role in family medicine and frontline services in Norway and the system allocates each citizen to a general practitioner as their regular doctor and first contact in case of non-acute illness. Young people are assigned to their parent´s GP. Except for a small excess fee for GP consultations, all services described in this study are publicly covered in full and easily approached by young people directly. Social workers at municipality level visit arenas such as schools, homes, and street corners as a part of their ambulatory care and coordination of health services for young people at risk. All schools in the study are state funded. Contact-teachers in the schools hold a special responsibility to know each pupil and to ensure their overall well-being. School-advisors support pupils with questions related to future education and follow up regarding social, pedagogical, and absence-related challenges. Many school-advisors have past experience as teachers, but some special competency on social or career advising is required. The local school health nurses work one or two days a week in designated schools. Based on the local child health clinic, they hold a special responsibility for health promotion and prevention among children and youth.

## 2.2 | Participants

To gain access, we presented our project to the leaders of seven schools, who discussed with us the relevance of our topic to their particular school. They highlighted practical curricula in two schools as most relevant, based upon multiple challenges including pupils with ‘diffuse’ bodily complaints. We also selected a third school offering elite sports curricula, as this was often mentioned as relevant in initial fieldwork meetings. The first author then performed ethnographic fieldwork involving participant observation and ethnographic conversations in classrooms and staff rooms in the selected schools, as well as focus group discussions with different existing inter-professional, pupil and teacher groups. We asked school nurses, school advisors, teachers as well as public social workers visiting the schools to assist youth at risk, to participate in individual interviewing. We approached two GPs for participation, recommended to us by other professionals as experienced and interested in caring for young people with MUS, and sent out an open email invitation to local GPs. One GP replied to the open invitation and was included with the other two. Ten out of 12 interviewees were women, reflecting an overall higher percentage of women in the professional settings we approached. All had 10 or more years of professional experience in their fields, showed interest in our topic, and completed interviewing as planned.

### 2.3 | Data

Data analysed for this study derive from 12 individual 60–90 min interviews conducted from April to July 2016 with three GPs, two social workers (SWs), three school nurses(SNs), one school advisor (SAs), and three high school teachers(Ts). The number of interviewees was a pragmatic decision, to allow more extensive fieldwork on the interviewees and young people experiencing MUS. Using semi-structured interviewing partly inspired by adapted versions of the life mode interview (Andenæs, 2012, Haavind, 2007), we asked the professionals to describe their own care interactions with young people with MUS (see above) and to share ongoing care processes, success stories, and dilemmas they had experienced and attempted to overcome with a focus on their present practices. These stories were probed during interviewing for explanatory models, goals, communicative challenges, and strategies involving language use. The interviews were supported by participant observation and ethnographic conversations. The first author wrote reflexive, analytic memos after each interview, transcribed verbatim, and drew charts of domains and semantic relationships (Spradley, 1979) to guide developing reflection. The last author audited the development of the interview guide, initial transcripts and memos, and all authors engaged in ongoing reflective, analytic dialogue.

### 2.4 | Analysis

We analysed the interviews according to general principles for thematic analysis, applying a constructionist and theoretically informed inquiry into latent and semantic levels of meaning (Clarke & Braun, 2017). The first author coded transcripts by hand, explored themes within each interview, then within professions and across professional boundaries. Finally, we compared overarching themes to initial themes in individual interviews for consistency and variation. To capture and understand care responses, the analysis was inspired by anthropological accounts of performative aspects, that is, how language 'does' reality and crafts both subjects and bodies (Kirmayer, 2000; Kleinmann, Das, & Lock, 1997).

### 2.5 | Ethics

The Norwegian Centre for Research Data approved this study in August 2014 (ID 39362). We provided information for the schools about the first author's presence and aims, obtained informed, written consent from the professionals invited to interview, and adhered to ethical scientific conduct.

## 3 | FINDINGS

The young people and their cases which were brought up in the interviews all had routine or scheduled encounters with the professional in question. They were between 16 and 23 years and presented mild to severe levels of tiredness, headaches, abdominal, and musculoskeletal pain with no clear pathology. In most cases the young person also presented challenges such as family conflicts, experiences of violence, abuse and/ or bullying, school and peer-related stress, and/ or emotional difficulties connected to these. The various professionals had clear ideas about the aetiology of the persistent bodily complaints they had encountered, emphasising as a start the role of social aspects in accordance with a biopsychosocial model. All professionals had experienced communicative dilemmas related to these symptom presentations. None had received specific guidelines about communication and MUS, but shared experience-based approaches to solve the dilemmas they were facing. In the following, we first present the ideas and explanatory frameworks emphasised by all professionals encountered in the fieldwork.

### 3.1 | Knowing *"what it really is"*: professional vocabularies for the role of social suffering

All the professionals emphasised the impact of relational challenges such as absent parents, experiences of violence, abuse, or bullying as well as the pressure of partly unreasonable demands placed on youth in present-day society. They used terms such as psychosocial or psychosomatic to denote how life experiences and emotional reactions were interconnected with bodily complaints:

> "Right now we have a rush of pupils wanting to quit. Quite a lot of it is psychosomatic complaints. Often connected to their private lives, or their childhoods. Bullying. Things like that over time." (T01)

Most professionals also referred to societal pressure, visible according to the GPs in the types of symptoms seen in the bodies of those most vulnerable:

> ”Life in modern society is challenging. And you don't measure up. And maybe 20 years ago people would feel more shoulder or back pain. Now people are more worn out." (GP01)

All professionals sometimes also used the category of 'the psychological' about emotional reactions to the sum of social stressors, not to denote separation from organic disease but to emphasise complexity and interconnectedness:

> "They often don't come with just the physical, it's a big package, right, where physical and psychological factors are intertwined (…) And then we begin, assessing, and there's a bit too much at school… and arguing with her parents. And then there's the bodily reaction to that." (SN01)

The school nurses were careful not to go into what they labelled '*the trap*' of thinking that everything was explained psychologically.

Similarly, the social workers did not question the physical reality of persistent bodily complaints, despite their assumed social aetiology. Rather, they understood them as natural expressions of unprocessed struggles in life and therefore one of many risk factors these youth were exposed to.

In general, all professionals emphasised the role of social factors in persistent bodily complaints, with slight differences in terminology and emphasis within a biopsychosocial understanding. At the same time, they were wary of terminology and its possible ramifications.

## 3.2 | Responding within delimiting language games

The following excerpt from the interview with a school nurse may illustrate initial interaction between the professional and the young person:

> 'A 17 year old pupil came one day with an aching finger. Came with kind of an order, as they often do. - With his hand in the doorway, like he didn´t even want to enter the room. I was only allowed to inspect his finger, to look for signs of inflammation. We looked at the finger once, twice, three times (smiling). Then he came back with an aching knee, and I took him in. I investigated his knee, and this time I tried to ask a few open questions. How he was, how he was doing. General stuff like that. And then I began to sense something else. In that finger. And that knee. And that was when I began catching it. But I still didn't know what it was. I don't know until it's been said out loud'. (SN02)

All participants described adapting to and tinkering with biomedical expert language and lay discourses of psychological vulnerability in youth. They described efforts to avoid expressions that might be interpreted as delegitimising psychologisation and cause additional suffering. Furthermore, to take bodily illness experiences seriously and to protect the care alliance, the professionals adapted their initial responses by postponing a more holistic inquiry into potential connections with social or emotional aspects:

> 'I always ask about how they're doing in school. If they have friends and so on. But not until I've asked about the purely physical things. So they don't think right away that I think it's only psychological'. (GP03)

Through such careful expression, the professionals managed communicative dilemmas with a flexible approach resembling that described in previous literature on GPs (Hansen, Rosendal, Fink, & Risør, 2013; Woivalin, Krantz, Mantyranta, & Ringsberg, 2004). Such presentations and responses, which we call delimiting language games (Das, 1996; Wittgenstein, 1958), were however ineffective in acknowledging the assumed complexity of these young people's suffering. In many cases, the professionals instead achieved a relational congruence of trust and alliance as a basis for subsequent care. While other research has pointed to negative attitudes in the health system towards patients presenting MUS (i.e. Shattock, Williamson, Caldwell, Anderson, & Peters, 2013), the professionals in our study did not express this nor frustration towards the ill youth, but towards health service barriers and limitations in language.

## 3.3 | Tinkering with terminology and sick roles

Another reason emphasised by the professionals for careful tinkering with authoritative language was to gain societal recognition of suffering, thereby preventing marginalisation of youth. The school staff member routinely sent pupils with absence to their GPs for medical assessments and documentation that they were adhering to a medical regime:

> 'I have sent several to their GPs… It may look bad on their diplomas if they don't have everything in order'. (L03)

Similarly, the GPs approached physical and mental explanations and labels pragmatically, with social consequences in mind, rather than as neutral medical facts:

> 'If they've felt ill, I'll write sick leave. It can't be of any help to them if they're absent without permission'. (GP01)

Several professionals described manipulating with medical language elements and simplifying explanations, to normalise young people's deviance from increasingly standardised school pathways and to release resources:

> 'If we look at the criteria at the social services… We put a stamp on it to get help. We readily use health as the reason'. (SW02)

However, not all experiences of suffering were possible to translate and respond to using this language. Examples described by the social workers illustrated how the dependency of the care paradigm on reductionist categorisation silenced certain presentations, leading to experiences of neglect:

> 'The conclusion is nothing… no sick leave. No documentation for school absence… Even for us it takes a lot to tell others that this youth has a history that needs attention'. (SW02)

Furthermore, the professionals expressed concern about the potentially disempowering effects of the stories young people had learned to tell about their distress. The school staff member was concerned about how certain illness presentations were evoked, tied to medical authority, or dominant discourses on young people's psychological vulnerability, for example, explanations that did not necessarily provide guidelines for action:

> 'As the year passes, they dare tell some very tragic stories that are learned…In a way I don't want those illness stories that many are playing on towards me as a teacher… I don't want to let them stay in that victim role'. (T01)

To meet this challenge, the professionals acted as moral entrepreneurs by tinkering with health terms, attempting to acknowledge suffering, secure legitimate sick roles, and release resources to support the young person's needs.

## 3.4 | 'Walking in concert': achieving a more open dialogue

Following from the above, a second modality of care seemed to develop. The following excerpt with a GP might illustrate this:

> 'A 16 year old patient presented recurrent weight loss, headaches and stomach aches that inhibited her everyday activities. I've known her from she lay in her mother´s womb, and we also spent extra-long consultations over the course of four months to talk about her experiences. I asked her about her symptoms, and told her accompanying mother to listen with me. The girl gave a lot of descriptions. Then I asked in what situations she felt them the most and she described how she struggled to eat her lunch in the classroom. Because she was academically gifted, and helpful with other pupils, she had been asked to always sit with and take care of the worst behaving boy in her class. She could feel and see herself how straining this task was in her everyday. She had not dared to tell anyone, and her parents had seen it as a resource. After this, she and her mother finally spoke to the teacher and she was allowed to move to the other end of the classroom. She told a lot of these kinds of stories that built upon that theme, that others were seeing her qualities and wanted to use her. Eventually she managed to set her boundaries with teachers and peers. And her symptoms decreased'. (GP02)

In this modality, the professionals dismiss clinical terminology and tinker with new vocabularies, relating more to a practical care logic through mutual exploration. Close dialogue with pupils enabled teachers to adapt school-related demands to particular life situations, rather than relying upon standardised processes of definition and control:

> 'There are no general solutions. You just have to approach each individual. They're so different…but the solution is getting into a dialogue with the person'. (T02)

Achieving a more open dialogue, however, required trust. All professionals described efforts to build relationships strong enough to include psychosocial topics. For the social workers, creating a safe space for dialogue, even with the most taciturn youth, was often based on the young person's own concerns or interests:

> 'It's a method of trial and error. And what we do is very open. Like using my private network to walk a dog with one. Finding a door-opener'. (SW01)

The process of establishing a foundation for this kind of assessment took time, patience, and careful fine-tuning to the young person's cues, as one nurse stated:

> 'I'm trying to make a safe space to explore what her challenges are. Sensing this. Should I pause or can I move on? Walking in concert with youth so as not to scare them away. Curiosity must be aroused in the pupils themselves'. (SN03)

Once a dialogue necessary for more collaborative care was established with the young person, the professionals used empowering rhetoric that carefully explored and introduced new interpretations of persistent bodily complaints closer to their own explanatory frameworks, while still taking bodily suffering seriously:

> 'I say that I believe that they're suffering. And that we can't find out everything using clinical tests'. (GP03)

If the young person presented a repertoire of fragmented expressions about physical, social, and psychological suffering, the professional attempted to link these in more complex language games reflecting the individual experiences of the young person and aiming for a consistent story where he/she might recognise him/herself. By using a vocabulary developed together with the young person, a process resembling 'shared doctoring' could be initiated (Mol, 2008):

> 'When I get a story it's often two-sided… I hope I can ask the right questions that might open up a new landscape even for me'. (SW02)

Reframing symptoms collaboratively could release them from their old connotations and allow for more active, self-managing subjects:

> 'Trying to articulate the complaint and what they've thought about it. If it might be tied to stress or worry, to school or the family… And then it's almost as if they bring out their own ability to reflect …Feeling that it's about social things…Ready to make some powerful decisions'. (GP02)

A central goal for this modality of careful expression was to encourage new, more empowering stories that included social suffering to lay the foundation for self-care:

> 'I usually say: You aren't your backpack and a diagnosis is not who you are… I try to let them know they can do more than just telling things'. (T01)

However, this did not entail handing personal responsibility to the youth alone. Rather, the professionals remained persistently engaged, pleading their cause. Engaging in careful and caring dialogue with the young person, new stories were co-constructed rhetorically and medical reductionism was replaced with a more complex understanding, stressing social factors. This modality of care provided new communicative spaces in close care relationships that seemed to function as alternative frames for expression. Here, the professionals felt less tied to delimiting language and experienced achieving shared explanations to guide care interventions. Solutions beyond these encounters often focused on aspects of self-care, pointing the person towards commitment to relevant treatment and empowerment of everyday life.

## 4 | DISCUSSION

In this article, we have explored dilemmas and management strategies emphasised by professionals involved in care responses to youth presenting persistent bodily complaints. The dilemmas they share point to difficulties of bringing up social or psychosocial dimensions of health due to delimiting language use in the institutional framing. Especially we have focused on communicative themes in their management of these dilemmas, and have identified two main modalities of careful expression of social aspects of suffering in our findings. By careful expression we mean communicative care responses that involve careful attitudes towards the youth through pragmatic uses of the power of language. While an initial modality involves pragmatic and cautious adaptation to framing, a second modality involves person-centred dialogue to provide new frames and express empowering explanations.

First, the professionals described a need to adapt the biomedical and formal language used to classify health concerns in their care responses. This modality of careful expression shares some characteristics with flexible approaches (Woivalin et al., 2004) and pragmatic, innovative uses of biomedical labels and explanations in clinical encounters to accommodate patient expectations and social consequences (Aamland, Fosse, Ree, Abildsnes, & Malterud, 2017; Buchbinder, 2015; Mik-Meyer & Obling, 2012; Rasmussen, 2017). Although the role of diagnostic and/ or umbrella terminology as shown in previous research (e.g Stone, 2002) is not essential for these professionals, they are still concerned with the language available to express dimensions of health and illness. Our findings may expand the uses of such insights to other professions and care settings and illustrate the powerful role played by medical imaginaries and frameworks in more settings than the clinic. Still experiencing conceptual incongruence (May et al., 2004) in relation to their explanatory models in these encounters, the professionals in our study invest in care alliances, or 'relational congruence,' to build a foundation for solving communicative dilemmas at later stages (Johansen & Risør, 2017, p. 652).

If the professionals feel that a more open dialogue is possible, they seem to engage in a second modality of careful expression, reframing biomedical and formal language to tinker with new vocabularies and explanations. Several works have argued for a reframing of the clinical setting to better understand and manage illness aspects poorly captured by biomedical categories of psyche and soma, but approaches to reframing have varied in scope and clinical success (Stone, 2013,2014). The professionals in our study expressed concern and attempted to address their roles in framing care encounters through their language use, rather than merely aiming to educate (e.g. Woivalin et al., 2004) the person or correct his/her understanding of the illness. All the professionals seemed to rely on multifactorial explanations in line with a biopsychosocial model (Engel, 1977), oscillating in emphasis between the social and the psychosocial in relation to bodily complaints. The professionals found that the key to grasping connections between illness aspects and finding expressions of a shared understanding lay in each young person's particular stories about everyday life, and had to be explored using new vocabularies less tied to reductionist categories and more closely linked to individual life-worlds. Their experience-based strategies for achieving shared understandings with youth presenting persistent bodily complaints align with guideline recommendations to build supportive relationships, provide 'targeted' and tangible explanations in the language of the ill person and advice on everyday self-management (cf. Olde Hartman et al., 2017). As such they support the need for more person-centred approaches to care (Butler, Evans, Greaves, & Simpson, 2004). They also align with an integrative approach to communication and MUS that involves the ill person in mutual exploration of his or her history, symptom report, and exploration of clues about psychosocial factors (c.f. Kroenke, 2014).

A continuous issue of the analysis is communication regarding social dimensions of MUS. The professionals all emphasised adverse experiences in close social networks of family and peers, but also highlighted a broader critical view of conditions for socialisation and integration in the modern knowledge society, exposing youth to new forms of stress. Furthermore, the professionals recognised the role of discourse and practices of categorisation in producing youth vulnerability and at-risk-ness. Their responses and care interventions negotiate with societal sources of suffering, but it is difficult to influence these and interventions stay at the level of the individual youth at risk. Hence, they expressed a need for careful expression that normalises deviance and empowers the individual to cope with conditions and framing mechanisms understood as unhealthy. These conscious uses of language may be seen as particular expressions of a logic of care (Greco, 2012; cf. Mol, 2008). In the modalities of careful expression described by these professionals, categories are appropriated and new ones are created. Furthermore, stories are central tools of sense-making where the professionals find expression for social aspects of suffering together with each young person. However, they understand stories as 'learned', potentially reflecting larger narratives in the institutional and sociocultural context and not necessarily conducive to healthy life narratives for youth (Kirmayer, 2000). Furthermore, the professionals find that the wrong stories can enact reductionist and marginalising understandings of a notion of psychological vulnerability and personal blame that affects the youths' relationship to their bodies and themselves. Hence, the professionals feel a responsibility to teach better stories that perform differently. This enactment of self-management is double-edged, following a logic of care but also potentially bolstering neoliberal processes that individualise responsibility for social suffering (Foucault, 2008; Greco, 1993; Rose, 1999).

## 5 | CONCLUSION

Our study contributes with two modalities of care to overcome communicative challenges with young people with persistent and medically unexplained bodily symptoms, that may prove relevant for other settings, where experienced professionals tinker with 'logics of care' to counteract dilemmas connected to a medical and psychological institutional logic and a language of disease and treatment that, among other things, risks categorising young people unnecessarily rather than empower them.

## CONFLICT OF INTEREST

No potential conflict of interest was reported by the authors.

## ORCID

*Maria F. Kvamme* https://orcid.org/0000-0002-3943-7555

*Catharina E. A. Wang* https://orcid.org/0000-0002-7787-916X

*Mette B. Risør* https://orcid.org/0000-0002-7912-5804

## REFERENCES

Aamland, A., Fosse, A., Ree, E., Abildsnes, E., & Malterud, K. (2017). Helpful strategies for GPs seeing patients with medically unexplained physical symptoms: A focus group study. *British Journal of General Practice*, *67*(661), e572–e579. https://doi.org/10.3399/bjgp17X691697

Andenæs, A. (2012). From 'placement' to 'a child on the move': Methodological strategies to give children a more central position in Child Welfare Service. *Qualitative Social Work*, *11*, 486–501. https://doi.org/10.1177/1473325011408174

Buchbinder, M. H. (2010). Children's pain and the ethics of care. Retrieved from ProQuest Dissertations & Theses Global; Social Science Premium Collection.

Buchbinder, M. (2011). Personhood diagnostics: Personal attributes and clinical explanations of pain. *Medical Anthropology Quarterly*, *25*, 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*. Ann Arbor, MI: University of California Press.

Butler, C., Evans, M., Greaves, D., & Simpson, S. (2004). Medically unexplained symptoms: The biopsychosocial model found wanting. *Journal of the Royal Society of Medicine*, *97*, 219–222. https://doi.org/10.1177/014107680409700503

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*, 297–298. https://doi.org/10.1080/17439760.2016.1262613

Das, V. (1996). Language and body: Transactions in the construction of pain. *Dædalus: Journal of the American Academy of Arts and Sciences*, *125*(1), 67–91.

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

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

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

Foucault, M. (2008). *The Birth of Biopolitics: Lectures at the Collège de France 1978–1979*, (ed.) Sennelart, M., Trans. Burchell, G., Basingstoke, UK: Palgrave.

Geist, R., Weinstein, M., Walker, L., & Campo, J. V. (2008). Medically unexplained symptoms in young people: The doctor's dilemma. *Paediatrics & Child Health*, *13*, 487–491.

Greco, M. (1993). Psychosomatic subjects and the 'duty to be well'. *Personal Agency within. Economy and Society*, *22*, 357–372. https://doi.org/10.1080/03085149300000024

Greco, M. (2012). The classification and nomenclature of 'medically unexplained symptoms': Conflict, performativity and critique. *Social Science & Medicine*, *75*, 2362–2369. https://doi.org/10.1016/j.socscimed.2012.09.010

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). Copenhagen: Danmarks Pædagogiske Universitets Forlag.

Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice*, 3rd ed. London, UK: Routledge.

Hansen, H., Rosendal, M., Fink, P., & Risør, M. (2013). The general practitioner's consultation approaches to medically unexplained symptoms: A qualitative study. *ISRN Family Medicine*, *7*, https://doi.org/10.5402/2013/541604

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*, 2255–2263. https://doi.org/10.3109/09638288.2011.568663

Hinton, D., & Kirk, S. (2016). Families' and healthcare professionals' perceptions of healthcare services for children and young people with medically unexplained symptoms: A narrative review of the literature. *Health & Social Care in the Community*, *24*(1), 12–26. https://doi.org/10.1111/hsc.12184

IAPT, Improving Access to Psychological Therapies group. Department of Health. (2014). Medically unexplained symptoms/functional symptoms positive practice guide. Available from http://www.iapt.nhs.uk/silo/files/medically-unexplained-symptoms-postive-practice-guide-2014.pdf.

