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Noisy bodies and cancer diagnostics in Denmark: exploring the social life of medical semiotics

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Sofie lives with her husband, Christopher, in a small terraced house on the outskirts of a provincial town. Merrild was conducting ethnographic research on social differences in health and visited the couple shortly after Sofie was diagnosed with cancer for the second time. Eighteen years had passed since Sofie's first diagnosis and now the cancer has spread to her bones. When asked how her new diagnosis came about, Sofie embarked on an extended explanation:

Sofie: Well, for a long time I had really been in pain. But they [the doctors] did not really believe that it might be cancer in my bones. So, I was sent to phys [physiotherapy] and training, rehabilitation and what not. And then I was sent to another hospital, and I asked the doctor up there, if they could not damn well investigate whether it was cancer that had spread.

Merrild: You simply said that to them?

Sofie: Yes, well, they said that then it would be a completely different situation we were in. And I said to them, I know that. That was also the time when I was told that the pain

was a fictitious thing, you know. It cannot be measured, they said. But my daughter was there with me, and she says to him: 'When my mother says she is in pain, then she is in pain.' I asked them again if they would investigate, and he agreed, and sent me to yet another hospital that could do it fast, and I was scanned. The next day I was called up by our own doctor, and she told me that it was a cancer that had crumbled away the bones in my neck.

Social inequalities in health are intricate and rooted in complex configurations of social, cultural and biological differences that we are only beginning to understand and conceptualise (Nguyen and Peschard 2003; Seeberg and Meinert 2015). In the global south, structural violence in the forms of poverty, gendered inequalities and race- and caste-based discrimination limit access to healthcare (Farmer 1999). In such settings, inequalities in health increase and capitalise on structural vulnerabilities such as cramped living conditions, malnutrition and co-morbidities (Biehl, Good and Kleinman 2007; Farmer 1999). In comparison with countries in the global south, Danish society is characterised by a high degree of social equity and operates under the ideal of free and equal access to healthcare ideally available to all people living in Denmark. Yet health inequalities have always been evident and are increasing (Udesen et al. 2020). Among people diagnosed with cancer between 2005 and 2013 (most recent data, 2022), only 53 per cent of those from the lowest income bracket had survived after five years (2010 and 2018), compared with 69 per cent of those from the highest income bracket (Olsen, Kjær and Dalton 2019). For males, life expectancy may fluctuate by as much as 10–13 years between those at the top and the bottom of the income ladder (Brønnum-Hansen and Baadsgaard 2008). These trends emphasise that welfare societies are not immune to the deepening social inequalities occurring globally. In Denmark, despite growing investment in cancer control programmes, the gap in life expectancy rates has been widening since the 1980s, while differences in relative survival for most cancers are becoming increasingly apparent (Dalton et al. 2019).

Looking closely at Sofie's life helps us to better understand what lies behind these numbers. She grew up in a poor family. She started working at the age of 13, first as a seamstress and then as a shop assistant. Her husband Christopher suffers from diabetes, irregular heart rhythms and liver disease after many years of heavy drinking. Sofie has three children from a previous marriage and her youngest



Figure 10.1 Picture of a social housing association in Denmark. Photo: The Danish Cancer Society.

son is mentally ill and lives in sheltered housing. Now, at 66, Sofie's bodily condition is a testimony to the adversity of her life (Kleinman and Kleinman 1994). Often racked with pain and enduring stiffness in her joints, she moves slowly around her small apartment, relying on a seat walker and sporadic assistance from Christopher. For several months before she was diagnosed with cancer, Sofie had endured diffuse and indistinct pain, but she was unable to convince her doctors that she did not need more physiotherapy, as they failed to see the distinction between Sofie's previous discomfort and her more recent pain. Now, after several major operations, Sofie's bones have crumbled and her backbone is held together by metal screws that enable her to hold her upper body somewhat upright.

Danish researchers have often pointed to gendered or social bias on the part of practitioners, as well as lifestyle differences and social and cultural differences in health-seeking behaviour and decision-making, including in relation to cancer (Ibfelt et al. 2013; Vilhelmsson and Östergren 2018). People with lower incomes and low levels of education are less likely than wealthier, better-educated people to seek medical care or recognise cancer symptoms and are more likely to have negative beliefs about cancer treatment (Hvidberg et al. 2015). While these studies are sensitive to how local actors embody meaning-making and engage with the healthcare system, more recently, clinical ethnographers have advanced the hypothesis that biomedical knowledge is 'biased', not in the sense that it is 'wrong', but in the sense that it is partial knowledge constructed from prevailing understandings of the body and society (Manderson and Ross 2020; Nguyen and Peschard 2003). For instance, if biological norms and diagnostic tests are standardised on middle-class, white populations, they may not

perform accurately in groups that differ biologically or in the way they articulate and embody changes. Dominant forms of knowledge of the body, and the care politics (Tronto 2012) and therapeutic practices through which the body is made visible or attended to, are central to our understandings of social inequalities in health (Manderson and Ross 2020). In some ways, by virtue of its efficacy, medicine has 'become an unwitting accomplice to biological inscription of social hierarchies', as noted by Nguyen and Peschard (2003: 457).