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 Counselling*, *100*, 647–654. https://doi.org/10.1016/j.pec.2016.11.015

Jutel, A. (2011). *Putting a name to it: Diagnosis in contemporary society*. Baltimore, PA: Johns Hopkins University Press.

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). Berkeley, CA: University of California Press.

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

Kleinman, A., Das, V., & Lock, M. (1997). *Social suffering*. Berkeley, Calif: University of California Press.

Kroenke, K. (2014). A practical and evidence-based approach to common symptoms: A narrative review. *Annals of Internal Medicine*, *161*, 579–586. https://doi.org/10.7326/M14-0461

Marcus, G. E. (1995). Ethnography in/ of the world system: The Emergence of Multi Sited Ethnography. *Annual Reviews of Anthropology*, *24*, 95–117. https://doi.org/10.1146/annurev.an.24.100195.000523

Marks, E. M., & Hunter, M. S. (2015). Medically unexplained symptoms: An acceptable term? *British Journal of Pain*, *9*(2), 109–114. https://doi.org/10.1177/2049463714535372

May, C., Allison, G., Chapple, A., 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*, 135–158. https://doi.org/10.1111/j.1467-9566.2004.00384.x

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

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

Mol, A., Moser, I., & Pols, J. (2010). *Care in practice: On tinkering in clinics, homes and farms*. *8, Matte Realities: Perspectives from Empirical Science Studies*. Bielefeld: Transcript Verlag.

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

Nijhof, S. L., Bleijenberg, G., Uiterwaal, C. S. P. M., Kimpen, J. L. L., & van de Putte, E. M. (2012). Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): A randomised controlled trial. *The Lancet*, *379*(9824), 1412–1418. https://doi.org/10.1016/S0140-6736(12)60025-7

Olde Hartman, T. C., Blankenstein, A. H., Molenaar, A. O., Bentz van den Berg, D., Van der Horst, H. E., Arnold, I. A., … Woutersen-Koch, H. (2013). NHG guideline on medically unexplained symptoms (MUS). *Huisarts Wet*, *56*(5), 222–230.

Olde Hartman, T., Hassink-Franke, L., Lucassen, P., Van Spaendonck, K., & 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*, 68. https://doi.org/10.1186/1471-2296-10-68

Olde Hartman, T., Rosendal, M., Aamland, A., Van Der Horst, H., Rosmalen, J., Burton, C., & Lucassen, P. (2017). What do guidelines and systematic reviews tell us about the management of medically unexplained symptoms in primary care? *BJGP Open*, *1*(3). Bjgpopen17X101061.

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), 245–252. https://doi.org/10.1016/S0022-3999(96)00292-9

Pols, J. (2003). Enforcing patient rights or improving care? The interference of two modes of doing good in mental health care. *Sociology of Health & Illness*, *25*, 320–347. https://doi.org/10.1111/1467-9566.00349

Rasmussen, E. (2017). Balancing medical accuracy and diagnostic consequences: Diagnosing medically unexplained symptoms in primary care. *Sociology of Health & Illness*, *39*, 1227–1241. https://doi.org/10.1111/1467-9566.12581

Ring, A., Dowrick, C., Humphris, G., & Salmon, P. (2004). Do patients with unexplained physical symptoms pressurise general practitioners for somatic treatment? A qualitative study. *BMJ*, *328*, 1057–1060. https://doi.org/10.1136/bmj.38057.622639.EE

Risør, M. (2009). Illness explanations among patients with medically unexplained symptoms: Different idioms for different contexts. *Health: an Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, *13*, 505–521. https://doi.org/10.1177%2F1363459308336794

Rose, N. (1999). *Governing the soul: The shaping of the private self*, 2nd ed. London, UK: Free Association Books.

Rosendal, M., Christensen, K., Agersnap, L., Fink, P., & Nielsen, C. (2013). Dansk selskab for almen medicin: Klinisk vejledning for almen praksis. funktionelle lidelser. Available from www.dsam.dk.

Rosendal, M., Olde Hartman, T., 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*, 18. https://doi.org/10.1186/s12875-017-0592-6

Rosendal, M., Toft, T., Fink, P., Christensen, K. S., & Olesen, F. (2003). Recognition and treatment of functional disorders in family practice using the extended reattribution and management model. *Journal of Psychosomatic Research*, *55*, 118. https://doi.org/10.1016/S0022-3999(03)00426-4

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

Salmon, P., Dowrick, C. F., 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*, 171–176.

Scott, W. R., Ruef, M., Mendel, P., & Caronna, C. (2000). *Institutional change and health care organizations: From professional dominance to managed care*. Chicago, UK: University of Chicago Press.

Shattock, L., Williamson, H., Caldwell, K., Anderson, K., & Peters, S. (2013). 'They've just got symptoms without science': Medical Trainees' acquisition of negative attitudes towards patients with medically unexplained symptoms. *Patient Education and Counseling*, *91*(2), 249–254. https://doi.org/10.1016/j.pec.2012.12.015

Smith-Morris, C. (2018). Care as virtue, care as critical frame: A discussion of four recent ethnographies. *Medical Anthropology*, *1–7*, https://doi.org/10.1080/01459740.2018.1429430

Spradley, J. (1979). *The ethnographic interview*. New York, NY: Holt, Rinehart & Winston.

Stone, J., Wojcik, W., Durrance, D., Carson, A., Lewis, S., Mackenzie, L., … Sharpe, M. (2002). What should we say to patients with symptoms unexplained by disease? The "number needed to offend". *BMJ*, *325*(7378), 1449–1450. https://doi.org/10.1136/bmj.325.7378.1449

Stone, L. (2013). Reframing chaos: A qualitative study of GPs managing patients with medically unexplained symptoms. *Australian Family Physician*, *42*, 1–7.

Stone, L. (2014). Managing the consultation with patients with medically unexplained symptoms: A grounded theory study of supervisors and registrars in general practice. *BMC Family Practice*, *15*, 1–15. https://doi.org/10.1186/s12875-014-0192-7

Thornton, P. H., & Ocasio, W. (1999). Institutional logics and the historical contingency of power in organizations: Executive succession in the higher education publishing industry. *American Journal of Sociology*, *105*, 801–843. https://doi.org/10.1086/210361

Van Ravenzwaaij, J., Olde Hartman, T., Van Ravesteijn, H., Eveleigh, R., Van Rijswijk, E., & Lucassen, P. (2010). Explanatory models of medically unexplained symptoms: A qualitative analysis of the literature. *Mental Health in Family Medicine*, *7*, 223–231.

Ware, N. C. (1999). Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. *Culture, Medicine and Psychiatry*, *23*, 303–331. https://doi.org/10.1023/A:1005577823045

Wittgenstein, L. (1958). *The Blue and Brown Books*. London: Basil Blackwell.

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

## BIOGRAPHIES

**Maria F. Kvamme** is a Phd student at the General Practice Research Unit at UiT- the Arctic University of Norway. Her PhD is based upon an anthropological fieldwork on communicative challenges in the understanding and treatment of medically unexplained symptoms in youth. She has a master in anthropology from Visual Cultural Studies, and experience in public service outreach work with youth in Norway. Her main fields of interest are social aspects of health, youth, marginalisation and inclusion processes, and the use of ethnographic and collaborative film.

**Catharina E. A. Wang** is a professor, specialist in clinical psychology, and the head of Clinical Research Group at the Department of Psychology at UiT The Artic University of Norway. Her scientific work includes research activities within the fields of depression, prevention of mental health problems, low-threshold and self-help, and evidence-based and alternative treatment approaches. She has worked with different research methods and designs including quantitative and qualitative methods, experimental designs, clinical trials, projective tests, user surveys, and the development of new healthcare.

**Trond Waage** is associated professor at Visual Cultural Studies in Tromsø, Norway and holds a PhD in Social Anthropology with specialisation in Visual Anthropology. Trond has done research in Northern Norway and Northern Cameroon, where he has explored the themes of youth, urbanisation, ethnicity, gender, religion, and visual anthropology. Trond has worked at the Department of Social Anthropology and been connected to Visual Cultural Studies since 1994. Since 2006 Trond also has teaching experience in Visual Anthropology from University of Bamako, Mali. His interests include inclusive visual methods and local community dialogue.

**Mette B. Risør** is a professor in medical anthropology. She has a longstanding research interest in the negotiation of symptoms and sensations in clinical encounters, linked to illness experiences and healthcare seeking practices. In particular, this has been applied to studies on functional disorders, cancer, and lifestyle diseases with an emphasis on the interface between knowledge production and the crafting of relationality, bodies and subjectivities. Her position at the General Practice Research Unit of UiT creates the basis for an interdisciplinary approach to both her research and teaching.

**How to cite this article:** Kvamme MF, Wang CEA, Waage T, Risør MB. Careful expressions of social aspects: How local professionals in high school settings, municipal services, and general practice communicate care to youth presenting persistent bodily complaints. *Health Soc Care Community*. 2019;00:1–10. https://doi.org/10.1111/hsc.12762

# ‘Fixing my Life’: Young People’s Everyday Efforts towards Recovery from Persistent Bodily Complaints

Abstract: Little is known about the perspectives of young persons suffering from medically unexplained symptoms. This study aims to explore the experiences and strategies of young Norwegians related to incipient and persistent health complaints affecting everyday life functioning. The study is based on field notes, video material and interview transcripts relating to twelve girls and five boys between 14 and 23, encountered in an anthropological multi-sited fieldwork in 2015 and 2016 in a small Norwegian town, through health services and selected schools. A central theme is the emphasis upon social and existential constraints seemingly framed by a social imaginary of youth more than a medical imaginary, and their active engagements to ‘fix’ their lives through what we identify as two main modalities of self-care. Navigating temporal and relational aspects of sociocultural configurations of youth in their social environments, they imagine and enact alternative qualifying positions better adapted to constraints, personal preferences and needs. Our findings may add to understandings of the needs and strategies of young sufferers of medically unexplained symptoms, relevant for health and social care encounters.

Keywords: youth; subjectivity; self-care; ordinary ethics; medically unexplained symptoms; film

## Introduction

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

In the first conversations with Anne, she smiled shyly and answered many questions with a hesitant ‘I don’t know’. Anne was a key interlocutor in the study presented in this paper, participating in interviews and collaborative filmmaking. Our mutual process of getting beyond her many ‘I don´t knows’ over the following year turned out to reflect broader processes of recovery in her life. Anne had grown up in a ‘war zone’ between her now divorced parents and experienced bullying since she started school. Supported by her mother, school nurse and mental health therapist, she tied many of her recurrent colds, infections, headaches, gastrointestinal problems and episodes of fatigue to past and present adverse experiences. She had illness episodes after involvement in parental conflicts, and when confronted with challenging peer situations or oral presentations at school. During interviews and small talk with Anne, she especially emphasised her own everyday efforts to become more certain about herself as a person, to prevent further illness episodes and overcome her present condition. Anne found 'relief' by explicitly expressing her needs to teachers and the school nurse, and speaking up on behalf of other pupils struggling with non-acceptance of their health related limitations and self-presentation. Such efforts seemed to support a new vision of herself as a person that made her help other vulnerable young people:

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

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

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

## Materials and methods

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

We base the analysis in this sub-study on field notes, video material and interview transcripts relating to twelve girls and five boys between 14 and 23. [Table near here] Professionals referred nine young participants. These participants were wholly or partially out of school and work due to their complex health challenges. Eight pupils contacted the first author directly in the schools, one of them guided by his school health nurse. All participants were current or previous clients of school nurses, mental health services and/or social workers, and some had previously been diagnosed with anxiety, PTSD or depression. We applied visual methods (Youth Gaze methodology) to explore otherwise hard to reach aspects of their experience (Pink 2007, MacDougall 2006, Waage 2016), and to engage in ongoing analytical and reflective dialogue with the participants (Waage 2013). We also conducted nineteen in-depth interviews with thirteen of the participants. These were life form interviews (Haavind 2007), involving detailed questions about a recent day in order to let experiences, events, relationships and involvements emerge in relation to their everyday context. We then analysed the interviews and field notes using thematic analysis, applying a constructionist informed inquiry into latent and semantic levels of meaning (Braun and Clarke 2006). The analysis was also informed by anthropological theoretical discussions on youth, subjectivity and everyday forms of agency (Biehl, Good, and Kleinman 2007; Dalsgård et al. 2014; Das 2012; Lambek 2010; Vigh 2006, 2009a, 2009b).

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

## Inspirations from an anthropology of youth

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

Recent qualitative additions to the literature on MUS in youth have emphasized the meaning of a peer relational and cultural context (e.g. Moulin et al 2015). Youth is a flexible and contestable social category (Bucholtz 2002; Cole and Durham 2007). Anthropologists argue that young people are expected to relate to their futures in culturally defined ways (Cole and Durham 2007), and are considered at risk due to their struggles to achieve what is considered ‘good’ transitions (Dalsgård et al. 2008). Yet they also negotiate their possibilities through their challenges (Dalsgård et al. 2014) and may seek imagined futures (Cole and Durham 2007). Imagined future possible selves are ‘grounded in … past experiences and present circumstances’, but may also ‘motivate intentional changes in behaviour and action’ in the present (Hardgrove, Rootham, and McDowell 2015, p.165). Such efforts to adjust one’s temporal experience, or ‘time work’ (Flaherty 2011), may account for both socialisation and self-determination, cultural continuity and change. Vigh (2009) argues that we are all constantly engaged in navigating our social environments, coping with social pressures and considering these pressures in relation to present possibilities and envisioned trajectories. Approaching youth as a moving position (Christiansen, Utas, and Vigh 2006; Vigh 2006), we take into account how young people experiencing MUS are positioned as well as how they try to move within social positioning in their environment. Constraints, pressures and how young people relate to them in everyday life, may be understood as a social imaginary that incorporates the way people 'imagine' (Taylor 2004, 23-26) their social existence, and how they 'fit together with others' (ibid.), a sense of expectations and legitimacy and more or less implicit and/or habitual repertoires of possible ways to act. Through social imaginaries, young people interpret past and present aspects of their social existence, and envision their potential in ways that guide action (Vigh 2006, 2009b). This includes their health related explanatory models and how they navigate social configurations of youth with persistent bodily complaints.

## Subjectivity and ethics in everyday life

To further explore forms of navigation and agency related to young people's experiences of bodily and social constraints with MUS, we draw on recent anthropological conceptualisations of subjectivity and ethics in everyday life (e.g. Biehl, Good, and Kleinman 2007; Das 2012; Lambek 2010). The concept of subjectivity generally directs our attention to 'actors' thoughts, sentiments and embodied sensibilities, and, especially, their sense of self and self-world relations' (Holland and Leander 2004, 127). Recent approaches within anthropology have emphasised the existential complexity of the individual subject (Ortner 2005, 2006), viewing subjectivities as more open-ended, unfinishable entities than predefined identities or subject positions. By attending to subjectivity in ethnographic terms, Biehl, Good, and Kleinman (2007) seek to develop our understanding of how persons are constituted through social experience, while still accounting for how subjects endure experiences reflexively and emotionally.

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

## ‘Fixing my life’

We begin by briefly presenting how our young participants emphasised social and existential constraints as the worst and most important elements to overcome. Like Anne, all stressed complex relations between illness and life-world. Their illness affected their everyday life and future life prospects of who they could become as persons; conversely, certain life experiences seemed to affect their health and how illness was experienced. A central theme, the experience of disordered, disrupted or imbalanced young lives in need of ‘fixing’, emerges in all accounts. This ‘fixing’ required reflexive efforts of self-care, coping with their symptoms and promoting their overall health, in dialogue with their social environments.

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

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

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

> Every day at school is a battle. I can hardly pay attention to the teacher writing on the blackboard. Tests are the worst. It seems like stress makes it worse, and I can

> almost not sit still because of the pain. In a way it has made me an underachiever (Lasse)

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

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

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

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

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

Ultimately, their understanding of their constraints and the practices needed to overcome them relate to everyday tasks and expectations rather than bodily suffering alone. Their hopes and goals seem to be framed by a social imaginary of youth as much if not more than by a medical imaginary. All participants expressed a need to act upon their overall suffering and constraints, seeming in part to embrace ‘repertoires’ of legitimate action (Taylor 2004, 23-26). They thus seem to relate to cultural models that value active anticipatory engagement to repair life in a productive world and suffer successfully (Frank 1997; Hay 2010, 271). Adding to this, we also find traces of everyday reflexivity (Biehl, Good, and Kleinman 2007), cultural critique and production in their practices (Bucholtz 2002).

### *1: Imagining future selves*

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

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

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

Anne had been recruited partly due to her presumed strength in visual rather than verbal communication. However, in our collaborative filmmaking, we struggled for a while to find a topic for her film. Anne’s initial filming assignment showed a silent gaze at other people´s feet. Reflecting on her footage together it became clear how vulnerable Anne felt regarding what others might see and how they might judge a film focusing on herself. However, some of her dawning sensibilities and critical judgments surfaced in editing, as she looked for ‘interestingly different’ images and decided against adding music she used to listen to ‘only because other people liked it’. In subsequent visits to Anne´s home, she shared everyday episodes she had experienced since we last met with increasing trust and critical reflexivity. Through participant observation and ethnographic conversations in their home, it became clear that Anne´s developing interpretations of how she had reached where she was, how she fitted in with others and who she could be as a person were supported by her mother and therapist, using stories from her everyday life. Realising that she was not alone in experiencing illness constraints and external judgements, she began to adopt an alternative sense of competency and agency:

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

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

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

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

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

> I´ve always been interested in constructions, but when it came to deciding upon my future career, I had to consider my back first. Now I´m aiming to become a health secretary. I have always been a caring person. (Julie)

Kine's process may further illustrate how our participants seemed to be engaging in forms of 'timework' (Flaherty 2011), by imagining future 'possible selves'

(Hardgrove, Rootham, and McDowell 2015) that seemed to motivate enactment of forward-oriented new roles for themselves in the present. The first author met Kine, struggling with chronic pain, anxiety and depression, in one of the local high schools. During visits in the school, Kine and several of her co-pupils emphasized their caring class environment. Kine played an active role in communicating classmates' needs and constraints due to the pupils' many health complaints and strong resistance to expectations and judgement on their performance. In an individual interview, she revealed background experiences that motivated her present role:

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

Kine felt let down by her family and by care workers for several years. She struggled emotionally and her legs and stomach started to hurt persistently. At one point, Kine was actually met by a couple of officials who saw her potential, restoring some of her faith in adults and most importantly, in herself:

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

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

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

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

> It’s easy for me to sympathize with how they feel because I had so many negative experiences with previous teachers.

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

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

Taking activist, broker and caring roles provided new hope to overcome past constraints and perhaps rework them into resources for the future. An ongoing formation of what was experienced as legitimate yet viable ‘possible selves’ seemed to motivate all to health promoting everyday life changes and management strategies. In the words of Mattingly (2010), they attempt to envision and enact ´imagined future selves´, mainly by drawing upon positive and negative social experiences as sources of hope and negotiating sociocultural expectations of good lives. This theme of cultivating hope for future adulthood is especially significant as it focuses on alleviating social and existential suffering more than bodily symptoms alone.

### *2: Efforts to ‘be oneself’ with others*

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

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

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

> Normally, I don’t care too much, because there’s a lot I have to say. And then I feel kind of tiresome (Sofie).

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

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

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

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

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

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

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

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

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

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

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

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

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

## Discussion

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

Although levels of suffering varied between participants at school and those out of school and work, every participant’s processes of becoming were in some aspects vulnerable and uncertain. A central theme in their everyday self-care practices was their valuing of and active efforts at ‘fixing’ their lives, i.e. getting their lives ‘in order’ by navigating temporal and relational tensions in their social environments. Firstly, we focused on their evolving navigation in temporal tensions in youth, in transitions understood as ‘problematic’, and showed how they imagined their potential through on-going future-oriented processes of interpretation. These efforts resemble forms of time-work (Flaherty 2011), described in ethnographies on youth facing constraints in other sociocultural contexts (e.g. Dalsberg et al. 2014). They also seem motivated and influenced by the formation of future possible adult selves. This illustrates the potential benefit emphasized by Hargreave, Rootham and McDowell (2015) of young people´s future imagining to motivate intentional action in the present. Our findings underscore however the need for our young participants to navigate ‘pressures’ on them as youth and as ill; in other words social expectations and ideals of the possible selves they ought to aspire to and by what means, by adjusting what a good and healthy path and level of participation may be for them. In these processes, our young participants engage selectively with digital platforms such as YouTube and Facebook chats to support alternative learning opportunities and enact possible selves. The affordances of digital platforms and their role in constituting identity, both constraining and enabling, could have been emphasized even more, in line with Hanckel et al (2019).

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

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

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

## Conclusion

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

## Acknowlegements

We sincerely wish to thank all participants for sharing their time and experience with us. The project fell outside of the jurisdiction of the Regional Committee for Medical and Health Research Ethics (Decision 20xx/xxxx/REC xxxxx), according to the Health Research Law §§ 2 and 9, and the Research Ethics Law § 4. Approval of data protection and quality assurance on information and consent forms was provided by the Norwegian Centre for Research Data (NSD ID xxxxx).

## Disclosure statement

No potential conflict of interest was reported by the authors.

## References

Aamland A, Malterud K, Werner EL. 2014. Patients with persistent medically unexplained physical symptoms: a descriptive study from Norwegian general practice. *BMC Fam Pract*. 15:107. doi:10.1186/1471-2296-15-107

Alonzo, A. 1979. “Everyday Illness Behavior: A Situational Approach to Health Status Deviations.” *Social Science and Medicine*, 13a(4): 397-404.

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

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

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

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

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

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

Das, V. 2012. “Ordinary Ethics”, in *A Companion to Moral Anthropology*, edited by Fassin, D. Vol. 20 of Blackwell Companions to Anthropology. Chichester: Wiley-Blackwell.