In this chapter we suggest that medical representations of cancer symptoms, or what we refer to as medical semiotics, and the promise of bodily distinctions that these representations bring into diagnostic infrastructures, are imaginaries that augment the deepening of social inequalities in health in Denmark. Through detailed examination of ethnographic cases, we explore what we call 'the noisy bodies' (Merrild, Vedsted and Andersen 2017: 14) of people who live on the margins of the Danish welfare society. We ask how they experience, attend to and represent their bodies and we describe the limitations they face in making the kinds of bodily distinctions that are encouraged by contemporary cancer care politics advocating 'early diagnosis' and 'do not delay' messages (Andersen 2017).

Material and methods

In this chapter we draw on data from interlinked ethnographic field studies conducted by Merrild, Offersen and Andersen on cancer diagnostics between 2012 and 2019. The studies were part of a research portfolio carried out in a multidisciplinary research centre at Aarhus University, in Denmark, observing ongoing changes in cancer control. All studies explored everyday forms of embodiment, people's perceptions of cancer, cancer symptoms and healthcare-seeking practices. Intermittently from 2012 to 2019, Merrild and Offersen worked in different sites in suburban and rural areas in Jutland, Denmark, among different social classes. Merrild carried out fieldwork among people who lived in socially deprived areas, who had little or no education and low levels of income and who may be described as coming from disadvantaged backgrounds. Some of Merrild's interlocutors were suffering from cancer, and some were not (for example, Merrild and Andersen 2019). Offersen conducted fieldwork in two local communities: one could be characterised as middle class with ready access to regional services and one could be characterised as rural and 'remote' in terms of geography and access to healthcare services. Her

interlocutors were not suffering from cancer but did participate in national cancer screening programmes and would occasionally seek care on suspicion of cancer, along with other worries (Offersen et al. 2018). Andersen conducted fieldwork in suburban areas of Jutland, exploring clinical encounters and care-seeking practices in four general practice clinics between 2012 and 2018 and visiting people in their homes; all her interlocutors had sought care on the basis of suspected cancer (Andersen 2017). In total, we conducted 89 interviews with potential patients on healthcare-seeking experiences and everyday embodied experiences of cancer risks and symptoms and more than 50 interviews with healthcare professionals in GP clinics – nurses, receptionists and GPs – on their experiences of diagnostic encounters. Although we worked with some people who were suffering from cancer, the majority of our interlocutors were not. This meant that we relied on prospective empirical material on embodied experience and diagnostics when exploring peoples' notions of cancer symptoms and healthcare seeking. People with migrant backgrounds (such as Kurds, Somalis or Arabs) were present in our fields, as patients or health professionals in GP clinics or as neighbours and community members in the local settings where Merrild and Offersen worked. None of our key interlocutors or interviewees represented these migrant groups, however. We realise that this is not an innocuous decision; it somewhat speaks to a conceptualisation of the existence of bounded cultures or an imagined sameness among 'indigenous Danes' (Rytter 2019). However, as suggested in the literature on inequalities in health, people with migrant backgrounds, particularly people from Arab and African countries, may face particular language- or stigma-related problems when engaging with the Danish healthcare system (Rosenkrands et al. 2020). Also, due to their experiences of replacements, racism and economic hardships, their health status and the social sufferings that mark their lives may differ from that of people with non-migrant backgrounds (Ølholm et al. 2016). Due to these potential differences in life experiences and health status, we decided not to include them as interviewees and key interlocutors in our studies.

In writing this chapter, we draw on cases from our respective fieldwork, focusing on people who may be characterised as living less privileged lives in relation to income, education and social status, illuminating the embodiment of social inequalities observed across our data. In this chapter we present the lives of Jenny and Sofie, both of whom Merrild followed for more than a year.