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

Eminson, D. M. 2007. “Medically Unexplained Symptoms in Children and Adolescents.” *Clinical Psychology Review,* 27: 855-871. doi:10.1016/j.cpr.2007.07.007

Farmer, A., T. Fowler, and J. Scourfield, et al. 2004. “Prevalence of Chronic Disabling Fatigue in Children and Adolescents.” *British Journal of Psychiatry*, 184: 477-481. doi:10.1192/bjp.184.6.477

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

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

Frank, A. W. 1997. “Illness as Moral Occasion: Restoring Agency to Ill People.” *Health*, 1(2): 131-148. doi:10.1177/136345939700100201

Greco, M. 1993. “Psychosomatic Subjects and the ‘Duty to Be Well’: Personal Agency Within Medical Rationality.” *Economy and Society,* 22 (3): 357-372. doi:10.1080/03085149300000024

Guba, E. G., & Lincoln, Y. S. 1994. Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage Publications.

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

Hanckel, B., S. Vivienne, P. Byron, B. Robards, & B. Churchill. 2019. ‘That’s not necessarily for them’: LGBTIQ+ young people, social media platform affordances and identity curation.” *Media, Culture & Society,* 41(8): 1261–1278. doi:10.1177/0163443719846612

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

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

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

Kirmayer, L. J., D. Groleau, K. J. Looper, and M. D. Dao. 2004. “Explaining Medically Unexplained Symptoms.” *The Canadian Journal of Psychiatry,* 49(10): 663-672. doi:10.1177/070674370404901003

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

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

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

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

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

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

May, C. R., Allison, G., Chapple, A., 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.

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

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

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

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

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

Rosendal, M., Olde Hartman, T., 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* 18:18. doi:10.1186/s12875-017-0592-6

Spradley, J. 1979. The Ethnographic Interview. New York: Holt, Rinehart & Winston.

Taylor, C. 2002. “Modern Social Imaginaries.” *Public Culture*, 14(1 [36]): 91-124. doi:10.1215/08992363-14-1-91

Swanson LM, Hamilton JC, Feldman MD. 2010. Physician-based estimates of medically unexplained symptoms. *Fam Pract.* 27(5):487–93. doi.org/10.1093/fampra/cmq051

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

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

Vigh, H. 2009b. “Wayward Migration: On Imagined Futures and Technological Voids.” *Ethnos*, 74(1): 91-109. https://doi.org/10.1080/00141840902751220

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

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

# 4 Concluding discussion

In this final chapter, I will discuss my main findings in relation to the aims of this thesis, and suggest some possible contributions to the research field of MUS and communication. The findings will be discussed under two main headings, after a brief presentation and discussion of my aims. Under the first heading, I discuss the main findings related to gaps in the literature concerning everyday life experiences and management strategies of young people with persistent symptoms. The thesis shows how the young participants of this project reflexively navigate their social environments and expectations of them, being youths with particular health challenges, and negotiate the meaning of their symptoms. Under the second heading, I discuss the main findings from professionals in schools and health and social care settings and relate them to topical discussions on how to achieve a shared understanding that addresses the concerns of the youths. This produces experience-based strategies to overcome communicative challenges, and achievements of co-construction of meaning for distress and crafting of empowering explanations. Both sections will, from different angles, relate the findings and the issue of MUS in youth to anthropological theoretical discussions on social suffering, subjectivity and youth.

The overall aim of this thesis was to provide knowledge of perspectives, concerns and management strategies of young people with persistent bodily complaints, where initial medical examinations had been unable to fully explain their condition, and to explore cultural and professional logics, perspectives and responses to suffering that affect the development of young subjects and their health-seeking practices. The object of study was “given an initial, baseline conceptual identity”, in this case MUS in youth, that turned out to be “contingent and malleable” as I traced it (cf. Marcus 1995, p. 106). I approached it using multi-sited assemblage ethnographic methodology to explore how it took shape as a certain kind of problem with more or less conceivable solutions (cf. Wahlberg, 2018; Foucault, 1984) in different contextual frames and locations in the community where young people’s persistent symptoms are interpreted and responded to. In order to attend empirically to how the understanding and management of MUS in youth are formed in various everyday and routine health and social care settings, I identified young people experiencing persistent symptoms and professionals involved in interpretation and management of their challenges. I then explored how “configurations of patterned knowledge-practices” (Wahlberg, 2018, 11) were manifested in their daily routines, health- seeking and sense-making practices and communicative care responses.

## 4.1 Reflexive navigation of youth with MUS

The main findings concerning everyday life experiences and management strategies of young people experiencing MUS are covered in papers I and III. In the first paper, titled "'Not a film about my slackness': making sense of medically unexplained illness in youth using visual collaborative methods" (Østbye et al., 2018), we focused on social aspects of illness experience and the potential of collaborative visual filmmaking in youth through an in-depth case study and narrative analysis. We found two main themes, titled *"Derailment"* 1 and 2, based upon "Peter's" own term and title of his film, which illustrate two interpretations of his illness experience.

The first theme, of illness experienced as an illegitimate and existentially frightening derailment from one's assigned path towards adulthood, may illustrate the key role played in the accounts of all the young participants of an "unmaking" (Scarry, 1985, Good 1994) of their lifeworlds, which is most concretely evident in the cases where the person is too ill to participate in school and other social contexts of youth. Building on Scarry's description of how suffering from acute pain shifts our embodied experience with "world-destroying" (1985, p. 29) effects, Good points to how chronic bodily suffering threatens the structure of everyday life experience, "flows out into the social world" and threatens to invade and disrupt a range of activities and tasks (Good 1994, p. 123). We find that the youths in our study experience symptoms that invade their experience of everyday life tasks, threatening at different levels of debilitation their school performance and who they feel they can be as persons with their peers. This finding is in alignment with and expands upon findings pointed to by Moulin et al (2015a) and Parslow (2017) of the particular challenges for young sufferers of MUS to negotiate role-constrictions as youth, constraints to participation and belonging with one's peers and the effect this may have on their developing sense of identity.

The second theme concerns a general configuration of illness experience as a space of opportunity, where the young person negotiates with and redefines the meaning of his or her illness, which influences the solutions and management strategies they envision and enact on a day to day basis. This may illustrate the equally central efforts at "remaking" evident in all accounts, described by Good as efforts to find meaning and "reconstitute" worlds unmade (1994, p. 128). This finding extends Corbin and Strauss' idea of the "work" (1985, 1988) done by chronically ill patients beyond the clinic and refers to the huge efforts of the young people with relatively recent symptoms to manage their symptoms, to care for themselves and to reconstruct a sense of biographical continuity. Other qualitative studies also describe young Norwegians experiencing MUS who engage in extensive meaning-making processes to understand and cope with their illness (e.g. Hareide et al., 2011). Our findings agree with Hareide et al. (2011) in their critical approach to previous questionnaire-based studies that describe young CFS/ME sufferers' explanations and coping strategies as "maladaptive" and/ or "passive" (e.g. Richards et al., 2006) and are in alignment with their interpretations of young people's meaning making and coping strategies related to their MUS as adaptive, flexible and experimental (Hareide et al 2011, p. 2261). Our findings also concur with Corbin and Strauss' point that this kind of work is often invisible from the outside and may escape the attention of the professionals involved (Corbin and Strauss, 1885, 1988). While some studies show that young people experiencing MUS cope by spending time with close friends (e.g. Moulin et al., 2015a), several of the participants in this study manage in everyday life by themselves with little or no support. The importance of taking into account the aspirations, interests and ongoing projects of young people presenting persistent symptoms in clinical encounters in order to tune into these concerns seems vital to achieve a shared understanding with them and to support their ongoing projects aimed at coping beyond the clinic.

In the third paper, titled "'Fixing my Life': Young People's Everyday Efforts towards Recovery from Persistent Bodily Complaints" (Kvamme et al., forthcoming), we explored the everyday strategies of young people with persistent and medically unexplained bodily complaints. Specifically, we found details on constraints they experience and how they countered them, what they hoped to achieve and what they considered 'good' in relation to others in this process. Through anthropological conceptualizations and approaches to youth and subjectivity, we were able to capture in our findings how the young people "navigate" their social environments through, by and despite their bodily constraints while mediated by aspects of framing, norms and morality (Vigh, 2009). At the same time they endure their experiences reflexively and emotionally (Biehl et al., 2007). The title illustrates an overall emphasis and key finding across the material (compare with above), that of actively remaking, or *"fixing"*, social and existential aspects and consequences of their illness more than limiting their illness experience to a bodily or somatic explanation. This latter point, that there is little interest in and talk centered around body and illness in a medical sense is a common theme across the material.

Parallel to this and in contrast to the findings by Moulin et al. that young people seek legitimating diagnoses (2015a), our findings show that the youths have an apparent lack of interest in achieving a medical label and medical assessments that do not seem to address their main concerns. Following Good (1994) and Kleinman, Das and Good (1997), we instead find that their bodily suffering is mediated and shaped as a social experience by standardised transitional paths, or *"rails"* to use Peter's metaphor, cultural representations, and moral expectations of them as ill and as youth. However, rather than working hard for "permission to be ill" like Nettleton's adult patients experiencing unnamed MUS (2006), the young participants in this study worked hard to " reconstitute" and maintain their relation to a social order (Good, 1994, 128), and to qualify through new paths despite their constraints. Thus, rather than being oriented towards a medical imaginary and concerned about achieving a legitimate sick role, their efforts seem equally or more oriented towards a social imaginary of youth. With the words of Ware (1999, p. 322), their distress intersects with cultural expectations of them as youth to activate "microsocial processes of marginalization". In the two modalities of self-care that we find, we trace efforts to counter experiences of role constriction and an orientation towards "fitting in" with cultural expectations of them as ill and as young, implying personal responsibility to participate in qualifying ways, and suffer successfully (Hay, 2010; Frank, 1997). The participants from the schools for example contained their symptoms as much as possible. However, many symptoms were not possible to contain, i.e. manage on the side and not letting intrude activities and participation. We also found that the youths demonstrated elements of cultural "critique" and "production" (Bucholtz, 2002, 535), in their efforts to negotiate and establish new ways of life that seemed better adapted to their challenges and needs, for example by changing school paths and defining new standards of "good" relationships and lives. Thus, their socially constituted experience of life with illness over time, in other words the "social course" of their illness (Ware, 1999), also seemed oriented towards a broad notion of "healing", to cope and move on to "heal or re-perform" (Risør, 2010, p. 141).

These findings are relevant to the field of MUS and communication for the insights they bring on experiences, concerns and additional challenges facing young patients compared to adults. Furthermore, they bring awareness and knowledge about youths' management strategies, and the amount of flexible, innovative and sometimes hidden work they engage in beyond the clinic, meriting professional attention for the development of person-centred care. Finally, these findings and the case of youth may also shed light upon the phenomenon of MUS more generally as situationally constituted through a process of negotiation with contributions by several actors, including the ill person, in flexibly shaping and giving meaning to MUS. MUS has been shown throughout this study to be a fluid phenomenon, often intangible, seemingly comprehensible but then again interpreted in very different ways by different actors – despite the attempt by medicine to make it a stable concept.

## 4.2 Gender dimensions

Gender is often discussed in relation to MUS and several issues of that discussion are relevant to our results, for example the specific gender of our participants in the light of studies on prevalence and distribution of symptoms, and the more social scientific approach where doing gender and enacting gender under specific social and cultural conditions come to the fore. Firstly, a higher number of girls than boys were recruited to our research project (COCHA). 11 of our participants were girls. 7 were boys; one of which was born with a female body and in the process of making sense of his transgender experience. Numerous research reports in Norway and internationally have found a significantly higher prevalence of MUS for women than for men (Leiknes et al 2007, Barsky, Peekna and Borus 2001, Creed, Henningsen and Fink 2011, van Eck van der Sluijs et al 2018, Keightley et al 2018), and of self-reported psychosomatic symptoms among young girls (e.g. Murberg and Bru 2004, Torsheim and Wold 2001, Bakken 2018). Studies have found that female patients more often than male patients agree to suggested psychosocial explanations for their bodily symptoms (‚Johansson,et al 1999, Soderlund and Malterud 2005).These numbers also correspond with an international consensus in the medical literature that women report more symptoms overall (psychological, explained as well as unexplained) (Creed, Henningsen and Fink 2011, 132-33, e.g. Kjeldsberg et al 2013), and are more frequent users of health care services (e.g. Verbrugge 1985). However, both the prevalence numbers on MUS and the higher report on symptoms for women than for men plus use of health services are notably connected to studies that draw their conclusions from patient populations, i.e. those in contact with the health system. In the general population, women are found to have more symptoms of somatization than men (Hiller et al 2006), and this is a common finding, however the difference is lower in the population than in clinical settings. It remains to be discussed what are the social and cultural determinants for this difference, both for clinical and non-clinical contexts and to explore the intersection of gender and health in clinical care and research. Parts of the literature have sought to understand these differences with departure in biological differences and/ or risk factors affecting women and girls disproportionally (e.g. Fillingim et al 2009, Johnson 2008). Fillingim et al 2009 for example discuss the likelihood that reproductive cycles affect perceptual sensitivity to account for a higher prevalence of medically unexplained pain among women. Others point to the role of adverse experiences in relation to MUS, for example sexual abuse, where girls and women are reportedly more exposed (Johnson 2008). While our research design does not provide an assessment of the distribution of MUS in the community where the fieldwork was performed, all our young participants with MUS, regardless of sex/gender, presented past or long-term acerbating challenges related to experiences of stress and/ or adverse psychosocial experiences. In the same line, prevalence rates of medically unexplained symptoms in the research literature does not necessarily reflect actual distribution in morbidity in general (Malterud 1993). Women's health complaints are more often classified by health professionals as psychosocial or unexplained (Claréus and Renström 2019, Ruiz and Verbrygge 1997, Brage and Tellnes 1992, Kroenke and Spitzer 1998, Werner 2001. Health professionals are furthermore found to suggest fewer somatic investigations and more self-care and lifestyle changes for female patients compared with male patients (Osika, Evengård and Nyberg 2008, Fillingim et al 2009), even in experimental studies based on presentation of otherwise anonymous, identical case stories (Hamberg et al 2002, Hamberg, Risberg and Johansson 2004). A more comprehensive understanding of how such statistical differences make a difference in young people's lives is needed (Schille-Rognmo et al., 2017; Solberg, 2018). In this study, we have not been intensively concerned with these aspects of gender. However, we have continuously noted, reflected and taken into account the observations we made on gender. This counts for the choice of a female dominated line in high school, the symptoms each participant experienced, the way the participants interacted and enacted themselves as gendered human beings and especially the attention to how they each in their spaces of possible actions were gendered and were 'doing gender'. This resulted in a specific part of the analysis of Peter in paper I but is also in the background of paper III.

Most scholars recognize the significance of deep rooted sociocultural perceptions about gender on the understanding, interpretation and management of symptoms and conditions as MUS (Hausteiner-Wiehle et al 2011), including medical modes of understanding health and illness (e.g. Hamberg 2008, Lian and Bondevik 2013, 2015, Malterud 2000). Gender describes variation between young girls and boys that is "attributable to society and culture" and ongoing social constructions of femininity and masculinity (Hamberg 2008, 237, Korsvik, Rogg and Rustad 2018). Lian and Bondevik (2015) for example illustrate how medically unexplained exhaustion or debilitating tiredness has been socially constructed and redefined over time according to culturally available repertoires of interpretation. -From being understood as a somatic disease caused by the strains of modernity and connoted with men into being a condition connoted with women and originating in the individual patient's psyche (ibid.). Established understandings based on previous research can also lead to stereotypical expectations, blindness to variation within gender categories and discriminatory practices, or "knowledge-mediated gender bias" (Hamberg K, Risberg G, Johansson 2004, p. 151). According to Malterud (2000, p. 605), gendered expectations and cultural stereotypes have contributed as a discrediting ”ruling force” in rhetorical spaces of primary care health encounters, especially for female patients presenting with medically unexplained illness. Inspired by feminist theory, Malterud defines rhetorical spaces as ”social locations whose tacit rules structure and limit the kinds of utterances that can be voiced with a reasonable expectation of being heard, understood and taken seriously" (ibid., cf. Code 1995, see Werner 2005). In line with this, Werner and Malterud (2003) found that the Norwegian women with medically unexplained chronic pain conditions participating in their study seemed to share specific competencies regarding how to seek health care, in order to appear credible and maintain personal dignity in the encounter. These competencies involved ways of performing, or ”doing”, gender and pain according to implicit rules to avoid stereotype classifications of them as women with MUS (cf. West and Zimmerman 1987). For example by balancing their clothing and bodily expression as being ill enough to merit care but composed enough to avoid being judged as mentally unstable. Gendered expectations and their interplay with illness may also be explored in everyday life and storytelling settings (e.g. Sallinen, Mengshoel and Solbrekke (2019). Through collecting life-stories from Norwegian and Finnish young men with the female-connoted medically unexplained condition fibromyalgia, Sallinen, Mengshoel and Solbrekke for example found that the men were all actively re-constructing their male identities. -By narrative comparison with expectations, with others, and with life before symptoms to form a new, "possible masculinity" acceptable for themselves in their present situation as well as for their social community (ibid.). In this project,. I have followed my young participants in settings outside of health encounters, but also find in these settings that they work hard to maintain credibility and dignity in their management of their MUS and their own paths to adult man- or womanhood. The remaking processes of our young participants involve efforts to redefine possible and acceptable femininities and masculinities in their situations. In our dialogue with Peter, for example, we find that he avoids being seen in clothes that make him look "slack".

Instead he dreams about being able to wear an intellectual coat that matches his new interest and that may begin to redefine him in a new masculine role where being sporty and physically strong is less essential to succeed.

Another dimension of gender and medically unexplained symptoms which we came across several times is the phenomenon of ‘flink pike’ /’flink pike syndromet’ (the good girl syndrome). This concept, related to mainly ambitious high school girls, popped up when talking to our research participants, reading the literature, in newspaper articles, social media and in common public debates. In the MUS context, the concept is especially used when talking about young girls having a diagnosis of chronic fatigue syndrome (CFS/ME), referring to their personality as characterized by being ‘high-achievers’ and prone to perfectionism (Morris et al 2013). But it is more and more applied to (and by) young girls in general who feel insecure, anxious, suffer from persistent symptoms and/or psychological distress (Madsen 2018), and refer to the notion as a kind of ‘idiom of distress’ (Kaiser & Weaver 2019) . This is a tendency, we also saw in our studies. To us, and to other scholars, ‘flink pike syndrom’ is an example of a gendered expression that seems to transform a positive capacity into illness, and produce a diagnosis-like explanatory framework. Madsen (2018) has traced the development of the concept through social media and news media into scientific literature, e.g. psychology, showing its overwhelming impact. The Norwegian state funded database, Youth Data, may be one type of knowledge production that influences self-reporting practices, self- perceptions and enactment of gendered youth roles, using medicalizing, essentializing language (Hydle 2019, Schille-Rognmo et al., 2017; Solberg, 2018). Discussing ‘flink pike syndromet’ is not intended to deny the sufferings of the young girls in question but to nuance and critically approach the social representations that linger in everyday life, that may sneak into scientific vocabulary, and have an impact on how young people think about themselves, perform themselves and perhaps apply ‘illness templates’ to their lives. Such movements and internalizations are gendered and become apparently even more gendered in the context of a society and culture where sensitivity to bodily changes seems to be prominent, and help-seeking seems to be cast in psychological terms or self-help, constituting the individual as responsible for her/his own life coping. Madsen refers to the tendency towards young women using e.g. therapeutic help such as visiting a psychologist much more than young men (Madsen 2018). To explain this, he suggests with reference to the British sociologist Rosalind Gill (ibid., 56) that maybe women feel the demands of neoliberalism more than men do, because women have become the model for an archetypical makeover of the self. This point is interesting because it seeks an explanation beyond the usual behavior distinctions, e.g. that women seek health-care more than men do. The young participants in study III, most of whom are girls, emphasize their own efforts of self-care, that includes intentional direction of one's "cares" and positive thinking to be *"good"*, adapt to narrow standards of normalcy in youth, and *"fix"* problematic aspects of their lives. Several of them experience failure to live up to this imaginary of youth, being cast as lazy, a dropout or otherwise problematic instead, but still envision ambitious career dreams for themselves. For Kine, being *"good"* in school as a young girl was a way, perhaps her only way, to repair experiences of being a *"problem child"* though childhood. But they also engage in acts of social critique and resistance, for example Anne, who stands up in a school environment seemingly dominated by boys, and seek *alternative* goods, or new normals, more adapted to their needs, ethical judgements and capacities. Ultimately, the phenomenon of 'flink pike' is vivid and used by afflicted young girls themselves and several narratives portray the different challenges they experience, in their relationships and on their own, suffering and being distressed. Social kinds (Hacking 1995) are products of many different types of knowledge and it is important to discuss, how certain concepts develop, circulate and become 'objectified' as social representations of gender.

## 4.3 Professional tinkering to attend to the problem of MUS in youth

One study pays specific attention to the perspectives of care providers. The main findings from professionals in schools and health and social care settings in the fieldwork are covered in Paper II. These findings confirm a widespread and holistic, or biopsychosocial understanding of MUS in youth in the Norwegian context of care, across a very varied range of experienced professionals (e.g. Gjems and Helgeland 2018, Helgeland and Førde 2017, Kirkengen 2005, 2018, Shonkoff et al 2013). They also demonstrate experience based strategies to overcome communicative barriers and dilemmas tied to cultural patterns of recognition, naming, categorization and explanation in the institutional context (c.f.. Helgeland and Førde 2017). The analysis resulted in a conceptualization of two main modalities of "careful expression" (Kvamme et al., 2019) whereby experienced professionals progressively, pragmatically and carefully experiment with language to recognize social aspects of suffering within a Norwegian context of care and/or a shared understanding with the young person. An initial modality involved “pragmatic and cautious adaptation to framing” (ibid., p. 2), framing here referring to institutional logics and language influenced by biomedical, scientific reductionism. A second modality involved “person-centred dialogue to provide *new* frames and seek to express empowering explanations” (ibid.). In this second modality of careful expression, the professionals experience an ability to express an understanding of MUS more compatible with the real life complexity of patient distress.