Cancer care politics and an expanding medical semiotics

Medical semiotics, or what by medical convention is considered the symptoms and signs of underlying disease, have, as eloquently shown by Angel Martinez-Hernandez (2000), historically played an important role in how physicians order and interpret patient bodies. Symptoms such as pains or dizziness have traditionally in biomedicine been considered ‘a patient’s subjective illness complaint’, which, through the inference of a physician, are either assigned to pathological categories or deemed subjective and clinically irrelevant (Martinez-Hernandez 2000: 5–7). Signs such as blood or lumps, on the other hand, were considered to constitute more direct semiotic references to biology and the diseased body (Martinez-Hernandez 2000). Since the publication of Foucault’s (1994) *The Birth of the Clinic* (first published in the late 1960s) social scientists have debated the continuing importance of signs and symptoms in medicine, some suggesting that the role of medical semiotics, and particularly symptoms, has been pushed to the background because of the increasing reliance on technology. It has been suggested that the patient is now scanned rather than listened to (Martinez-Hernandez 2000).

As Andersen (2017) has proposed elsewhere, however, the role of medical semiotics is increasingly important in building diagnostic infrastructures. Diagnostic infrastructures rely on people moving around (seeking care or being referred) and medical semiotics are important indicators of action in this process. This is also the case in contemporary cancer diagnostic infrastructures. In order to reap the benefits of biotechnologies such as PET and MRI scanners that can make early disease stages visible, it is essential that potential patients respond to ‘early’ signs and symptoms of disease. While Foucault (1994) predicted that medical practice of diagnosis by symptoms would vanish with the birth of anatomical pathology, we suggest that the biotechnologies that make the interior of bodies visible have not lessened the importance of symptoms to medicine, but they have somewhat changed their status from a signifier of disease (or risk) to a signifier of action. Contemporary care politics are directed towards the governing of the tactile, sensorial body.

This change in status, and the importance of medical semiotics to building diagnostic infrastructures, are evident in the cancer politics that have dominated the Danish healthcare system since the early 2000s. In the late 1990s, in contrast to other high-income nations, Denmark was struggling with high cancer morbidity and mortality and cancer epidemiologists and health promoters pointed to delay in diagnosis and treatment as the main culprit (Jensen, Mainz and Overgaard 2002).



Figure 10.2 ‘Colon cancer detected in due time can be cured’. Poster from a cancer-awareness campaign run by the Danish Cancer Society in 2014.

This brought about unparalleled regulation of the healthcare system, with an explicit focus on timely cancer diagnosis and treatment. The public and healthcare professionals were subject to several campaigns promoting ‘do not delay’ messages, which urged people to act on any perceived anomaly, such as a persistent cough, blood in stools or unexplained pain. Reference to cancer symptoms was also central in the clinical guidelines that serve as a reference point between general practice clinics and hospitals. In order to produce knowledge of relevance for early diagnosis initiatives, cancer epidemiologists and health promoters turned towards cancer symptoms (for example, [Hamilton 2010](#)), seeking to identify those ‘early symptoms’ through which ‘early stage cancer tumours’ make themselves perceptible to the sensing tactile body.

Epidemiological knowledge on the classification of symptoms of cancer is based on probability theory and provides quantified probabilities regarding the risk of having a cancer when experiencing a specific bodily sensation. From epidemiological as well as clinical perspectives, knowledge on what may be classified as a cancer symptom rests on the assumption that the ill body speaks to us through symptoms. Following this logic, symptoms may be identified in empirical research and grouped into taxonomies according to the underlying cancer thought to cause them. Although cancer risk as indicated by particular bodily sensations increases with age and when symptom categories cluster, it is assumed that a colon cancer (for example) will reveal itself in the same ways across humans of different ages or cultures, depending on the stage of the tumour growth.

Some early papers and discussions within the cancer epidemiological community suggested pursuing a 5 per cent risk strategy, meaning that people presenting in the clinic with symptoms indicating a 5 per cent risk of an underlying cancer should be further investigated. Leading epidemiologists and clinicians, however, quickly realised that this would result in a rather short list of cancer symptoms, which would not solve the problem of delay in presentation for diagnosis and treatment (see [Andersen 2017](#)). As an example, haemoptysis or coughing, which may indicate lung cancer, has predictive values of approximately 0.4 and 2.4 per cent when occurring as a single symptom among people seeking care. The same low risks are reproduced when exploring relations between rectal bleeding and colon cancer, or post-coital bleeding and ovarian cancer ([Hamilton 2009](#)). During the past decade, as early diagnosis and ‘do not delay’ messages have gained increasing political and public momentum, we have seen a vast expansion of what clinicians and epidemiologists now classify as cancer symptoms ([Andersen 2017](#)). Today, the lists of cancer symptoms in guidelines and awareness-raising campaigns are extensive. People are encouraged, for example, to seek care (and doctors are encouraged to raise cancer suspicion) if they experience tiredness, feel bloated, lose weight, if their digestive habits change, if they experience unexplained pain, if stiffness lingers for too long, if they cough or have an itch and so forth.