On the basis of our findings from how these experienced professionals engage in careful expression we may say that the idea of the insensitive professional who does not grasp the “cues” (Salmon et al., 2004) and emotional needs of the patient presenting persistent bodily health complaints (cf. Greco, 2012) is to some extent contradicted. We demonstrate the care involved in both modalities of careful expression, and how both seem oriented towards coping and caring rather than curing (Stone, 2014). Our participant’s long professional experience and experience based ways of knowing, may have supported communicative solutions in a “reciprocal relationship”, in contrast to “top-down scientific and evidence based knowledge” (Rasmussen and Rø 2018, 7)

The first modality of careful expression relies on and responds to contextual demands for the young person´s illness to be *“documented”* according to terms that indicate biomedical “facts”, to enable them to have “everything in order” (Kvamme et al 2019, p. 5). This seemed framed by elements of the apparatus or dispositif (ibid.) such as institutional logics, disciplining regulations and medical rationalities and explanations. The legitimacy of their absence from school or work as productive citizens, and/ or *“rights”* to individually adapted educational pathways to adulthood would thus be based conceptually on a notion of “evidence” or “truth” rather than on the experience of suffering that is shared with and empathically experienced by the professionals involved, and responded to by professional “tinkering” (Mol, 2008) with values that depend on the context.

The most radical form of reframing seems to be facilitated through a form of dialogue that establishes new, relational frames for communication. When the professionals engaged in the second modality of careful expression, they describe seeking to abandon the language inspired by medical rationality and focus on experience-near stories from the young person’s life; they pragmatically craft new expressions within new frames of trusting dialogue where they attempt to *“walk in concert with”* the young person and achieve a shared understanding (Kvamme et al., 2019, p. 6). This involves for example individual adaptation that builds upon relationships of trust and intimate knowledge of each student’s capacities and needs in the schools, often in cases where documentation and *”preferential rights”* to care is lacking. We also find that this modality seems aimed towards uses of professional rhetoric´s to counteract contextual discourses of vulnerability and victimhood in Norwegian youth and to prepare the young person for acts of self-care as an empowered subject. Salmon’s call for a “curriculum of explanation” (2007, p. 251) and Kleinman’s call for a heightened awareness of the role of care in education and research (Kleinman 2012) are interesting in relation to our study. Following from a logic of choice, the cultivation of self-management may entail a form of responsibilisation and disciplining of individual patients and/or citizens (Mol 2008), complicating our own ideals as researchers as well, of collaboration, shared understanding, dialogic approaches and empowerment (see Andersen & Pors 2016). Our findings add however also to a logic of care (Mol 2008, Moser and Pols 2010, p. 14), in terms of “persistent tinkering” by various professionals in the field, to attune to unhelpful life conditions that complicate ideals of liberation and self-management. Following from the logics and rationales of the professionals, the element of care, and establishemt of care teams with the young person is central if experience-based approaches to achieving empowering explanation is going to succeed. Our findings may furthermore illustrate potential applicability and transferability of a curriculum of innovative explanation to a broad range of professional settings within and beyond primary care.

## 4.4 Reflexive reframing of MUS

This thesis has approached the concept of MUS as a heuristic and sensitizing lens (Fangen 2011) and as a form of problematization (Foucault 1984). The phenomenon draws attention to “a social situation” (Kirmayer 2000), consisting of complex sociocultural relationships in which medical frameworks play a role and the meaning of distress is subject to interpretation, contestation and negotiation. The thesis contributes to the field of MUS and communication with insights of how MUS is a malleable “problem” and phenomenon, subject to interpretation in everyday life and primary care settings, through processes of reflexive negotiation of meaning that seem expressed and constituted by the “daily grind” (Wahlberg 2018, p. 13, 15) of responses in all sites. It demonstrates the importance of paying attention to concerns and everyday strategies of meaning making.

It brings forward studies on primary care professionals who are seldom included in studies on clinical encounters of MUS and adds an experience-based approach that experienced professionals describe as effective for overcoming communicative dilemmas with young patients or service users in a broad range of school, primary health and social care settings, acknowledging the role of care. Our findings also suggest however, the need for additional reframing on higher levels of organization, to address social aspects of suffering beyond the level of the individual young person and health encounter.

Our findings adds to the literature and align with existing studies on the particular challenges facing young people experiencing MUS, to belong and participate in a context of youth. They demonstrate the importance of their own everyday life projects and efforts at meaning making that take place beyond the clinic, easily escaping the attention of professionals involved in their care. We also show that their efforts seem as much or more oriented towards an imaginary of youth as towards a medical imaginary.The thesis also contributes with insights to the field of youth research in general, pulling forward how young people experience illness in situated settings, how constraints and potentials of future qualifying positions in adulthood relate to their practices, how navigation of their social environments are mediated by expectations to act, stay well and participate in a context of youth as well as how subjectivities characterized by experiments of ‘becoming’ are inherent to this process. Our uses of visual methods and dialogical and collaborative approaches provide an example relevant to methodological development and theoretical discussion on how to overcome communicative barriers and achieve a shared understanding with young people in research and professional roles. Finally, the thesis contributes to the field of medical anthropology with insights on everyday illness experience in an urban context of youth, situational explanation not oriented towards the medical, and the potential for subjectivity as a theoretical frame to open up for ordinary ethics and the meaning of intersubjective relationships.

# References

Aamland, A. A., Malterud, K. M., & Werner, E. L. W. (2014). Patients with persistent medically unexplained physical symptoms: A descriptive study from Norwegian general practice. *BMC Family Practice, 15*(1), 107. http://hdl.handle.net/1956/8005

Aamland, A., Fosse, A., Ree, E., Abildsnes, E., & Malterud, K. (2017). Helpful strategies for GPs seeing patients with medically unexplained physical symptoms: A focus group study.*British Journal of General Practice*, *67*(661), e572-e579. https://doi.org/10.3399/ bjgp17X691697

Agar, M. (2006). An ethnography by any other name. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *7*(4), 1-24. http://nbn-resolving.de/urn:nbn:de:0114-fqs0604367

Aiarzaguena, J. M., Gaminde, I., Grandes, G., Salazar, A., Alonso, I., & Sanchez, A. (2009). Somatisation in primary care: Experiences of primary care physicians involved in a training program and in a randomised controlled trial. *BMC Family Practice, 10*, 73.

American Anthropological Association. (1998). *Code of Ethics.* https://s3.amazonaws.com/rdcms- aaa/files/production/public/ FileDownloads/pdfs/issues/policy-advocacy/upload/ethicscode.pdf

Amit, V. (2000). Introduction: constructing the field. In V. Amit (Ed.), *Constructing the field: Ethnographic fieldwork in the contemporary world* (pp. 1-18). New York, NY: Routledge.

Amit-Talai, V., & Wulff, H. (1995). *Youth cultures: A cross-cultural perspective*. London, UK: Routledge.

Anastasides, N., Chiusano, C., Gonzalez, C., Graff, F., Litke, D. R., McDonald, E., . . . McAndrew, L. M. (2019). Helpful ways providers can communicate about persistent medically unexplained physical symptoms. *BMC Family Practice, 20*(1), 13.

Andenæs, A. (2012). From 'placement' to 'a child on the move': Methodological strategies to give children a more central position in Child Welfare Service. *Qualitative Social Work, 11*, 486-501. doi: 10.1177/1473325011408174

Andersen, J., Tjørnhøj-Thomsen, T., Reventlow, S., & Davidsen, A. (2019). Initiating change: Negotiations of subjectivity in a Danish activation programme for young adults with psychosocial problems and common mental disorders. *Culture, Medicine* *and Psychiatry,* 2019, April 6 [Epub ahead of print]. doi:10.1007/s11013-019-09630-z.

Andersen, Julie Høgsgaard (2019): Questioning care. Anthropological perspectives on the care provided to young adults with psychosocial problems and common mental disorders. PhD thesis, Copenhagen: University of Copenhagen

Andersen, N., & Pors, J. (2016). *Public management in transition*. Policy Press.

Aronowitz, R. A. (2001). When do symptoms become a disease? *Annals of Internal Medicine, 134*(9), 803-808.

Aronowitz, R. A. (2008). Framing disease: An underappreciated mechanism for the social patterning of health. *Social Science & Medicine, 67*(1), 1-9.

Atkinson, P., Atkinson, P., Silverman, D., Becker, H., Geer, B., Hughes, E. C.,... & Voysey, M. (2003). Revisiting the relationship between participant observation and interviewing. In J.A. Holstein & J. F. Gubrium (Eds.), *Inside interviewing* (pp. 414-428). Thousand Oaks, CA: SAGE Publications. doi:10.4135/9781412984492

Austin, J. L., Sbisà, M., & Urmson, J. O. (1975). *How to do things with words* (2nd ed.). Cambridge, MA: Harvard University Press.

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

Bakken, A. (2018). *Ungdata 2018: Nasjonale resultater*. NOVA Rapport 8/18. Oslo: NOVA.

Bakken, I. J., Wensaas, K.-A., Furu, K., Grøneng, G. M., Stoltenberg, C., Øverland, S., & Håberg, S. E. (2017). General practice consultations and use of prescription drugs after changes to school absence policy. *Tidsskriftet for den norske legeforening, 137*(16). doi: 10.4045/tidsskr.17.0427

Barbour, R. S., & Kitzinger, J. (1999). Developing focus group research: Politics, theory and practice. London, UK: Sage.

Barrett, M. (2004). Paths to adulthood: Freedom, belonging, and temporalities in Mbunda biographies from Western Zambia. Uppsala, Sweden: Uppsala Studies in Cultural Anthropology.

Barsky, A. J., Orav, E. J., & Bates, D. W. (2005). Somatization increases medical utilization and costs independent of psychiatric and medical comorbidity. *Archives of General Psychiatry, 62,* 903-910.

Barsky AJ, Peekna HM, Borus JF. (2001). Somatic symptom reporting in women and men. Journal of General Internal Medicine, 16, 266–75. FRA CREED

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

Bell, S. E. (2000). Experiencing illness in/and narrative. In C. E. Bird, P. Conrad, & A. M. Fremons (Eds.), *Handbook of Medical Sociology* (5th ed.) (pp. 184-199). Upper Saddle River,  NJ: Prentice Hall.

Bengtson, M. (2007). Ungdommens prosjekt. In H. Haavind & H. Øvereide (Eds.), *Barn og unge i psykoterapi. Samspill og utvikling* (pp. 185-203). Oslo: Gyldendal Norsk Forlag AS.

Biehl, J., Good, B., & Kleinman, A. (Eds.). (2007). *Subjectivity: Ethnographic investigations.* Berkeley, CA: University of California Press.

Biehl, J., & Moran-Thomas, A. (2009). Symptom: Subjectivities, social ills, technologies. *Annual Review of Anthropology, 38*(1), 267-288.

Binder, P. E., Holgersen, H., & Nielsen, G. H. (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.

Bloor, M. (2001). *Focus groups in social research* (Introducing qualitative methods). London, UK: Sage.

Borrell-Carrió F, Suchman AL, Epstein RM. The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. Ann Fam Med 2004; 2: 576 - 82. [PubMed][CrossRef]

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

Bourdieu, P. (1990). *The logic of practice* (R. Nice, Trans.). Stanford, CA: Stanford University Press.

Bowker, Geoffrey C. and Susan Leigh Star, (2000). Sorting Things Out: Classification and Its Consequences, Cambridge, MA: MIT Press.

Brage, S., & Tellnes, G. (1992). ICPC i allmennpraksis. Tidsskrift for Norsk Lægeforeningen,112, 2656-2659.

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

Buchbinder, M. H. (2010). *Children's pain and the ethics of care.* Los Angeles, CA: University of California Press.

Buchbinder, M. (2015). *All in your head: Making sense of pediatric pain.* Berkeley, CA: University of California Press.Bucholtz, M. (2002). Youth and cultural practice.

*Annual Review of Anthropology, 31*(1), 525-552. doi:10.1146/annurev.anthro.31.040402.085443

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.

Bury, M. (2016). Chronic illness, self-management and the rhetoric of empowerment. In G. Scambler (Ed.), *New directions in the sociology of chronic and disabling conditions: Assaults on the lifeworld* (pp. 161-179). London, UK: Palgrave Macmillan.

Butler, C., Evans, M., Greaves, D., & Simpson, S. (2004). Medically un-explained symptoms: The biopsychosocial model found wanting. *Journal of the Royal Society of Medicine, 97,* 219- 222. https://doi. org/10.1177/014107680409700503

Canavera, K., Allen, J., & Johnson, L.-M. (2018). The need for improved access to mental health services for youth with medically unexplained symptoms. *American Journal of Bioethics, 18*(5), 29-31.

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

Carter, Stacy M & Little, Miles: Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies and Methods in Qualitative Research Qualitative Health Research, vol 17(10) 2007 1316-1328

Castoriadis, C. (1997/1987) The imaginary institution of society. Cambridge, UK: Polity Press.

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). Oxford, UK: Berghahn.

Chenhall, R., Davison, B., Fitz, J., Pearse, T., & Senior, K. (2013). Engaging youth in sexual health research: Refining a 'youth friendly' method in the Northern Territory, Australia.
*Visual Anthropology Review, 29*(2), 123-132.

Christiansen, C., Utas, M., & Vigh, H. (Eds.). (2006). *Navigating youth, generating adulthood: Social becoming in an African context.* Uppsala, Sweden: Nordiska Afrikainstitutet.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5*, 168-197.

Claréus, B., & Renström, E. A. (2019). Physicians' gender bias in the diagnostic assessment of medically unexplained symptoms and its effect on patient-physician relations. Scandinavian journal of psychology, 60(4), 338–347. doi:10.1111/sjop.12545

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology, 12,* 297-298. doi:10.1080/17439760.(2016).1262613

Clifford, J. (1983). On ethnographic authority. *Representations, 1*(2), 118-145.

Clifford, J., & Marcus, G. E. (Eds.) (1986). *Writing culture: The poetics and politics of ethnography*. Berkeley, CA: University of California Press.

Coe CL, Laudenslager ML. Psychosocial influences on immunity, including effects on immune maturation and senescence. Brain Behav Immun. 2007;21(8):1000-1008.

Code, Lorraine (1999). Rhetorical Spaces: Essays on Gendered Locations. _Mind_ 108 (429):157-159

Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: complementary research strategies.* Thousand Oaks, CA: Sage.

Cole, J., & Durham, D. (Eds.). (2007). *Generations and globalization: Youth, age, and family in the new world economy*. Bloomington, IN: Indiana University Press.

Cole, J., & Durham, D. (Eds.). (2008). *Figuring the future: Globalization and temporalities of children and youth*. Santa Fe, NM: SAR Press.

Corbin, J., & Strauss, A. L. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology, 8*, 224-247.

Corbin, J., & Strauss, A. L. (1988). *Unending work and care: Managing chronic illness at home.* San Francisco, CA: Jossey Bass.

Cox, S., Drew, S., Guillemin, M., Howell, C., Warr, D., & Waycott, J. (2014). *Guidelines for ethical visual research methods.* Melbourne, Australia: The University of Melbourne. http://vrc.org.au/guidelines-for-ethical-visual-research-methods

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

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*, 5-8.

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

Csordas, T. J. (1990). Embodiment as a paradigm for anthropology. *Ethos, 18*(1), 5-47.

Csordas, T. J. (Ed.). (1994) *Embodiment and experience: The existential ground of culture and self (Cambridge studies in medical anthropology)*. Cambridge, UK: Cambridge 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, Denmark.

Dalsgård, A. L. (2014). Standing apart: On time, affect, and discernment in Nordeste, Brazil. In A. L. Dalsgård, M. D. Frederiksen, S. Højlund, & L. Meinert (Eds.), *Ethnographies of youth and temporality: Time objectified* (pp. 97-116). Philadelphia, PA: Temple University Press.

Dalsgård, A. L., Frederiksen, M. D., Højlund, S., & Meinert, L. (2014). *Ethnographies of youth and temporality: Time objectified*. Philadelphia, PA: Temple University Press.

Dalsgård, A. L., Franch, M., & Scott, R. P. (2008). Dominant ideas, uncertain lives: The meaning of youth in Recife. In K. Hansen, A. L. Dalsgård, & K. V. Gough (Eds.), *Youth and the city in the global south* (pp. 49-73). Bloomington, IN: Indiana University Press.

Dalsgaard, A. L., & Frederiksen, M. D. (2013). Out of conclusion: On recurrence and open-endedness in life and analysis. *Social Analysis, 57*(1), 50-63.

Das, V. (1997). Language and body: Transactions in the construction of pain. In A. Kleinman, V. Das, & M. Lock (Eds.), *Social suffering* (pp. 67-91). Berkeley, CA: University of California Press.

Das, V. (2007). *Life and words: Violence and the descent into the ordinary.* Berkeley, CA: University of California Press.

Das, V. (2012). Ordinary ethics. In D. Fassin (Ed.). *A companion to moral anthropology* (pp. 133-149). Vol. 20 of Blackwell companions to anthropology. Chichester, UK: Wiley-Blackwell.

Das, V., & Das, R. K. (2007). How the body speaks: Illness and the lifeworld among the urban poor. In J. Biehl, B. Good, & A. Kleinman (Eds.), *Subjectivity: Ethnographic investigations* (pp. 66-97). Berkeley, CA: University of California Press.

Das, V., & Kleinman, A. (2001). Introduction. In V. Das, A. Kleinman, M. Lock, M. Ramphele, & P. Reynolds (Eds.). *Remaking a world: Violence, social suffering, and recovery* (pp. 1-30). Berkeley, CA: University of California Press.

Davidson, L., & Chan, K. K. S. (2014). Common factors: Evidence-based practice and recovery. *Psychiatric Services, 65*(5), 675-677.

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

De Ridder, K. A., Pape, K., Johnsen, R., Holmen, T. L., Westin, S., & Bjørngaard, J. H. (2013). Adolescent health and high school dropout: A prospective cohort study of 9000 Norwegian adolescents (The Young-HUNT). *PLoS One, 8*(9), e74954.

Desjarlais, R., & Throop, J. (2011). Phenomenological approaches in anthropology. *Annual Review of Anthropology, 40*, 87-102.

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

Durham, D. (2000). Youth and the social imagination in Africa: Introduction to Parts 1 and 2. *Anthropological Quarterly 73*(3), 113-120.

Durham, D. (2004). Disappearing youth: Youth as a social shifter in Botswana. *American Ethnologist, 31*(4), 589-605.

Egedius, T. (2014) Hvorfor er kvinner mer borte fra jobben enn menn? Aftenposten. Retrieved from http://www.aftenposten.no/amagasinet/Hvorfor-er kvinner-mer-borte-fra- jobben-enn-menn-7725977.html

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes. Chicago guides to writing, editing, and publishing.* Chicago, IL: University of Chicago Press.

Eminson, D. (2007). Medically unexplained symptoms in children and adolescents. *Clinical Psychology Review, 27*(7), 855-871.

Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196,* 129-136.

Eriksen, I. M., Sletten, M. A., Bakken, A., & von Soest, T. (2017). *Stress og press blant ungdom: Erfaringer, årsaker og utbredelse av psykiske helseplager*. NOVA Rapport 6/17. Oslo: NOVA.

Eriksen, T., Kerry, R., Mumford, S., Lie, S., & Anjum, R. (2013). At the borders of medical reasoning: Aetiological and ontological challenges of medically unexplained symptoms. *Philosophy, Ethics, and Humanities in Medicine, 8*(1), 11.

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

Fangen, K. (2010). *Deltagende observasjon* (2nd ed.). Bergen: Fagbokforlaget 2010.

Farmer, A., Fowler, T., Scourfield, J., & Thapar, A. (2004). Prevalence of chronic disabling fatigue in children and adolescents. *British Journal of Psychiatry, 184*, 477-481. doi:10.1192/bjp.184.6.477

Feld , Steven ( 2003) Introduction in: Feld , Steven (ed) Ciné-Ethnography, Jean Rouch . Minneapolis and London : University of Minnesota Press .

Fillingim RB, King CD, Ribeiro-Dasilva MC, Rahim-Williams B, Riley JL 3rd. Sex, gender and pain: a review of recent clinical and experimental findings. Journal of Pain 2009; 10: 447–85.

Fink, P. (1992). Surgery and medical treatment in persistent somatizing patients. *Journal of Psychosomatic Research, 36*(5), 439-447.

Fink, P., & Rosendal, M. (Eds.). (2015). *Functional disorders and medically unexplained symptoms: Assessment and treatment*. Aarhus, Denmark: Aarhus University Press.

Fink, P., Rosendal, M., & Olesen, F. (2005). Classification of somatisation and functional somatic symptoms in primary care. *Australian and New Zealand Journal of Psychiatry, 39*, 772-781.

Fisher, M. J. (2007). Epilogue. In J. Biehl, B. Good, & A. Kleinman (Eds.), *Subjectivity: Ethnographic investigations* (pp. 423-447). Berkeley, CA: University of California Press.

Flaherty, M. (2011). *The textures of time: Agency and temporal experience.* Philadelphia, PA: Temple University Press.

Flores, C. Y. (2007). Sharing anthropology: collaborative video experiences among maya film-makers in post-war Guatemala. In S. Pink (Ed.), *Visual Interventions. Applied visual anthropology* (pp. 209-224). New York, NY: Berghahn.

Flynn, T. W., Smith, B., & Chou, R. (2011). Appropriate use of diagnostic imaging in low back pain: a reminder that unnecessary imaging may do as much harm as good. *Journal of Orthopaedic and Sports Physical Therapy, 41*(11), 838-846.

Forgeron, P. A., Evans, J., McGrath, P. J., Stevens, B., & Finley, G. A. (2013). Living with difference: Exploring the social self of adolescents with chronic pain. *Pain Research and Management, 18*(6), e115-e123. https://doi.org/10.1155/2013/120632.

Foucault, M. (1977). *The order of things: An archaeology of the human sciences*. London, UK: Tavistock.

Foucault, M. (1984). Politics, polemics and problematizations. In P. Rabinow (Ed.), *The Foucault reader* (pp. 381-390). Harmondsworth, UK: Penguin.

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

Frank, A. W. (1997). Illness as moral occasion: Restoring agency to ill people. *Health, 1*(2), 131-148. doi:10.1177/136345939700100201

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

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

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

Frederiksen, K., Lomborg, K., & Beedholm, K. (2015). Foucault's notion of problematization: a methodological discussion of the application of Foucault's later work to nursing research. *Nursing Inquiry, 22*(3), 202-209.

Frederiksen, M. D. (2013). *Young men, time, and boredom in the Republic of Georgia.* Philadelphia, PA: Temple University Press.

Frederiksen, M. D. (2014). Heterochronic atmospheres: Affect, materiality, and youth in depression. In A. L. Dalsgård, M. D. Frederiksen, S. Højlund, & L. Meinert (Eds.), *Ethnographies of youth and temporality: Time objectified* (pp. 81-97). Philadelphia, PA: Temple University Press.

Frederiksen, M. D., & Dalsgård, A. L. (2014). Introduction: Time Objectified. In A. L. Dalsgård, M. D. Frederiksen, S. Højlund, & L. Meinert (Eds.), *Ethnographies of youth and temporality: Time objectified* (pp. 1-22). Philadelphia, PA: Temple University Press.

Furness, P., Glazebrook, C., Tay, J., Abbas, K., & Slaveska-Hollis, K. (2009). Medically unexplained physical symptoms in children: Exploring hospital staff perceptions. *Clinical Child Psychology and Psychiatry, 14*(4), 575-587.

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

Gaonkar, D. P. (2002). Toward new imaginaries: An introduction. *Public Culture, 14*(1), 1-20.

Geertz, C. (1973). *The Interpretation of Cultures: Selected essays.* New York. NY: Basic Books.

Geertz, C. (1988). *Works and Lives*. Stanford, CA: Stanford University Press.

Geist, R., Weinstein, M., Walker, L., & Campo, J. V. (2008). Medically unexplained symptoms in young people: The doctor's dilemma. *Paediatrics & Child Health, 13,* 487-491.

Gerrard, Siri (1993) "I would like to stay here, but not at any price". Fishing culture and youth culture under transformation), in Kåre Heggen, Jon Olav Myktebust & Thormod Øia (eds.) *Youth in local communities*. Oslo: Samlaget.

Giddens, A. (1979). *Central problems in social theory: Action, structure and contradiction in social analysis.* Berkeley, CA: University of California Press.

Gilroy, P. (2002). *There ain't no black in the Union Jack: The cultural politics of race and nation* (2nd ed.). London, UK: Routledge.

Gjems, S. (2016). "Det sitter mellom ørene" ; medisinsk uforklarte symptomer hos barn og unge. Tidsskrift for Norsk Psykologforening, 53(2), 112-116.

Gjems, S., & Helgeland, H. (2018). A young boy with unexplained headache and paralysis. *Tidsskrift for Den Norske Laegeforening, 138*(13), 1260-2.

Glenton, C. (2003). Chronic back pain sufferers – striving for the sick role. *Social Science & Medicine, 57*, 2243-2252.

Goffman, E. (1959). The presentation of self in everyday life (Doubleday Anchor books). Garden City, N.Y: Doubleday.

Goffman, E. (1974). Frame analysis : An essay on the organization of experience (Harper torchbooks). New York: Harper & Row.

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

Good, B. J. (1986). Explanatory models and care-seeking: A critical account. In S. McHugh & T. M. Vallis (Eds.), *Illness behavior: A multidisciplinary model* (pp. 161-172). New York, NY: Plenum Press.

Gormley, K. J. (2014). Medically unexplained symptoms: the need for effective communication and an integrated care strategy. *British Journal of Community Nursing, 19*(2), 86-90.

Gran, S. (2014). Diagnose: Overveldelse. Morgenbladet. Retrieved from https://morgenbladet.no/ideer/2014/diagnose_overveldelse

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

Greco, M. (2012). The classification and nomenclature of ‘medically unexplained symptoms’: Conflict, performativity and critique. *Social Science & Medicine, 75*(12), 2362-2369.

Greco, M. (2017). Pragmatics of explanation: Creative accountability in the care of ‘medically unexplained symptoms’. *The Sociological Review, 65*(2_suppl), 110-129.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage Publications.

Gubrium, A. C., Hill, A. L., & Flicker, S. (2014). A situated practice of ethics for participatory visual and digital methods in public health research and practice: A focus on digital storytelling. *The American Journal of Public Health, 104*(9), 1606-1614.

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

Gullestad, M. (1996). From obedience to negotiation: Dilemmas in the transmission of values between the generations in Norway. *Journal of the Royal Anthropological Institute, 2*(1), 25- 42.

Gullestad, M. (1999). Antropologisk kunnskap for hvem? Moderne virkeligheter og utfordringer for sosialantropologien. *Norsk Antropologisk Tidsskrift, 10*(2), 81-97.

Gullestad, M. (2001). Likhetens grenser. In M. E. Lien, H. Lidén, & H. Vike (Eds.), *Likhetens paradokser. Antropologiske undersøkelser i det moderne Norge* (pp. 32-67). Oslo: Universitetsforlaget.

Guthrie, E. (2008). Medically unexplained symptoms in primary care. *Advances in Psychiatric Treatment, 14*(6), 432-440.

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

Haavind, H. (2011). Utvikling og deltakelse. Livsformsintervju som klinisk instrument med barn og unge. In A. L. Von der Lippe and M. H. Rønnestad (Eds.), *Det kliniske intervjuet* (pp. 133-153). Oslo: Gyldendal akademisk.

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, UK: Cambridge University Press.

Hacking, I. (1995). The looping effects of human kinds. I D. Sperber, D. Premack & A. J. Premack (red.), *Causal cognition: A multidisciplinary debate* (s. 351–383). New York: Oxford University Press.

Hadler, N. M. (1996). If you have to prove you are ill, you can’t get well: The object lesson of fibromyalgia. *Spine, 21*(20), 2397-2400.

Hahn, R. A. (1983). Rethinking “illness” and “disease”. *Contributions to Asian Studies, 18*, 1-23.

Hahn, S. R. (2001). Physical symptoms and physician-experienced difficulty in the physician-patient relationship. *Annals of Internal Medicine, 134*(9 Pt 2), 897-904.

Haller, H., Cramer, H., Lauche, R., & Dobos, G. (2015). Somatoform disorders and medically unexplained symptoms in primary care—a systematic review and meta-analysis of prevalence. *Deutsches Ärzteblatt International, 112,* 279–87. doi:10.3238/arztebl.(2015).0279

Halvorsen, K. (2007). Legitimacy of welfare states in transitions from homogeneity to multiculturality: “A matter of trust”. In B. Veghte & S. Mau (Eds.), *The welfare state, legitimacy and social justice* (pp. 239-259). Aldershot, UK: Ashgate.

Hamberg, K. (2008). Gender Bias in Medicine. Women's Health, 4(3), 237-243.

Hamberg K, Risberg G, Johansson EE. (2004) Male and female physicians show different patterns of gender bias: a paper-case study of management of irritable bowel syndrome. Scand J Public Health. 2004;32(2):144-52.

Hamberg K, Risberg G, Johansson EE, Westman G.(2002). Gender bias in physicians’ management of neck pain: a study of the answers in a Swedish national examination. J Wom Health Gender-Based Med.; 11: 653 – 65.

Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice* (3rd ed.). London, UK: Routledge.

Han, S., & Antrosio, J. (2015). The editors’ note: Approaching youth in anthropology. *Open Anthropology 3*(2).

Hansen T.B., Steenberg L.M., Palic S. & Elklit A. (2012) A review of psychological factors related to bullying victimization in schools. Aggression and Violent Behavior 17, 383–387.

Haraway, D. (1991). *Simians, cyborgs and women. The reinvention of nature.* London, UK: FAB.

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*, 2255-2263. https://doi. org/10.3109/09638288.(2011).568663

Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual studies, 17*, 13-26

Hartman TC. (2017). Medically unexplained symptoms: the person, the symptoms and the dialogue. *Fam Pract.*, 34(2):245–51.

Hausteiner-Wiehle, Constanze, Gudrun Schneider, Sing Lee, Athula Sumathipala and Francis Creed (2011) Chapter 6: Gender, lifespan and cultural aspects, in: CreeD, Henningsen Francis, Peter, Per Fink.(2011) (eds) Medically unexplained symptoms, somatisation, and bodily distress : developing better clinical services / [edited byUniversity Press, Cambridge

Hay, M. (2010). Suffering in a productive world: Chronic illness, visibility, and the space beyond agency. *American Ethnologist, 37*(2), 259-274. doi:10.1111/j.1548-1425.(2010).01254.x

Hegna, K., Ødegård, G., & Strandbu, Å. (2013). En «sykt seriøs» ungdomsgenerasjon? *Tidsskrift for Norsk Psykologforening, 50*(4), 374-377.

Heijmans, M., olde Hartman T. C., van Weel-Baumgarten, E., Dowrick, C., Lucassen, P. L., & van Weel, C. (2011). Experts’ opinions on the management of medically unexplained symptoms in primary care. A qualitative analysis of narrative reviews and scientific editorials. *Family Practice, 28*(4), 444-455.

Helgeland, H., & Förde, S. (2017). Children and adolescents with unexplained physical symptoms. Tidsskrift for Den Norske Laegeforening, 137(6), 433-4.

Henningsen, E., Gotaas, N., & Feiring, M. (2008). *Møter med ungdom i velferdsstatens frontlinje. Arbeidsmetoder, samarbeid og dokumentasjonspraksis i oppsøkende ungdomsarbeid*. NIBR-rapport: 2008:2.

Henningsen, P., Fink, P., Hausteiner-Wiehle, C., & Rief, W. (2011). Terminology, classification and concepts. In F. Creed, P. Henningsen, & P. Fink (Eds.), *Medically* *unexplained symptoms, somatisation and bodily distress: Developing better clinical services* (pp. 43-68). Cambridge, UK: Cambridge University Press. doi:10.1017/CBO9780511977862.003

Henningsen, P., Zipfel, S., Sattel, H., & Creed, F. (2018). Management of functional somatic syndromes and bodily distress. *Psychotherapy and Psychosomatics, 87*(1), 12-31.

Hiller, W., Rief, W., & Brähler, E. (2006). Somatization in the population: from mild bodily misperceptions to disabling symptoms. *Social Psychiatry and Psychiatric Epidemiology, 41*, 704-712. 10.1007/s00127-006-0082-y

Hinton, D., & Kirk, S. (2016). Families' and healthcare professionals' perceptions of healthcare services for children and young people with medically unexplained symptoms: A narrative review of the literature. *Health & Social Care in the Community, 24*(1), 12-26. https://doi. org/10.1111/hsc.12184

Holland, D., & Leander, K. (2004). Ethnographic studies of positioning and subjectivity: An introduction. *Ethos, 32*(2), 127-139. doi:10.1525/eth.2004.32.2.127

Hollnagel H, Malterud K. Shifting attention from objective risk factors to patients' self-assessed health resources. A clinical model for general practice. Family Practice 1995; 12: 423-9

Hope, Siren (fortcoming) The objectification and gaze of at-risk youths An anthropological study of at-risk youths' reflexive filmmaking in three institutional contexts, Dissertation, UiT, The Arctic University of Norway

Holquist, M. (2002). *Dialogism: Bakhtin and his world* (2nd ed.). London, UK: Routledge. Holstein, B. (1996). Triangulering - metoderedskap og validitetsinstrument. In I. M. Lunde &

P. Ramhøj (Eds.), *Humanistisk forskning inden for sundhedsvidenskab* (pp. 315-328). Copenhagen: Akademisk forlag.

Holtedahl, L. (1998). Formidling som verktøy i kunnskapsetablering; eksempler fra Tromsø og Kamerun. In *Kulturstudier. Kulturforståelse, kulturbrytning og kulturpolitikk* (pp. 193- 219). Bergen: Kulturstudier.

Houwen, J., Lucassen, P. L. B. J., Stappers, H. W., Assendelft, P. J. J., van Dulmen, S., & olde Hartman, T. C. (2017). Medically unexplained symptoms: the person, the symptoms and the dialogue. *Family Practice, 34*(2), 245-251. https://doi.org/10.1093/fampra/cmw132

Houwen, J., Lucassen, P. L. B. J., Stappers, H. W., Assendelft, P. J. J., van Dulmen, S., & olde Hartman, T. C. (2017). Improving GP communication in consultations on medically unexplained symptoms: a qualitative interview study with patients in primary care. *British Journal of General Practice, 67*(663), e716–e723. doi: 10.3399/bjgp17X692537

Hulgaard, D. R. (2018). *Family-based treatment for severe functional disorders in youngsters: Experiences of youngsters and parents in the transition from a paediatric to a child and adolescent mental health setting*. Odense: Syddansk Universitet. Det Sundhedsvidenskabelige Fakultet.

Hulgaard, D. R., Rask, C. U., Risor, M. B., & Dehlholm, G. (2020). Illness perceptions of youths with functional disorders and their parents: An interpretative phenomenological analysis study. Clinical Child Psychology and Psychiatry, 25(1), 45–61. https://doi.org/10.1177/1359104519846194

Hutchinson, S. A., Wilson, M. E., & Wilson, H. S. (1994). Benefits of participating in research interviews. *Journal of Nursing Scholarship*, *26*(2), 161-166.

Hydèn, L., & Sachs, L. (1998). Suffering, hope and diagnosis: On the negotiation of chronic fatigue syndrome. Health, 2(2), 175-193.

Hydén, L. C. (1997). Illness and narrative. *Sociology of Health & Illness*, *19*(1), 48-69.

Hydle, I. (2019). Tord Larsen, Emil A. Røyrvik (Red.): Trangen til å telle. Objektivering, måling og standardisering som samfunnspraksis. Norsk Antropologisk Tidsskrift, 30(02), 170-173.

Hyggen, C., & Stefansen, K. (2016). Sosiologiske blikk på ungdom og ungdomstid. *Sosiologi I Dag*, *46*(3-4), 5-8.

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

Jadhav, S., Jain, S., Kannuri, N. K., Bayetti, C., & Barua, M. (2015). Ecologies of suffering: Mental health in India. *Economic and Political Weekly*, *50*(20), 12-15

Johansen, M.-L., & Risør, M. B. (2016). What is the problem with medically unexplained symptoms for GPs? A meta-synthesis of qualitative studies. Patient Education and Counselling, 100(4), 647-654.

Johansson EE, Hamberg K, Westman G, Lindgren G. The meanings of pain: an exploration of women’s descriptions of symptoms. Social Science and Medicine 1999; 48: 1791–802.

Johnson S. (2008) Medically Unexplained Illness. Gender and Biopsychosocial Implications. Washington: American Psychological Association

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

Johnson-Hanks, J. (2014). Waiting for the start: Flexibility and the question of convergence. In A. L. Dalsgård, M. D. Frederiksen, S. Højlund, & L. Meinert (Eds.), *Ethnographies of youth and temporality: Time objectified* (pp. 23-40). Philadelphia, PA: Temple University Press.

Joustra, M. L., Janssens, K. A., Bultmann, U., & Rosmalen, J. G. (2015). Functional limitations in functional somatic syndromes and well-defined medical diseases. Results from the general population cohort LifeLines. *Journal of Psychosomatic Research, 79*(2), 94-99.

Jutel, A. (2010). Medically unexplained symptoms and the disease label. *Social Theory & Health, 8*(3), 229-245.

Jutel, A. (2011). *Putting a name to it: Diagnosis in contemporary society*. Baltimore, PA: Johns Hopkins University Press.

Jørgensen, A. (2007). Filmmaking as Ethnographic Dialogues: Rouch's Family of "Scoundrels" in Niger. *Visual Anthropology, 20*(1), 57-73.

Kaiser, B. N., & Jo Weaver, L. (2019). Culture-bound syndromes, idioms of distress, and cultural concepts of distress: New directions for an old concept in psychological anthropology. Transcultural Psychiatry, 56(4), 589–598. https://doi.org/10.1177/1363461519862708

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*, 23-28.

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*(C), 107- 113.

Kashikar-Zuck, S., Lynch, A. M., Graham, T. B., Swain, N. F., Mullen, S. M., & Noll, R. B. (2007). Social functioning and peer relationships of adolescents with juvenile fibromyalgia syndrome. *Arthritis Care & Research, 57*(3), 474-480.

Katon, W., Lin, E., Von Korff, M., Russo, J., Lipscomb, P., & Bush, T. (1991). Somatization – a spectrum of severity. *American Journal of Psychiatry, 148*, 34-40.

Keightley P, Reay RE, Pavli P, Looi JC. (2018) Inflammatory bowel disease-related fatigue is correlated with depression and gender. Australas Psychiatry. 2018 Oct;26(5):508-513. doi: 10.1177/1039856218772245. Epub 2018 May 8.

Kirkengen, A. (2018). From wholes to fragments to wholes-what gets lost in translation? Journal of Evaluation in Clinical Practice, 24(5), 1145-1149. Kirkengen, A. (2005). Hvordan krenkede barn blir syke voksne. Oslo: Universitetsforl.

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). Berkeley, CA: University of California Press.

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

Kjeldsberg,, M. et al. (2013). Symptom reporting in a general population in Norway: Results from the Ullensaker study. Scandinavian Journal of Primary Health Care, [s. l.], v. 31, n. 1, p. 36–42, 2013. DOI 10.3109/02813432.2012.751697. Disponível em: https://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=104315022&site=ehost-live. Acesso em: 19 fev. 2020.

Kleinman, A. (1986). *Social origins of distress and disease, depression, neurasthenia, and pain in modern China*. New Haven, CT: Yale University Press.

Kleinman, A. (1988). *The illness narratives: suffering, healing, and the human condition.* New York, NY: Basic Books.

Kleinman, A. (1992). Pain and resistance: The delegitimization and relegitimization of local worlds. In M.-J. DelVecchio Good, P. E. Brodwin, B. J. Good, & A. Kleinman (Eds.), *Pain as human experience* (pp. 169-194). Berkeley, CA: University of California Press.

Kleinman, A. (2012).The art of medicine. Caregiving as moral experience. *The Lancet, 380*, 1550-1552.

Kleinman, A. (2013). From illness as culture to caregiving as moral experience. *New England Journal of Medicine, 368*, 1376-1377.

Kleinman, A., & Becker, A. E. (1998). “Sociosomatics”: the contributions of anthropology to psychosomatic medicine. *Psychosomatic Medicine, 60*, 389-393.

Kleinman, A., Das, V., & Lock, M. (Eds.). (1997). *Social suffering*. Berkeley, CA: University of California Press.

Kleinman, A., & Kleinman, J. (1994). How bodies remember: Social memory and bodily experience of criticism, resistance, and delegitimation following China's Cultural Revolution. *New Literary History, 25*, 707-723.

Kleinman, A., & van der Geest, S. (2009). 'Care' in health care: Remaking the moral world of medicine. *Medische Antropologie, 21*(1), 159-168.

Korsvik, Trine Rogg & Linda Marie Rustad,( 2018). What is the gender dimension in research? Case studies in interdisciplinary research. English translation: Trine Rogg Korsvik & Connie J. Stultz., Kilden genderresearch.no

Kozlowska K. Functional somatic symptoms in childhood and adolescence. Curr Opin Psychiatry 2013; 26: 485 - 92. [PubMed][CrossRef]

Knapstad, M. L. (2013). De sykt flinke. Aftenposten, 17 August 2013. Retrieved from: https://www.aftenposten.no/norge/i/9m6Pl/De-sykt-flinke

Konijnenberg, A., Uiterwaal, C., Kimpen, J., van der Hoeven, J., Buitelaar, J., & de Graeff-Meeder, E. (2005). Children with unexplained chronic pain: Substantial impairment in everyday life. *Archives of Disease in Childhood, 90*(7), 680-686.

Kroenke, K., & Spitzer, R. L. (1998). Gender differences in the reporting of physical and somatoform symptoms. Psychosomatic Medicine, 60(2), 150-155.

Kroenke, K. (2014). A practical and evidence-based approach to common symptoms: A narrative review. *Annals of Internal Medicine, 161*(8), 579-586.

Kroenke, K., & Mangelsdorff, A. D. (1989). Common symptoms in ambulatory care: incidence, evaluation, therapy, and outcome. *American Journal of Medicine, 86,* 262-266.

Kroenke, K., & Price, R. K. (1993). Symptoms in the community. Prevalence, classification, and psychiatric comorbidity. *Archives of Internal Medicine, 53*, 2474-2480. doi: 10.1001/archinte.1993.0041021010(2011).

Krøijer, S. (2014). Aske's dead time: An exploration of the qualities of time among left-radical activists in Denmark. In A. L. Dalsgård, M. D. Frederiksen, S. Højlund, & L. Meinert (Eds.), *Ethnographies of youth and temporality: Time objectified* (pp. 57-80). Philadelphia, PA: Temple University Press.

Krueger, R. A., & Casey, M. A. (2009). *Focus groups: A practical guide for applied research*(4th ed.). Los Angeles, CA: Sage.

Kvale, S., & Brinkmann, S. (2009). *Det kvalitative forskningsintervju* (T. Anderssen & J. Rygge, Trans.) (2nd ed.). Oslo: Gyldendal akademisk.

Kvamme, M., Wang, C., Waage, T., & Risør, M. (2019). Careful expressions of social aspects: How local professionals in high school settings, municipal services, and general practice communicate care to youth presenting persistent bodily complaints. *Health & Social Care in the Community,* April 10, 2019.

Kvamme Steinsvik, M. (2004). *"Innføringa holdt sæ uttaførr": Sosiale mønstre blant ungdommer på en skole med en innføringsklasse for minoritetsspråklige elever* (Thesis). University of Tromsø.

Lambek, M. (Ed.). (2010). *Ordinary ethics: Anthropology, language, and action.* New York, NY: Fordham University Press. https://ebookcentral.proquest.com

Larsen, T., & Røyrvik, E. (2017). Trangen til å telle : Objektivering, måling og standardisering som samfunnspraksis. Oslo: Scandinavian Academic Press.

Larun L, Malterud K. Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies. Patient Educ Couns 2007; 69: 20-28

Lassiter, L. E. (2005). *The Chicago guide to collaborative ethnography.* Chicago, IL: University of Chicago Press.

Leder, D. (1990). *The absent body*. Chicago, IL: University of Chicago Press.

Leiknes, K. A., Finset, A., Moum, T., & Sandanger, I. (2007). Course and predictors of medically unexplained pain symptoms in the general population. *Journal of Psychosomatic Research, 62*(2), 119-128.

Lian, O., & Bondevik, H. (2015). Medical constructions of long-term exhaustion, past and present. Sociology of Health & Illness, 37(6), 920-935.