As noted by [Offersen and colleagues \(2016\)](#), this list of symptom categories feeds into the production of a cancer discourse that teaches us that a cancer may be hiding in silence within our bodies and it reminds us that bodies, in our contemporary world, are heavily invested with meaning. Medical semiotics carry social meanings, and contemporary biomedicine encourages self-conscious and hyper-vigilant forms of embodied attention and meaning-making ([Jain 2013](#); [Nichter 2008](#)). Moreover, as we now describe, the medical semiotics of cancer does not consider the biological human body as a site of both considerable commonality and difference ([Lock 1993](#); [Lock and Nguyen 2010](#)). Nor does it take into account that that people’s perceptions of potential illness are continually altered from the standpoints of different bodies embedded in a world of practice and future.

Attending to noisy bodies

The interpretation of embodied sensations as symptoms of potential disease is always a social process, as are the movements (such as care

seeking) that follow the recognition of symptoms (Merrild, Vedsted and Andersen 2017; Offersen et al. 2016). Hinton, Howes and Kirmayer (2008) describe sensations as social and cultural schemas, while Hay (2010) emphasises the need to understand how bodily representations are formed and when sensations are perceived as ‘symptoms of underlying disease’. Such perspectives emphasise that the processes by which bodily representations occur must be studied across cultural and historical contexts (Hinton, Howes and Kirmayer 2008). With the concept of the noisy body, we would like to take the discussion further, to emphasise what Kleinman and Kleinman (1994: 710) called ‘the unfolding of culture into the body’ and what Lock (1993: xxii–xxiv) has described as ‘local biology’. Lock posited the idea of local biologies to account for ethnographic findings that symptom experiences at the end of menstruation differed significantly between women in Japan and women in North America. Lock insisted that this difference was not merely due to cultural differences in bodily representations, but was also material, in the sense that female bodies in Japan and in North America should not be considered as similar specimens of a universal body (Lock 1993). She asserted that the concept of local biologies accounts for the way in which ‘the embodied experience of physical sensations, including those of well-being, health, and illness, is in part informed by the material body, itself contingent on evolutionary, environmental, social and individual variables’ (Lock 1993: 39).

While the Kleinmans did not conceptualise the biological basis of embodied experiences in the same way as Lock, they share the idea of the biological body as both culturally inscribed, and – as critical for understanding our argument – consequential to social practices, such as the making of bodily distinctions. Reflecting on empirical work on the effects of decades of trauma in China, since pre-World War II revolutions through to Tiananmen Square, they describe symptoms as ‘lived memories’ (Kleinman and Kleinman 1994: 713–715), bridging troublesome social contexts of their interlocutors and their bodily selves. They state that the body responds to trauma with bodily symptoms, hence bodies and cultures are interwoven, with this ‘interweaving’ situated in the body-self, which they define as the ‘transpersonal moral-somatic medium of local worlds’ (Kleinman and Kleinman 1994: 716). These concepts suggest that embodied experiences, and the ways in which they are attended to and interpreted, are informed not only by cultural understandings of physiology, health and illness, but also by the ways that medicines, foods and social hardship may act in and on the biological body. The cultural representations of bodies and the transformation of

sensations into symptoms differ across cultural and historical settings, but in addition, the flesh (Frank 1995) or the material biological bodies (Lock 1993) differ. We emphasise this interweaving of social inequality and embodied experience through the concept of noisy bodies. The notion of noisy body reminds us that bodies are flesh, and flesh cannot, as Frank (1995) insisted, be denied. But as body-selves, people experience and make sense of their material bodies in particular ways and this has implications for healthcare seeking and how, when or if people engage in diagnostics (Andersen, Nichter and Risør 2017).