Lian OS, Bondevik H. Diagnosenes sosiologi: Medisinske forståelser av utmattede kvinner – før og nå. Sosiologisk Tidsskrift. 2013;21(4):329-352

Lidén, E., Björk-Brämberg, E., & Svensson, S. (2015). The meaning of learning to live with medically unexplained symptoms as narrated by patients in primary care: A phenomenological–hermeneutic study. *International Journal of Qualitative Studies on Health and Well-being, 10*(1), 1-11.

Lidén, E., & Yaghmaiy, K. (2017). The meaning of encounters with health professionals in primary health care as reported by patients with medically unexplained symptoms. *Nordic Journal of Nursing Research, 37*(2), 70-77.

Loizos, P. (1992). Admissible evidence?: Film in anthropology. In P. I. Crawford & D. Turton (Eds.), *Film as Ethnography* (pp. 50-65). Manchester, UK: Manchester University Press.

Luhrmann, T. M. (2006). Subjectivity. *Anthropological Theory*, *6*(3), 345-361. https://doi.org/10.1177/1463499606066892

Lund, H. (2012). Generasjon meg: Først meg selv, så meg selv. Aftenposten. Retreived from https://www.aftenposten.no/meninger/kommentar/i/BRqQG/Forst-meg-selv_-sa-meg-selv

MacDonald and Leary 2005). Why does social exclusion hurt? The relationship between social and physical pain. … ++++

MacDougall, D. (1991). Whose Story Is It? *Visual Anthropology Review*, *7*(2), 2-10.

MacDougall, D. (1997). The visual in anthropology. In M. Banks & H. Morphy (Eds.), *Rethinking visual anthropology* (pp. 276-295). London, UK: New Haven Press.

MacDougall, D. (1998). *Transcultural cinema.* Princeton, NJ: Princeton University Press.

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

Madsen, Ole Jacob (2018). *Generasjon prestasjon – hva er det som feiler oss?*. Oslo: Universitetsforlaget, ISBN: 9788215030647

Malterud, Kirsti, Aase Aamland (2019). Medically unexplained symptoms: are we making progress?. British Journal of General Practice; 69 (681): 164-165. DOI: 10.3399/bjgp19X701885

Malterud, K. (1993. Vanlige helseplager hos kvinner – ubestemte og diffuse? I B. Schei, G. Botten, & J. Sundby (Red.). Kvinnemedisin. (s. 259-272). Oslo: AdNotam: Gyldendal.

Malterud, K. (2000). Symptoms as a source of medical knowledge: Understanding medically unexplained disorders in women. Family Medicine, 32(9), 603-611.

Malterud, Kirsti; Taksdal, Arnhild (2007) Shared Spaces for Reflection: Approaching Medically Unexplained Disorders. Junctures : The Journal for Thematic Dialogue (9). s. 27-38

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

Marks, E. M., & Hunter, M. S. (2015). Medically unexplained symptoms: an acceptable term? *British Journal of Pain*, *9*(2), 109-114. doi:10.1177/2049463714535372

Markussen, E., & Nifu Step. (2009). *Videregående opplæring for (nesten) alle*(Kunnskapspolitiske studier). Oslo: Cappelen akademisk.

Mathers, N., Jones, N., & Hannay, D. (1995). Heartsink patients: a study of their general practitioners. *British Journal of General Practice, 45*(395), 293-296.

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

Mattingly, C. (2010). *The paradox of hope: Journeys through a clinical borderland*. Berkeley, CA: University of California Press.

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.

Maxwell, J. A. (2005). Qualitative research design: An interactive approach (2nd ed.). Thousand Oaks, CA: Sage.

May, C. R., Allison, G., Chapple, A., 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.

May, C. R., Rose, M. J., & Johnstone, F. C. (2000). Dealing with doubt. How patients account for non-specific chronic low back pain. *Journal of Psychosomatic Research, 49*, 223-225.

McEwen, B. S. and Getz, L. (2013). Lifetime experiences, the brain and personalized medicine: an integrative perspective. Metabolism: clinical and experimental, 64 (3 suppl 1), 2-10. Doi:http://dx.doi.org/10.1016/j.metabol.2012.08.020

McRobbie, A. (1999). *In the culture society: art, fashion and popular music*. London, UK: Routledge.

Mead, M. (1928). *Coming of age in Samoa: A psychological study of primitive youth for Western civilization*. New York, NY: William Morrow.

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

Mikkelsson, M., Salminen, J. J., & Kautiainen, H. (1997). Non-specific musculoskeletal pain in preadolescents. Prevalence and 1-year persistence. *Pain, 73*, 29-35.

Mik-Meyer, N., & Obling, A. (2012). The negotiation of the sick role: General practitioners' classification of patients with medically unexplained symptoms. *Sociology of Health & Illness, 34*, 1025-1038. https://doi.org/10.1111/j.1467-9566.(2011).01448.x

Ministry of Justice and Public Security (2000). *Lov om behandling av personopplysninger* (LOV-2000-04-14-3, last modified LOV-2013-01-11-3) [Personal Data Act]. Oslo: Ministry of Justice and Public Security.

Mishler, E.G. (1984). The discourse of medicine. Dialectics of medical interviews. Norwood. Nj.Ablex publishing Company

Mishler, E. G. (1995). Models of narrative analysis: A typology. *Journal of Narrative & Life History, 5*(2), 77-123.

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

Mol, A., Moser, I., & Pols, J. (2010). *Care in practice: On tinkering in clinics, homes and farms*. Bielefeld, Germany: Transcript Verlag.

Mortimer, L. (2007). The Texture of Events and the Stuff of Dreams: Jean Rouch at the Heart of Film and Anthropology. Australian Journal of Anthropology, 18(3), 264-275.

Mørch, S. (2010). Ungdomsforskningen som perspektiv og mulighed. *Psyke & Logos, 31*(1), 34.

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,* 307-316. doi: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*, 317-326.

Murberg, T., & Bru, E. (2004). School-Related Stress and Psychosomatic Symptoms among Norwegian Adolescents. School Psychology International, 25(3), 317-332.

Myrtveit Sæther, S., Sivertsen, B., Haugland, S., Bøe, T., & Hysing, M. (2018). Health complaints in late adolescence; Frequency, factor structure and the association with socio- economic status. *Scandinavian Journal of Public Health, 46*(1), 141-149.

Mæland, E. (2016). Hvorfor er vi så besatt av flinke piker? Kilden. http://kjonnsforskning.no/nb/2016/02/hvorfor-er-vi-sa-besatt-av-flinke-piker

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

Nettleton, S. (2006). ‘I just want permission to be ill’: Towards a sociology of medically unexplained symptoms. *Social Science & Medicine, 62,* 1167-1178. doi: 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.

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

Nichter, M. (2008). Coming to our senses: Appreciating the sensorial in medical anthropology. *Transcultural Psychiatry 45*(2), 163-197. doi:10.1177/1363461508089764

, M. (2010). Idioms of Distress Revisited. Culture, Medicine, and Psychiatry, 34(2), 401-416.

Nordin, T., Hartz, A., Noyes, R., Anderson, M., Rosenbaum, M., James, P., . . . Levy, B. (2006). Empirically identified goals for the management of unexplained symptoms. *Family Medicine, 38*(7), 476-482.

Nordtug, B. og G. Engelsrud (2016). "Boken som mangler, ord som går på tomgang og sykt flinke jenter: Kunnskap og helse." Tidsskrift for kjønnsforskning 3–4:151–168.

Norwegian Supervisory Authority. (2014). *Regulations on the processing of personal data.* Oslo: Norwegian Supervisory Authority. http://www.datatilsynet.no/English/Regulations/Personal-Data-Act1/

Nyberg Filippa MD, PhD Ingrid Osika MA Birgitta Evengård MD, PhD (2008). “The Laundry Bag Project”– unequal distribution of dermatological healthcare resources for male and female psoriatic patients in Sweden. International Journal of DermatologyVolume 47, Issue 2. doi.org/10.1111/j.1365-4632.2008.03485.x

Ogden, J., Branson, R., Bryett, A., Campbell, A., Febles, A., Ferguson, I.,. . .Tayler, M. (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.

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,* 68.

olde Hartman, T. C., Rosendal, M., Aamland, A., Van Der Horst, H., Rosmalen, J., Burton, C., & Lucassen, P. (2017). What do guidelines and systematic reviews tell us about the management of medically unexplained symptoms in primary care? *BJGP Open, 1*(3).Bjgpopen17X101061.

olde Hartman, T. C., van Rijswijk, E., van Dulmen, S., van Weel-Baumgarten, E., Lucassen L. B. J., & van Weel, C. (2013). How patients and family physicians communicate about persistent medically unexplained symptoms. A qualitative study of video-recorded consultations. *Patient Education and Counselling, 90*, 354-360.

Ortner, S. (Ed.). (1999). *The fate of culture: Geertz and beyond*. Berkeley, CA: University of California Press.

Ortner, S. (2005). Subjectivity and cultural critique. *Anthropological Theory, 5*(1), 31-52. doi:10.1177/1463499605050867

Østbye, S. V., Kvamme, M. F., Wang, C. E. A., Haavind, H., Waage, T., & Risør, M. B. (2018). 'Not a film about my slackness': Making sense of medically unexplained illness in youth using collaborative visual methods. *Health*, 1-21. https://doi.org/10.1177/1363459318785696

Parish, S. M. (2008). *Subjectivity and suffering in American culture.* New York, NY: Palgrave Macmillan.

Parslow, R., Harris, S., Broughton, J., Alattas, A., Crawley, E., Haywood, K., & Shaw, A. (2017). Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): A systematic review and meta-ethnography of qualitative studies. *BMJ Open, 7*(1), E012633.

Pedersen , P, Moilanen , M (2012), The northern Scandinavian regions- similarities and differences. In: Bæck, U., & Paulgaard, G. (2012). *Rural futures? : Finding one's place within changing labour markets*. Stamsund: Orkana akademisk.

Peirce, C. S. (1979). *Collected papers of Charles Sanders Peirce* (orig. 1933). Cambridge, MA: Belknap Press.

Perquin C.W., Hazebroek-Kampschreur A.A.J.M., Hunfeld J.A.M. et al. (2000) Pain in children and adolescents: a common experience. Pain 87, 51–58.

Peters, S., Rogers, A., Salmon, P., Gask, L., Dowrick, C., Towey, M., . . . Morriss, R. (2009). What do patients choose to tell their doctors? Qualitative analysis of potential barriers to reattributing medically unexplained symptoms. *Journal of General Internal Medicine, 24*(4), 443-449.

Peters, S., Stanley, I., Rose, M., & Salmon, P. (1998). Patients with medically unexplained symptoms: Sources of patients' authority and implications for demands on medical care.

*Social Science & Medicine, 46*(4), 559-565.

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), 245-252.

Piault , Marc Henri (2006) The "Ciné-trance" and the Reign of the Subject: Jean Rouch . In Memories of the Origins of Ethnographic Film . Beate Engelbrecht , ed. Pp. 363 – 375 . Bern, Berlin, et al. : Peter Lang . [Google Scholar]

Picariello, F., Ali, S., Moss-Morris, R., & Chalder, T. (2015). The most popular terms for medically unexplained symptoms: the views of CFS patients. *Journal of Psychosomatic Research, 78*, 420-426.

Pink, S. (2006). *The future of visual anthropology – Engaging the senses.* London, UK: Routledge.

Pink, S. (2007a). *Doing visual ethnography.* London: Sage Publications.

Pink, S. (Ed.). (2007b). *Visual interventions: Applied visual anthropology.* New York, NY: Berghahn.

Pols, J. (2003). Enforcing patient rights or improving care? The interference of two modes of doing good in mental health care. *Sociology of Health & Illness, 25*, 320-347. doi: 10.1111/1467-9566.00349

Rasmussen, E.B., & Rø, K. I. (2018). How general practitioners understand and handle medically unexplained symptoms: a focus group study. BMC Fam Pract 19, 50 (2018) doi:10.1186/s12875-018-0745-2

Rasmussen, E. (2017). Balancing medical accuracy and diagnostic consequences: Diagnosing medically unexplained symptoms in primary care. *Sociology of Health & Illness, 39,* 1227- 1241. https://doi. org/10.1111/1467-9566.12581

Reynolds, Malvina. 81967) 'Little Boxes' (1962 song) Malvina Reynolds Sings the Truth, Columbia Records,. CS-9414

Rhee, H., Miles, M., Halpern, C., & Holditch-Davis, D. (2005). Prevalence of recurrent physical symptoms in U.S. adolescents. *Pediatric Nursing, 31*(4), 314-319, 350.

Rief, W., & Hiller, W. (1999). Toward empirically based criteria for the classification of somatoform disorders. *Journal of Psychosomatic Research, 46*(6), 507-518.

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

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles, CA: 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,* 1505- 1515.

Risør, M. B. (2009). Illness explanations and medically unexplained symptoms – Different idioms for different contexts. *Health 13*(5), 505-521.

Risør, M. B. (2010). Healing and recovery as a social process among patients with medically unexplained symptoms (MUS). In S. Fainzang, H. E. Hem, & M. B. Risør (Eds.), *The taste for knowledge. Medical anthropology facing medical realities* (pp. 133-149). Aarhus, Denmark: Aarhus University Press.

Robson, C. R., & Lian, O. S. (2017). "Blaming, shaming, humiliation": Stigmatising medical interactions among people with non-epileptic seizures. *Wellcome Open Research, 2,* 55.

Robson, C. R., & Lian, O. S. (2016). *"Are you saying she's mentally ill then?" Explaining medically unexplained seizures in clinical encounters.* Norges forskningsråd: 212978

M., Fink, P., Falkoe, E., Hansen, H. S., & Olesen, F. (2007). Improving the classification of medically unexplained symptoms in primary care. *European Journal of Psychiatry, 21*, 25-36.

Rosendal, M., Jarbøl, D. E., Pedersen, A. F., & Andersen, R. S. (2013). Multiple perspectives on symptom interpretation in primary care research. *BMC Family Practice, 14*, 167. doi:10.1186/1471-2296-14-167

Rosendal, M., olde Hartman, T., 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*, 18. doi: 10.1186/s12875-017-0592-6

Rosendal, M., Olesen, F., & Fink, P. (2005). Management of medically unexplained symptoms: Includes diagnosis, specific treatments, and appropriate communication. *British Medical Journal, 330*(7481), 4-5. doi:10.1136/bmj.330.7481.4

Rosenthal, G. (2003). The healing effects of storytelling: On the conditions of curative storytelling in the context of research and counseling. *Qualitative Inquiry, 9*(6), 915-933.

Rouch, J., & Morin, E. (1961). *Chronicle of a summer* [Motion picture]. Paris, France: The Criterion Collection.

Rouch: [1973] On the Vicissitudes of the Self: The Possessed Dancer, the Magician, the Sorcerer, the Filmmaker, and the Ethnographer. in: Feld , Steven (ed) Ciné-Ethnography, Jean Rouch . Minneapolis and London : University of Minnesota Press . [Google Scholar]

Ruby, J. (2005). The last 20 years of visual anthropology – a critical review. Visual Studies, 20(2), 159-170.Rudebeck, C. (2012). *Kropp och ord i en allmänläkares rum*. Lund, Sweden: Studentlitteratur.

Rugkåsa, M. (2010). *Transformasjon og integrasjon: Kvalifisering av minoritetsetniske kvinner til arbeid og deltakelse i den norske velferdsstaten.* No. 242, 289. Department of Social Anthropology, University of Oslo.

Rugkåsa, M. (2011). Velferdsambisiøsitet – sivilisering og normalisering: Statlig velferdspolitikks betydning for forming av borgeres subjektivitet. *Norsk Antropologisk Tidsskrift*, *22*(03-04), 245-256.

Ruiz MT, Verbrygge LM. A two way view of gender bias in medicine. J Epidemiol Community Health 1997. 51: 106 – 9.

Ruyter, K. W. (Ed.). (2003). *Forskningsetikk. Beskyttelse av enkeltpersoner og samfunn*. Oslo: Gyldendal Akademisk.

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

Salmon, P., Dowrick, C. F., 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., Humphris, G. M., Ring, A., Davies, J. C., & Dowrick, C. F. (2006). Why do primary care physicians propose medical care to patients with medically unexplained symptoms? A new method of sequence analysis to test theories of patient pressure. *Psychosomatic Medicine, 68*, 570-577.

Salmon, P., Peters, S., Clifford, R., Iredale, W., Gask, L., Rogers, A., & Morriss, R. (2007). Why do general practitioners decline training to improve management of medically unexplained symptoms? *Journal of General Internal Medicine, 22*(5), 565-571. doi:10.1007/s11606-006-0094-z

Salmon, P., Peters, S., & Stanley, I. (1999). Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *British Medical Journal, 318*(7180), 372-376.

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; discussion 61-62.

Sandberg, S. (2009), Gangster, victim or both? The interdiscursive construction of sameness and difference in self-presentations. The British Journal of Sociology, 60: 523-542. doi:10.1111/j.1468-4446.2009.01254.x

Sandberg, S., & Pedersen, W. (2011). Street capital. In *Street capital* (p. Street capital, Chapter 3). Policy Press.

Sanjek, R. (1990). On ethnographic validity. In R. Sanjek (Ed.), *Fieldnotes. The makings of anthropology* (pp. 385-418). Ithaca, NY: Cornell University Press.

Sartain, S., Clarke, C., & Heyman, R. (2000). Hearing the voices of children with chronic illness. *Journal of Advanced Nursing, 32*(4), 913-921.

Scarry, E. (1985). *The body in pain: The making and unmaking of the world.* New York, NY: Oxford University Press.

Schille-Rognmo, M. (2017). *Ungdata, mental health and gender differences. A study of gendered mental health re-enactments in Ungdata's DLTC youth surveys* (Thesis). UiT The Arctic University of Norway.

Schulte I.E. & Petermann F. (2011) Familial risk factors for the development of somatoform symptoms and disorders in children and adolescents: a systematic review. Child Psychiatry and Human Development 42, 569–583.

Schulte, I., Petermann, F., & Noeker, M. (2010). Functional abdominal pain in childhood: From etiology to maladaptation. *Psychotherapy and Psychosomatics, 79*(2), 73-86.

Shonkoff, J., Boyce, W., & Mcewen, B. (2009). Neuroscience, Molecular Biology, and the Childhood Roots of Health Disparities: Building a New Framework for Health Promotion and Disease Prevention. *JAMA, 301*(21), 2252-2259.

Scott, W. R., Ruef, M., Mendel, P., & Caronna, C. (2000). *Institutional change and health care organizations: From professional dominance to managed care.* Chicago, IL: University of Chicago Press.

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). Thousand Oaks, CA: SAGE.

Schutz, A. (1996/1973) *Collected papers*. The Hague, Netherlands: Nijhoff.

Skårderud, F. (2014). De unge sliterne. Aftenposten. Retrieved from: https://www.aftenposten.no/meninger/i/5VOw1/De-unge-sliterne

Sletten, M. (2017). Psykiske plager blant ungdom: sosiale forskjeller og historien om de flinke pikene. In Oppvekstrapporten 2017: *Økte forskjeller – gjør det noe?* (pp. 124-147). Oslo: Directorate for Children, Youth and Family Affairs.

Smith, R. C., Fortin, A. H., Dwamena, F., & Frankel, R. M. (2013). An evidence-based patient-centered method makes the biopsychosocial model scientific. *Patient Education and Counseling, 91*(3), 265-270.

Smith-Morris, C. (2018). Care as virtue, care as critical frame: A discussion of four recent ethnographies. *Medical Anthropology, 37*(5), 426-432. doi: 10.1080/01459740.(2018).1429430

Solberg, P. O. (2018). Skeptisk til sykeliggjøring. *Tidsskrift for Norsk psykologforening, 56*(2), 86-89.

Spradley, J. (1979). *The ethnographic interview*. New York, NY: Holt, Rinehart & Winston.

Stanley, I. M., Peters, S., & Salmon, P. (2002). A primary care perspective on prevailing assumptions about persistent medically unexplained physical symptoms. *International Journal of Psychiatry in Medicine, 32*, 125-140.

Steihaug S, Malterud K. Recognition and reciprocity in encounters with women with chronic muscular pain. Scand J Prim Health Care 2002;20: 151-6.

Steihaug S, Ahlsen B, Malterud K. ``I am allowed to be myself ’ ’ : women with chronic muscular pain being recognized. Scand J Public Health 2002; 30: 281-7.

Stige, B., Malterud, K., & Midtgarden, T. (2009). Toward an agenda for evaluation of qualitative research. *Qualitative Health Research, 19*(10), 1504-1516. doi:10.1177/1049732309348501

Stone, J., Wojcik, W., Durrance, D., Carson, A., Lewis, S., Mackenzie, L., ... Sharpe, M. (2002). What should we say to patients with symptoms unexplained by disease? The “number needed to offend”. *British Medical Journal, 325*(7378), 1449-1450. https://doi.org/10.1136/bmj.325. 7378.1449

Stone, L. (2013). Reframing chaos: A qualitative study of GPs managing patients with medically unexplained symptoms. *Australian Family Physician, 42*, 1-7.

Stone, L. (2014). Managing the consultation with patients with medically unexplained symptoms: A grounded theory study of supervisors and registrars in general practice. *BMC Family Practice, 15*, 1-15. https://doi.org/10.1186/s12875-014-0192-7

Suris, J. C., Belanger, R. E., Ambresin, A. E., Chabloz, J. M., & Michaud, P. A. (2011). Extra burden of psychosomatic complaints among adolescents suffering from chronic conditions.*Journal of Developmental & Behavioral Pediatrics, 32*(4), 328-331. http://dx.doi.org/10.1097/DBP.0b013e3181fa5727.

Soderlund A, Malterud K. Why did I get chronic fatigue syndrome? A qualitative interview study of causal attributions in women patients. Scandinavian Journal of Primary Health Care 2005; 23:A€242–7.

Taylor, C. (2002). Modern social imaginaries. *Public Culture, 14*(1 [36]), 91-124. doi:10.1215/08992363-14-1-91

Taylor, D. C., Szatmari, P., Boyle, M. H., & Offord, D. R. (1996). Somatization and the vocabulary of everyday bodily experiences and concerns: A community study of adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry, 35*(4), 491-499.

Thornton, P. H. & Ocasio, W. (1999). Institutional logics and the historical contingency of power in organizations: Executive succession in the higher education publishing industry. *American Journal of Sociology 105*, 801-843. doi: 10.1086/210361

Torsheim, T., & Wold, B. (2001). School-Related Stress, School Support, and Somatic Complaints: A General Population Study. Journal of Adolescent Research, 16(3), 293-303.

Timmermans, S., & Tavory, I. (2012). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory, 30*(3), 167-186.

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

Van Den Eede F., Haccuria T., De Venter M. & Moorkens G. (2012) Childhood sexual abuse and chronic fatigue syndrome. The British Journal of Psychiatry 200, 164–165.

van Eck van der Sluijs JF, Ten Have M, de Graaf R, Rijnders CAT, van Marwijk HWJ, van der Feltz-Cornelis CM. (2018) Predictors of Persistent Medically Unexplained Physical Symptoms: Findings From a General Population Study. Front Psychiatry. 2018 Nov 20;9:613. doi: 10.3389/fpsyt.2018.00613. eCollection 2018. PubMed PMID: 30524322; PubMed Central PMCID: PMC6262298.

van Ravenzwaaij, J., olde Hartman, T., van Ravesteijn, H., Eveleigh, R., van Rijswijk, E., & Lucassen, P. (2010). Explanatory models of medically unexplained symptoms: A qualitative analysis of the literature. *Mental Health in Family Medicine, 7*, 223-231.

Verbrugge L. Gender and health: An update on hypotheses and evidence. Journal of Health and Social Behaviour 1985; 26: 156–82.

Vertov, D., Tsivian, Y., & Alloy Orchestra. (1929). *Man with a movie camera* [Motion picture]. London: British Film Institute.

Vigh, H. E. (2006). The colour of destruction: on racialization, geno-globality and the social imaginary in Bissau. *Anthropological Theory, 6*(4), 481-500. doi:10.1177/1463499606071598

Vigh, H. E. (2009). Motion squared: A second look at the concept of social navigation. *Anthropological Theory, 9*(4), 419-438. doi:10.1177/1463499609356044 Vike, H. (1994). Norden. In S. Howell & M. Melhuus (Eds.), *Fjærn og nær. Sosialantropologiske perspektiver på verdens samfunn og kulturer*. Oslo: AdNotam Gyldendal.

Vike, H. (2004). *Velferd uten grenser. Den norske velferdsstaten ved veiskillet*. Oslo: Akribe.

Vogt, K. (2017). Vår utålmodighet med ungdom. *Tidsskrift for Samfunnsforskning, 58*(01), 105-119.

Waage, T. (2007). Om bilders potensial i samfunnsforskning. *Sosiologi I Dag, 37*(1), 95-104.

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: 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). Paris: Éditions des archives contemporaines.

Waage, T. (2018). To recognize uncertainty: Film, anthropological discovery procedures and knowledge about life among migrants in urban Cameroon. *Norsk Antropologisk Tidsskrift, 29*(3-4), 199-220. doi:10.18261/issn.1504-2898-2018-03-04-07 https://www.idunn.no/nat/2018/03-04/aa_gjenkjenne_usikkerhet

Wadel, C. (1991). *Feltarbeid i egen kultur: en innføring i kvalitativt orientert samfunnsforskning.* Flekkefjord: SEEK.

Wahlberg, A. (2018). *Good quality: The routinization of sperm banking in China.* Oakland, CA: University of California Press.

Walker, L. S., Dengler-Crish, C. M., Rippel, S., & Bruehl. S. (2010). Functional abdominal pain in childhood and adolescence increases risk for chronic pain in adulthood. *Pain, 150*(3), 568-572.

Wang, C., Wright, R., Hope, S., & Waage, T. (2012). Youth Gaze: Self-reflective filmmaking as a therapeutic method. *Tidsskrift for Norsk Psykologforening, 49*(9), 861-869.

Ware, N. (1998). Sociosomatics and illness course in chronic fatigue syndrome. *Psychosomatic Medicine, 60*(4), 394-401.

Ware, N. C. (1999). Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. *Culture, Medicine and Psychiatry, 23*, 303-331. https://doi.org/10.1023/A:1005577823045

Weiland, A., van de Kraats, R. E., Blankenstein, A. H., van Saase, J. L., van der Molen, H. T., Bramer, W. M.,… Arends, L. R. (2012). 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. *Perspectives on Medical Education, 1*(4), 192-206.

Weisblatt, E. U., Hindley, P., & Rask, C. (2011). Medically unexplained symptoms in children and adolescents. In Creed, F., Henningsen, P., & Fink, P. (Eds.), *Medically unexplained symptoms, somatisation and bodily distress: Developing better clinical services* (pp. 158-174). Cambridge, UK: Cambridge University Press.

Wergeland, E. (2012). Hvorfor har kvinner høyere sykefravær enn menn? *Arbeidstilsynets fagblad Arbeidervern, 6*. Retrieved from http://www.arbeidstilsynet

Werner, A. (2001). Kvinner med kroniske muskelsmerter - “(u)seriøse” pasienter? I Malterud, K. (Red.) Kvinners ubestemte helseplager. Oslo: Pax forlag, 121-136.

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.

Werner, A. (2005). Kampen for (tro)verdighet: kvinner med "ubestemte" helseplager i møtet med legen og dagliglivet. (no. 249), Det medisinske fakultet, Universitetet i Oslo Unipub, Oslo.

Werner A, Malterud K. (2005) “The pain isn’t as disabling as it used to be”: How can the patient experience empowerment instead of vulnerability in the consultation? Scand J Publ Health 33(Suppl 66): 41-46.

West, C., & Zimmerman, D. H. (1987). Doing gender. Gender and Society, 1(2), 125–151.

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.

Wilkinson, I. (2001). Thinking with suffering. *Cultural Values, 5*(4), 421-444.

Willis, P. (1977). *Learning to labour: How working class kids get working class jobs.* Farnborough: Saxon House.

Winger A1, Ekstedt M, Wyller VB, Helseth S. (2014). 'Sometimes it feels as if the world goes on without me': adolescents' experiences of living with chronic fatigue syndrome. J Clin Nurs. Sep;23(17-18):2649-57. doi: 10.1111/jocn.12522.

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

Worth, S., & Adair, J. (1972). *Through Navajo eyes - an exploration in film communication and anthropology*. Bloomington, IN: Indiana University Press.

Young, A. (1982). The anthropologies of illness and sickness. *Annual Review of Anthropology, 11*, 257-285. http://www.jstor.org/stable/2155783

Yon K, Nettleton S, Walters K, et al. (2015) Junior doctors’ experiences of managing patients with medically unexplained symptoms: a qualitative study. BMJ Open; 5(12): e009593.

Zonneveld, L. N., Sprangers, M. A., Kooiman, C. G., van 't Spijker, A., & Busschbach, J. J. (2013). Patients with unexplained physical symptoms have poorer quality of life and higher costs than other patient groups: A cross-sectional study on burden. *BMC Health Services Research, 13*(1), 520

Østbye, S.V., Wang, C.E.A., Granheim, I.P.H., Kristensen, K.E. & Risør, M.B. (2018). 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). https://doi.org/10.1186/s13033-018-0232-0

Østbye, S.V., Kvamme, M.F., Wang, C.E.A., Haavind, H., Waage, T. & Risør, M.B. (2018). ‘Not a film about my slackness’: Making sense of medically unexplained illness in youth using collaborative visual methods. *Health*, 1-21. https://doi.org/10.1177/1363459318785696

Øia, T., & Vestel, V. (2014). Generasjonskløfta som forsvant. Et ungdomsbilde i endring.Tidsskrift for ungdomsforskning, 14(1), 99-133.

Åsbring, P., & Närvänen, A.-L. (2002). Women’s Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia. Qualitative Health Research, 12(2), 148–160. https://doi.org/10.1177/104973230201200202

Intervjuguide, Livsformsintervju

**Intro:** Som vi har snakket om tidligere, så er vi interessert i å lære mer om

- hvordan det er å være ungdom og streve med ulike kroppslige plager som det kan være vanskelig å forklare
- og hvordan ditt hverdagsliv er
- og ditt forhold til de personene som står deg nær
- og dine erfaringer med behandling eller hvordan hjelp du har fått

Jeg tenker at jeg vil lære mye om hvordan det er ved å se hvordan hverdagene dine er. Gjennom uka. (Det er bare du som vet hvordan det er, sånn kan du hjelpe meg å forstå. Vi kan begynne med dagen i går, for den er kanskje lettest å huske;

1. **Kan du fortelle meg om dagen i går?**
2. **Morgenen, hvordan forløp den,**
    a. når stod du opp, hvem vekket deg
    b. hvem var hjemme, hvem var ikke til stede
    c. forhold til de ulike familiemedlemmene
    d. spiste du frokost, hva spiste du
    e. hvordan følte du deg
    f. hvordan opplever du dette, hvordan forstår?
    g. skulle du på skolen, hvordan kom du deg i så fall dit
    h. Var dette som det pleier å være eller var noe annerledes
3. **Hvordan var den videre dagen – timene på skolen,**
    a. aktiviteter og gjøremål, fag, lunsjen
    b. steder - hvor var du? Pauser, i klasserommet
    c. hvem var du sammen med i løpet av dagen, er det dem du bruker å være mest sammen med? Hvem er du aldri med?
    d. Hva gjorde/ gjør dere i lag? Pratet/r om?
    e. lærere, noen voksne du prater med, hva snakket dere om
    f. jevnaldrende
4. **Hvordan var timene etter skolen**
    a. hva gjorde du da, interesser, plikter
    b. måltider, lesing, musikk
    c. væresteder, bruk av sosiale medier
    d. klær og stil, trening
    e. kontakt med eventuelle behandlere, tanker knyttet til
5. **Hvordan var kvelden,**
    a. Når kom du hjem, la deg? (fast slik?)
    b. Kveldsmat, prat med noen?
    c. Når la du deg, fikk du sove med det samme eller var det vanskelig å sove?
    d. Hvorfor tror du det var slik, følelser og tanker dukket opp
6. **Hvis vi ser på uka som var, hvordan forløp den?**

**UTDYPENDE/ UTFORSKE/ NYSGJERRIG:**

- **Hva skjedde så?**
- **Hvordan var d for deg** at det skjedde/ å være der? (hva syns, opplevelse, følelse)
- **Hvem** var der, hva betydde det at x var der? Mest betydningsfulle personer
- **Strategier**, hva gjorde du da?
- **Hva prøver å få til?** Begrensninger, bekymringer, muligheter
- Plagene, utforske egne erfaringer i relevant kontekst, faktiske hendelser, **hvor** er det best/ verst?
- **Som det pleier?** Eller noe spes.?
- Som forventet?
- Hvordan var det før?
- Framtiden? Hva tror, håper, vil oppnå likt/ annerledes
- **Hva sier dine foreldre, venner, lege mm** om det du forteller her?

FDG GUIDE SKOLEUNGDOM

1. **Presentasjonsrunde:** Jeg tenker vi starter med en kort presentasjonsrunde slik at jeg får et inntrykk av hvordan dere havnet på ---- og hvordan dere kjenner hverandre i klassen + alle får hørt sin stemme med en gang.
2. Hvordan snakker dere om helse i klassen?
3. Hvilke helseplager er det lett å være åpne om med venner/ klassen?
4. Enn på fritida?
5. Har dere opplevd å overhøre at elever på skolen er baksnakket på grunn av helseplager, ex ift fravær?
6. Vil dere si at det er noe som er typisk for deres ---- klasser? Enn andre klasser?
7. Hva betyr god helse for ungdom i dag? (Hva har jevnaldrende å si? Enn skole? Familie?)
8. Hva bør ungdom gjøre for å unngå helseplager?

9. **ØVELSE kategorier plager:** Hvilke helseplager og/ eller diagnoser har dere hørt om? (**gruppemylder, en skriver dem på en lapp på vegne av gruppa**)
    a. Hva tenker dere om dem?
    b. Hvordan vil dere gruppere dem?
    c. Hva kjennetegner hver kategori?
    d. Hvor henvender man seg best for å få hjelp med de ulike?
    e. Hvordan håndterer man best å ha de ulike?
    f. Hva gjør det med hvordan dere tenker om andre unge om dere hører at de har fått en eller flere av disse?
    g. Når er det greit å være borte fra skolen?
10. **Når søker** ungdom dere kjenner hjelp for sine helseplager? **Hva må til**?
11. Er det forskjell på gutter og jenter her? (ex skolehelsetjenesten)
12. **Hvilke helse tilbud** fungerer for ungdom og hvorfor?

TRIGGERE:

**AVISKLIPP OM UNGE STRESSEDE/ GENERASJON PERFEKT**

13. Mange unge jeg har møtt snakker om «stress». Hvilke tanker har dere om stress blant unge i dag?

**AVISUTKLIPP: «HVORFOR BLIR FLINKE PIKER SYKE MENS FLINKE GUTTER HAR SUKSESS?»**

14. Hva tenker dere om en slik medietekst? Kjenner dere dere igjen i dette?
15. Er det forskjell på hvordan jenter og gutter håndterer (press i) hverdagen?

## HVEM SØKER VI?

Vi søker deg som er mellom 15 og 19 år med helseplager som påvirker ditt hverdagsliv uten at legen finner noen medisinsk forklaring.

Har du lyst til å delta på et forskningsprosjekt hvor du får lære å lage film om hvordan det er å være ung i Tromsø i dag, eller om dine opplevelser i møte med helsevesenet?

### Premiere og dialogvisning for deltagere som ønsker det

De deltagerne som ønsker det kan vise sine ferdige filmer på vår premierekveld, hvor de selv inviterer for eksempel foreldre/ foresatte, nære fagpersoner og venner til å være publikum.

Det vil og bli arrangert en dialogvisning hvor de som ønsker det presenterer sin film for inviterte helsepersonell og andre som møter ungdom med uforklarte helseplager i jobben sin.

Hvem kunne du tenke deg å invitere til å se din film?

## UNGDOMSBLIKK

Ta kontakt
dersom du kunne tenke deg å
delta eller bare vil møtes for
å få mer informasjon!

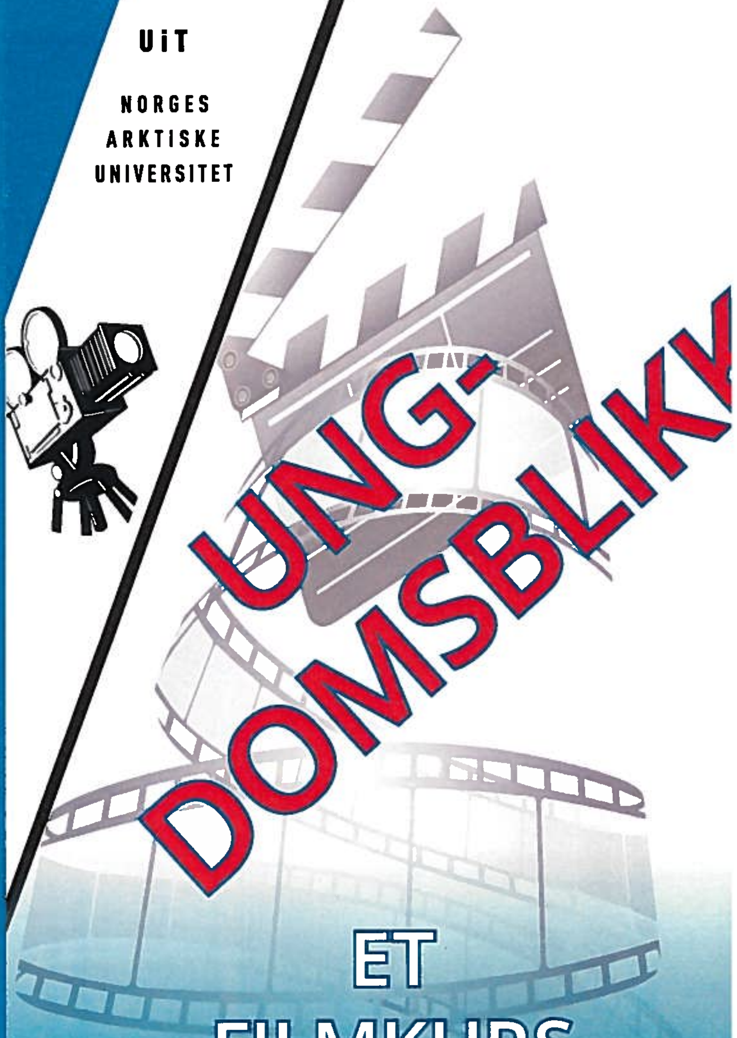
Snakk med kursholder
Maria F. Kvamme

maria.f.kvamme@uit.no

tlf. 971 82 260

UiT / NORGES ARKTISKE UNIVERSITET
9037 Tromsø . postmottak@uit.no
Sentralbord: 77644000, Faks: 77644900

UiT
NORGES
ARKTISKE
UNIVERSITET



# UNG-DOMSBLIKK

## ET FILMKURS FOR UNGDOM

uit.no

# HVA ER UNGDOMSBLIKK?

## Praktisk dokumentarfilm kurs

Kurset vil vare 5-6 uker høsten 2015 med max10 deltagere. Gruppa møtes to til tre ganger i uken utenom skoletid. Opplegget er fleksibelt og vil tilpasses etter hvert som vi ser hva som passer best for deg og gruppa.

Du lærer videofilming, redigering på mac og historiefortelling med film gjennom praktiske øvelser. Det legges opp til at alle får ferdigstilt sin egen film på ca 15 minutter. Mot slutten av kurset får du utdelt kursbevis som viser hva du har lært.

Filmkurset er del av et forskningsprosjekt om helsemøter og hverdagsliv for ungdom med uforklarte helseplager. Vi starter med et intervju før kurset hvor vi blir litt kjent med deg og lærer litt om dine erfaringer.

## Om kurslederne

Maria

Silje

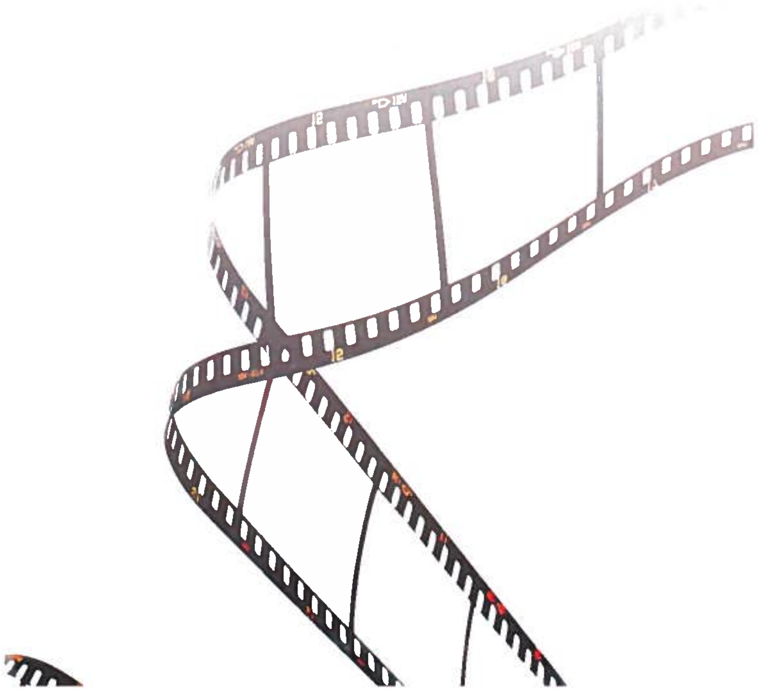
Vi som skal holde kursene er forskerstudentene
Maria F. Kvamme (medisinsk antropologi) og
Silje V. Østbye (psykologi).
Vi skal også samarbeide med prosjektleder og
veiledere Mette Bech Risør, psykologspesialist
Catharina Wang og filmantropolog Trond Waage.

## Ungdommers blikk

Vi voksne kan lett misforstå hvordan ungdommer egentlig opplever viktige tema. Ungdomsblikk metoden gir et verktøy for å løfte deres perspektiver frem.

## Jobb med egne tema for filmen

Du får jobbe med egne tema for filmen under veiledning. Gjennom hele prosessen legges det opp til refleksjon og tilbakemelding til filmmateriale og temaer som dere er opptatte av. Filmarbeidet kan på denne måten gi nye oppdagelser for både deg selv, kurslederne og andre omkring deg.



# SPØRSMÅL OG SVAR

## Hva skal forskningsmaterialet brukes til?

Vi ønsker å bruke filmkursprosessen som en metode for å forstå hvordan ungdom selv opplever sin hverdag og møter med helsevesen. Filmmaterialet og det som skjer i kurset gir andre typer forskningsdata enn for eksempel intervjuer. Materialet skal brukes i to doktorgradsavhandlinger som publiseres i 2018.

Vi tror også mange helseansatte som møter ungdom i jobben sin kan lære av å se ungdommers filmer i undervisning. Du bestemmer selv hvem som får se din film.

## Har dere taushetsplikt?

Vi er underlagt taushetsplikt, og strenge regler for behandling av personlig informasjon. Filmene som lages vil ikke kunne vises offentlig uten ditt samtykke til dette.

## Kan jeg trekke meg underveis dersom jeg likevel ikke ønsker å delta?

Det er fullt mulig å trekke seg fra filmkurs og forskningsprosjekt når som helst i prosessen.

Forespørsel til ungdom om deltakelse i forskningsprosjektet

## *"Medisinsk uforklarte fysiske helseplager hos ungdom i Tromsø, -utfordringer i kommunikasjon, forståelse og behandling"*

**Bakgrunn og hensikt**
Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Vi ønsker med dette å bidra til bedre forståelse og helsehjelp for ungdom med fysiske helseplager som er vanskelige å forklare. Eksempler på helseplager kan være hodepine, mageplager, muskel og leddsmerter, utmattelse med mer. Plagene kan være langvarige og gå ut over for eksempel skolegang og venne-nettverk. Du er spurt om å delta fordi du er mellom 13 og 23 år og har opplevd slike plager selv i minst et halvt år.

2015 og vår 2016 vil antropolog Maria Fredriksen Kvamme gjennomføre kvalitative intervju, deltagende observasjon i unges hverdagsliv og selvrefleksive filmkurs for ungdom (Ungdomsblikk). Målet er å få mer kunnskap om hvordan ungdom med slike plager og deres sosiale omgivelser i hverdagsliv og helsevesen opplever og håndterer dette, og å bidra til økt forståelse. - Mellom ungdom og deres omgivelser, mellom pasient og helsevesen. Filmkurset vil gjennomføres i samarbeid med psykolog og forsker Silje Vagli Østbye. Silje har ellers fokus på unges møter med spesialisthelsetjenesten. Prosjektet er et samarbeid mellom tre avdelinger ved Universitetet i Tromsø: Allmennmedisinsk forskningsenhet ved seniorforsker Mette Bech Risør (prosjektleder), Institutt for Psykologi ved professor Catharina E. A. Wang og Visuelle Kulturstudier ved ass. professor Trond Waage.

**Hva innebærer studien for ungdom med symptomer:**
Vi ønsker å forstå mer om hvordan du opplever din hverdag og dine møter med helsevesenet. Hvis du ønsker å delta, vil vi starte med et intervju hvor jeg spør litt om din helse i forhold til hverdagssituasjoner og møter med helsevesen. Etter dette velger du selv hvordan du vil delta:

- KUN INTERVJU: Delta på kun 1-3 intervju til med litt tid imellom i løpet av 2015
- FILMKURS? Du kan også velge å delta på filmkurs høsten 2015 og lære å uttrykke deg om å være ung i din situasjon gjennom dokumentarfilm. Filmkurset vil være på ettermiddagstid og vare noen uker, eller som tilpasset opplegg. (Se flyer for mer om filmkurs)
- PRESENTERE FILMEN DIN TIL VOKSNE SOM DU TENKER BØR SE DEN? Vi tror både forskere, folk i helsevesenet og andre har mye å lære av ungdommers egne film presentasjoner, og vi vil sammen med de unge invitere det riktige publikum for deres filmer til en felles dialogvisning.
- VISE HVORDAN DET ER I HVERDAGSLIV FOR UNGDOM? Du kan la Maria være med i enkelte hverdags situasjoner du velger selv, for at vi bedre skal forstå hvordan hverdagsliv og helsemøter ser ut for ungdom. For eksempel:- slappe av hjemme, henge ut med venner ute eller på nett, på aktiviteter, helsehjelp-møter eller noe på skolen. Dette kalles deltagende observasjon, fordi forskeren skal forstå gjennom å delta, og samtidig klare å beskrive situasjoner utenifra. Hvis du synes det er greit vil vi bli enige underveis om intervju med en forelder eller sammen med venner.

Fordi vi er opptatt av et helsetema kreves samtykke fra foreldre opp til fylte 18 år.

**Mulige fordeler og ulemper**
Noen kan oppleve det som en ulempe å møte til intervju. Intervjuene kan fleksibelt avtales til steder og tider som passer deltageren best. Det kan og oppleves bra og nyttig å få frem egne erfaringer.

Ungdommer som deltar på filmkurs kan utforske nye sider ved seg selv gjennom kursprosessen, lære å uttrykke seg gjennom film, få erfaringer med mestring, oppleve økt forståelse fra de voksne og økt selvtillit. Noen kan oppleve at de blir slitne av å møte på kurs. Metodikken er fleksibel og kan tilpasses om deltageres symptombelasting er stor. Filmkurset kan og sette i gang prosesser i deltagere som de trenger å snakke om. På kurset vil vi legge vekt på at ungdom setter grenser for seg selv og hva de vil dele på filmen. Ungdom som melder behov for oppfølging vil få tilbud om kontakt med kommunalt hjelpeapparat.

Voksne som står rundt ungdommene kan gjennom filmprosess og dialogmøte få et innblikk i deres opplevelser og erfaringer. Dette kan være en måte å bidra til bedre kommunikasjon mellom ungdommer og de som søker å forstå. Samlet kan studiet gi økt kunnskap om hvilke tiltak vi trenger lokalt for å bedre møte problemstillingen.

**Hva skjer med informasjonen?**
Kvalitative data registreres som lydfiler, tekstfiler og lyd/filmopptak. Alle personopplysninger vil bli behandlet konfidensielt, og det er bare prosjektgruppen (prosjektledere, stipendiater) som har tilgang til dem. Datamaterialet anonymiseres. Intervjuer tas opp med en liten båndopptager når den som intervjues samtykker til dette. Opptakene skrives ned (transkriberes) uten navn og slettes. Personopplysninger og opptak lagres adskilt fra øvrige data på selvstendig harddisk beskyttet av brukernavn og passord. Bidragsytere vil får lese igjennom evt. tekst hvor de er sitert (eller beskrevet) under pseudonym, om de ønsker dette. Deltakerne vil bli anonymisert så de ikke vil kunne gjenkjennes i skriftlige publikasjoner. Prosjektet skal etter planen avsluttes 31. 08. 2018. Datamaterialets kobling mot navnelister, epostadresser, mobilnumre mv. slettes/makuleres; lyd- og bilder slettes/makuleres, men hvis informanten ønsker å bevare egen film som personlig produkt og/eller gir tillatelse til at den kan brukes i pedagogisk sammenheng slettes den ikke.

**Frivillig deltakelse**
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for eventuell videre kontakt med helsevesen eller universitet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte stipendiat Maria Fredriksen Kvamme, på telefon 971 82 260, eller prosjektleder og seniorforsker Mette Beck Risør på telefon 77 62 33 40, begge ved Allmennmedisinsk forskningsenhet AFE, Institutt for Samfunnsmedisin ISM.

Med vennlig hilsen
Maria Fredriksen Kvamme,
stipendiat (doktorgradsstudent)
ved AFE, Institutt for samfunnsmedisin
maria.f.kvamme@uit.no
Telefon: 971 82 260 (776 23 345)

# Samtykke til deltakelse i studien - ungdom

Jeg er villig til å delta i studien ved

☐ Intervju
☐ Filmkurs 2015
☐ Deltagende observasjon (Jeg avgjør selv underveis når og hvor det er greit)

--------------------------------------------------------------------------------------------------------------------
(Signert av prosjektdeltaker, dato)

Foreldres / foresattes samtykke for deltagelse ved
☐ Intervju
☐ Filmkurs 2015
☐ Deltagende observasjon

--------------------------------------------------------------------------------------------------------------------
(Signert av foresatte, dato)
Er selv fylt 18 år ☐

Jeg bekrefter å ha gitt informasjon om studien

--------------------------------------------------------------------------------------------------------------------
(Signert, rolle i studien, dato)

UiT
NORGES
ARKTISKE
UNIVERSITET

Til foresatte;

## Forespørsel om deltagelse i forskningsprosjektet
## *”Medisinsk uforklarte fysiske helseplager hos ungdom i Tromsø, -utfordringer i kommunikasjon, forståelse og behandling”*

### Bakgrunn og hensikt

Dette er en forespørsel til deg som foresatt om at din sønn/ datter deltar i et forskningsprosjekt. Målet med prosjektet er å bidra med kunnskap til bedre forståelse og helsehjelp/ tiltak for ungdom hvor langvarig uavklarte helseplager har gått ut over skolegang og vennenettverk med mer.

Manglende medisinsk forklaring eller diagnose kan skape utfordringer i hverdagsliv og i møter med helsevesen. Vi ønsker mer kunnskap om:

1) Hvordan beskriver og forstår ungdommene sine symptomer, sykdomserfaringer og sykdomsforløp?
2) Hvordan opplever og møter de sosiale omgivelsene ungdommene og deres situasjon? (familie, venner, sosialt nettverk, lokalsamfunn, skole og helsetjenester)
3) Hvilken betydning har møter i ulike sosiale sammenhenger for opplevelse og håndtering

Vi inviterer ungdom til å delta om de har eller har hatt helseplager som hodepine, mageplager, muskel- og leddsmerter, utmattelse eller andre. Plagene skal ha vart i seks måneder eller mer, uten at lege eller andre har funnet noen god medisinsk forklaring. Fordi vi er opptatt av et helsetema kreves samtykke fra foreldre/ foresatte til ungdom opp til fylte 18 år som ønsker å delta. Vi som står bak dette prosjektet er prosjektansvarlig og professor i medisinsk antropologi Mette Beck Risør, professor og psykologspesialist Catharina E. A. Wang, ass. professor og antropolog med film Trond Waage, og filmkursholdere og forskere Maria Fredriksen Kvamme og Silje Vagli Østbye. Vi jobber alle ved UiT, Norges Arktiske Universitet.

### Hva innebærer studien for din sønn/ datter? Mulige fordeler og ulemper

Din sønn/ datter velger selv sammen med foreldre/ foresatte om han/ hun ønsker at undertegnedes erfaringer fra samarbeid i filmkurs kan brukes anonymt som del i et forskningsprosjekt. Han/ hun kan også velge å supplere med intervju. Erfaringer fra filmkurs inkluderer kunnskap om hans/ hennes forståelse av sin hverdag og helse før og nå og hvordan samarbeid og planlegging omkring visuelle uttrykk kan bidra til refleksjon for den voksne og for ungdommen selv.

Noen kan oppleve det som en ulempe å delta på intervju. Intervjuene kan fleksibelt avtales til steder og tider som passer deltageren best. Det kan og oppleves nyttig å få fram egne erfaringer. Samlet kan studiet gi økt kunnskap om hvilke tiltak vi trenger lokalt for å bedre møte problemstillingen.

### Hva skjer med informasjonen?

Alle personopplysninger vil bli behandlet konfidensielt, og det er bare prosjektgruppen (prosjektledere, stipendiater) som har tilgang til dem. Datamaterialet anonymiseres. Eventuelle intervjuer tas opp med en liten båndopptager når den som intervjues samtykker til dette. Opptakene skrives ned (transkriberes) uten navn og slettes. Kvalitative data registreres som lydfiler, tekstfiler og eventuelt filmopptak.

Deltakere vil få lese igjennom evt. tekst hvor de er sitert (eller beskrevet) under pseudonym, om de ønsker dette. Deltakerne vil bli anonymisert så de ikke vil kunne gjenkjennes i skriftlige publikasjoner. Personopplysninger og opptak lagres adskilt fra øvrige data på selvstendig harddisk beskyttet av brukernavn og passord. Prosjektet skal etter planen avsluttes 31. 08. 2018. Datamaterialets kobling mot navnelister, epostadresser, mobilnumre mv. slettes/makuleres; lyd- og bilder slettes/makuleres, men hvis ungdommen ønsker å bevare egen film som personlig produkt og/eller gir tillatelse til at den kan brukes i pedagogisk sammenheng slettes den ikke.

**Frivillig deltagelse**
Vedlagt dette brevet er en samtykkeerklæring. Vi ber deg/dere vennligst undertegne dette skjemaet for å samtykke til at deres sønn/datter deltar i forskningsprosjektet. Det er frivillig å delta i studien. Dere kan når som helst og uten å oppgi noen grunn trekke deres samtykke. Dette vil ikke få konsekvenser for dere. Ta gjerne kontakt med spørsmål underveis med undertegnede på telefon 971 82 260.

Med vennlig hilsen
Maria Fredriksen Kvamme,
stipendiat (doktorgradsstudent) ved AFE, Institutt for samfunnsmedisin
maria.f.kvamme@uit.no Telefon: 971 82 260 (776 23 345)

# Samtykke til deltakelse i studien - foresatte

Foreldres / foresattes samtykke for sin sønn/ datters deltagelse.

-----------------------------------------------------------------------------------------------------------
(Signert av foresatte, dato)

Jeg bekrefter å ha gitt informasjon om studien

-----------------------------------------------------------------------------------------------------------
(Signert, rolle i studien, dato)

UiT
NORGES
ARKTISKE
UNIVERSITET

# Forespørsel til fagpersoner om deltakelse i forskningsprosjektet *"Medisinsk uforklarte fysiske helseplager hos ungdom i Tromsø, - utfordringer i kommunikasjon, forståelse og behandling"*

**Bakgrunn og hensikt**
Dette er et spørsmål til deg om å delta i et forskningsprosjekt. Vi ønsker med dette å bidra til bedre forståelse og helsehjelp for ungdom med fysiske helseplager som er vanskelige å forklare. Eksempler på helseplager kan være hodepine, mageplager, muskel og leddsmerter, utmattelse med mer, og plagene hos ungdommen skal ha vart i et halvt år eller mer. Manglende medisinsk forklaring eller diagnose kan skape utfordringer i møter med helsevesen, og plagene kan gå ut over skole og sosiale nettverk. Du er spurt om å delta fordi du møter noen av disse unge i jobben din.

I 2015 og vår 2016 vil antropologstipendiat Maria Fredriksen Kvamme gjennomføre kvalitative intervju med flere parter, deltagende observasjon i unges hverdagsliv og selvrefleksive filmkurs for ungdom (Ungdomsblikk). Målet er å få mer kunnskap om hvordan ungdom med slike plager og deres sosiale omgivelser i hverdagsliv og førstelinje helsevesen opplever og håndterer dette, og å bidra til økt forståelse. - Mellom ungdom og deres omgivelser, mellom pasient og helsevesen. Vi ønsker mer kunnskap om:
1) Hvordan beskriver og forstår ungdom sine symptomer, sykdomserfaringer og sykdomsforløp?
2) Hvordan opplever og møter de sosiale omgivelsene ungdommene og deres situasjon? (familie, venner, sosialt nettverk, lokalsamfunn, skole og helsetjenester)
3) Hvilken betydning har møter i ulike sosiale sammenhenger for opplevelse og håndtering?

Ungdom velger selv om de ønsker å delta på kun 1-4 intervju med litt tid imellom, eller om han/ hun og vil lære å uttrykke seg gjennom film utenfor skoletid. Se også Flyer for mer informasjon om filmkurs. Noen ungdom vil vurdere å la Maria være med i enkelte hverdags situasjoner de velger selv gjennom deltagende observasjon, for at vi bedre skal forstå hvordan hverdagsliv og helsemøter ser ut for dem. For eksempel slappe av hjemme, med venner ute eller på nett, på aktiviteter eller noe på skolen. Filmkurset vil gjennomføres i samarbeid med psykolog og forsker Silje Vagli Østbye. Silje har ellers fokus på unges møter med spesialisthelsetjenesten. Prosjektet er et samarbeid mellom tre avdelinger ved Universitetet i Tromsø: Allmennmedisinsk forskningsenhet ved professor Mette Bech Risør (prosjektleder), Institutt for Psykologi ved professor og psykologspesialist Catharina E. A. Wang og Visuelle Kulturstudier ved ass. professor Trond Waage.

**Hva innebærer studien for deg som møter ungdom i jobben**
Vi ønsker at du presenterer studien kort for aktuell ungdom ved hjelp av vårt informasjonsmateriell og at du ber om lov til å **formidle kontakt** - om de vil vurdere å delta og/ eller møtes uforpliktende for å få mer informasjon. Fordi vi er opptatt av et helsetema kreves at foreldre samtykker til at deres ungdom opp til 18 år deltar og på hvilken måte. Vi vil selv informere og innhente samtykke fra foreldre/ foresatte til ungdom som har lyst til å delta i direkte i prosjektet.

Fordi du har erfaring med målgruppa, ønsker vi å spørre noen av dere om å vurdere å delta i et **fokusgruppeintervju** med opp til 10 andre som jobber med ungdom **og/ eller i individuelle intervju** anonymt. Det er og fint å kun delta med å formidle ungdom om du ikke ønsker å bli intervjuet.

Tilstedeværelse i skolearenaer som del av ungdommenes hverdagsliv avklares med hver enkelt skoleledelse. Evt. observasjon i helserelevante klasseroms-situasjoner vil avklares med den unge, læreren, klassen i forkant. Medelever vil ikke presenteres individuelt gjenkjennbart, men som del av hans/ hennes jevn-alder miljø med fokus på mer generelle ungdomsperspektiver på helse. Det vil i samarbeid med den enkelte skole utarbeides kort informasjon for skolens elever og foreldregruppe hvor de kan reservere seg mot å bli tatt med i en slik generell beskrivelse. Om Maria følger ungdom du har formidlet i deltagende observasjon, vil det ikke forventes å være med inn i samtaler/ konsultasjoner. Unntaksvis kan dette avtales. Ved eventuell deltagelse i samarbeidsmøter hvor du kanskje er representert omkring enkeltungdom vil vi selv sørge for at dette er avklart på forhånd med ungdommen og foresatte. Mange fagpersoner vil og inviteres til et dialogmøte hvor ungdommene presenterer sine filmer.

**Mulige fordeler og ulemper**
Noen kan oppleve det som en ulempe å møte til intervju. Intervjuene kan fleksibelt avtales til steder og tider som passer deg best. Det kan og oppleves nyttig å få frem egne erfaringer. Eventuell informasjon fra deltagende observasjon hvor du er representert kan oppleves utrygt. Eventuell bruk av dette avklares med deg og anonymiseres. Se også avsnittet om personvern nedenfor. Voksne som står rundt ungdommene kan gjennom filmprosess og dialogmøte få et innblikk i deres opplevelser og erfaringer. Dette kan være en måte å bidra til bedre kommunikasjon mellom ungdommer og de som søker å forstå. Ungdommer som deltar på filmkurs kan utforske nye sider ved seg selv gjennom kursprosessen, lære å uttrykke seg gjennom film, få erfaringer med mestring, oppleve økt forståelse fra de voksne og økt selvtillit. Noen kan oppleve at de blir slitne av å møte på kurs. Metodikken er fleksibel og kan tilpasses deltagernes behov og form. Samlet kan studiet gi økt kunnskap om hvilke tiltak vi trenger lokalt for å bedre møte problemstillingen.

**Hva skjer med informasjonen?**
Alle personopplysninger vil bli behandlet konfidensielt, og det er bare prosjektgruppen (prosjektledere, stipendiater) som har tilgang til dem. Datamaterialet anonymiseres. Intervjuer tas opp med en liten båndopptager når den som intervjues samtykker til dette. Opptakene skrives ned (transkriberes) uten navn og slettes. Personopplysninger og opptak lagres adskilt fra øvrige data på selvstendig harddisk beskyttet av brukernavn og passord. Bidragsytere vil få lese igjennom evt. tekst hvor de er sitert (eller beskrevet) under pseudonym, om de ønsker dette. Deltakerne vil bli anonymisert så de ikke vil kunne gjenkjennes i skriftlige publikasjoner. Prosjektet skal etter planen avsluttes 31. 08. 2018. Datamaterialets kobling mot navnelister, epostadresser, mobilnumre mv. slettes/makuleres.

**Frivillig deltakelse**
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for deg. Dersom du ønsker å delta direkte med intervju, undertegner du samtykkeerklæringen på siste side. Dersom du senere ønsker å reservere deg mot generell observasjon, trekke deg eller har spørsmål til studien, kan du kontakte stipendiat Maria Fredriksen Kvamme, på telefon 971 82 260, eller prosjektleder og professor Mette Beck Risør på telefon 77 62 33 40, begge ved Allmennmedisinsk forskningsenhet AFE, Institutt for Samfunnsmedisin ISM.

Med vennlig hilsen
Maria Fredriksen Kvamme,
stipendiat (doktorgradsstudent) ved AFE, Institutt for samfunnsmedisin
maria.f.kvamme@uit.no Telefon: 971 82 260 (776 23 345)

# Samtykke til deltakelse i studien - fagperson

Jeg er villig til å delta i studien ved

☐ Fokusgruppeintervju
☐ Individuelle intervju

-----------------------------------------------------------------------------------------------------------
(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

-----------------------------------------------------------------------------------------------------------
(Signert, rolle i studien, dato)

## INTERVJUGUIDE FOR FAGPERSONER

**Introduksjon:** Som vi har snakket om tidligere, så er jeg interessert i å lære mer om dine erfaringer med ungdom du har møtt her hvor du jobber, som har presentert helseplager som ikke har vært så lette å finne medisinske forklaringer på. Jeg intervjuer fagpersoner i tillegg til ungdom fordi jeg ønsker å forstå problemstillingen sett fra ulike perspektiv. - Jeg tenker at jeg vil lære mye om ved å se hvordan denne problemstillingen har vært erfart fra deg som enkeltperson og som del av et kollegie, og hvordan du har erfart konkrete hendelser og forløp med ungdom, uten at jeg trenger å ha møtt dem eller vite hvem de er.

1. Hvilke erfaringer har du med slike helseplager, relatert til ungdom i jobbsammenheng?

2. Om du kunne tenke tilbake til en ungdom med en sånn problemstilling som du har møtt her, og fortelle om dine konkrete erfaringer og hvordan forløpet var?
    a. Hvordan kom det opp?
    b. Hva sa ungdommen selv?
    c. Oppstod det dilemmaer?
    d. Tok du det opp til drøfting med noen?
    e. Hva gjorde du?/ ønsket å få til?

3. Har dette vært en relativt vanlig problemstilling å møte her?
    a. Hva er det typiske?
    b. Hvordan snakkes dette om blant ansatte og ungdom?

4. Kommer du på andre eksempler på ungdom
    a. Hvor du opplevde at det var spesielt utfordrende å få til gode løsninger?
    b. Hvor du opplevde at du/ dere fikk til det dere ønsket?

5. Er din opplevelse typisk for mange andre i din type jobb/ på avdelingen tror du?
    a. Finnes det alternative oppfatninger eller måter å håndtere dette på som du har møtt?

6. Har dere hatt felles retningslinjer eller rutiner for hvordan å møte denne typen problemstillinger?
    a. Hvor har råd og veiledning kommet fra?
    b. Har du sett endringer i hvilke råd som gis?

7. Hvordan har du erfart samarbeid med andre instanser?

8. Hva ville vært ideell måte å møte disse unge, tror du?
9. Oppsummering. Hva har vært viktigste poenger? Noe du ønsker å tilføye?

**UTDYPENDE/ UTFORSKE/ NYSGJERRIG:**

- ➢ Hva skjedde så?
- ➢ Hvordan var dette for deg?
- ➢ Hvem deltok?
- ➢ Hva sier dine kollegaer om det du forteller her?
- ➢ Strategier, hva gjorde du da?
- ➢ Hva prøver å få til?
  Begrensninger
  Bekymringer
  Muligheter
- ➢ Som forventet?
- ➢ Hvordan var det før?
- ➢ Framtiden?