Sofie

In Denmark people rarely speak about social class. Danes, like other Scandinavians, like to think of themselves as living in a ‘classless society’ (*klasseløst samfund*). This does not mean that differences or social hierarchies do not exist. As suggested by the Danish anthropologist Steffen Jöhncke, it more likely reflects dominant cultural ideals that equate being middle class to being Danish. These ideals ‘veil rather than remove class as a structural principle’ (Jöhncke 2011: 46). As described, inequalities in health are deepening, as are differences in income and social hierarchies. The Danish welfare state is built on the ideal of universal coverage, with healthcare services, subsidised childcare, education and student grants and social security schemes all financed through income tax; access to most services is not means tested. Since the 1980s, however, neoliberal ideologies of governance have emerged with accompanying welfare state retractions and the consequences of this are unevenly distributed (Merrild and Andersen 2019; Vallgård 2019). Housing reforms, workforce reforms, restricted access to social benefits and the introduction of less generous unemployment benefits have made lives increasingly difficult for those most disadvantaged. The translation of inequality into precise figures is difficult, but conservative estimates suggest that 250,000 Danes (of a total population of 5.8 million) live in poverty. Despite Denmark’s publicly funded healthcare system, co-payments for medication and other out-of-pocket costs such as transport pose significant burdens on those from low-income households (Bakah and Raphael 2017). Moreover, circumstances such as being unemployed, being overweight or suffering from so-called lifestyle-related diseases increasingly function as social markers of failure and intensify stigma (Dencker-Larsen and Lundberg 2016).

Sofie and Christopher affirm these inequalities. They have both worked in unskilled jobs and unlike most of the Danish population, they live in a rented house instead of owning their own property. Before her first experience of cancer 18 years ago, Sofie undertook physically demanding, low-paid work. However, she has spent the past 13 years reliant on social benefits. Christopher, who used to work in a warehouse, also lives off early retirement benefits. He has been drinking heavily for many years, which has severely damaged his liver. He also suffers from diabetes, which is worsening as he does not follow the dietary recommendations. Early retirement and social welfare benefits are intended to support people who, due to health-related problems, are unable to work. Recently, however, the criteria to qualify for these benefits has changed, causing great concern to many who are dependent on them. Sofie and Christopher often complain about the ongoing assessment of their health by the state 'to make sure that they are still too sick to work', as Sofie says.

Despite changes in the distribution of social benefits, Sofie and Christopher enjoy free access to medical services, with their GP serving as the primary entry point. They are both experienced users of the health-care system. Christopher has a home nurse who visits fortnightly to check his medications, discuss lifestyle issues and engage in acute consultations due to falls, pains or other concerns. Sofie rarely contacts healthcare providers outside her scheduled appointments. She only consults with her GP when she needs to adjust her medications for cancer control and chronic pain and she is in regular contact with the hospital department which is monitoring the progression of her cancer.

Sofie likes to spend most of her time at home, trying to keep the house in order. She worries about how she is going to manage it as she easily tires and her joints are painful. Simple things like cleaning the top shelves in the kitchen cabinets are difficult and to do so, she has to ask her neighbour or her daughter for help. Christopher does not really help much. He sometimes vacuums the floor and Sofie does not think that she can expect more from him. 'He has not been used to doing that sort of stuff', she says. Sofie struggles to manage her and Christopher's day-to-day care and their failing, unstable bodies without relying too much on others. She does not complain, having grown up in a poor family where she had to contribute from an early age. Before meeting Christopher, she lived for many years as a single mother with three small children, so she is used to 'getting along' (*klare sig selv*), moving uncomfortably around using the walking chair, trying to position her body in a way that causes her least pain.

On several occasions before cancer in her neck was diagnosed, Sofie made attempts to voice her embodied experiences of pain and tiredness

and to articulate them in a way that would make sense to her GP, on whom she knew she had to rely in order to get the scan that she believed she needed. When asked how long she had experienced her pains, she answered: 'I tried to tell them about my pains, for almost a year I tried to explain. But they, well nobody really, wanted to accept that it hurt as much as it did.' Sofie finally decided to raise her voice, which, for her, was unusual: 'I was sure that it was cancer. But they didn't think so. To them it did not fit the pattern.'

If we think of the noisy body as a kind of body-self (Kleinman and Kleinman 1994) that expresses underlying diseases, traumas or memories of loss through sensorial changes, it becomes clear how people such as Sofie, who live difficult lives, do not benefit from an expanded medical sign system that feeds on clear associations between the specifics of bodily sensations and the classification of underlying disease and which considers cancer a standard disease, similar across biological bodies. Such a sign system does not enable Sofie to share her sentience or to 'recognise the early cancer symptoms'. Her pains could have 'just' been her old pains, not pains signifying new kinds of diseases; her tiredness could have 'just' been caused by her daily struggles to make ends meet. Sofie's situation thus exemplifies how lives marked by distress and illness shape noisy bodies that bear poor witness to the subtle sensorial changes that an early stage cancer might have produced. But it also shows how bodies are always, already, embedded in a series of culturally shared forms of knowledge that help organise them (Nichter 2008). Sofie had to raise her voice in order to be heard. Many of our interlocutors, living in difficult life circumstances, share this experience; often they must present their complaints several times to doctors and their symptom experiences are explained with reference to already identified diseases.

Noisy bodies are thus easily rejected in the clinical setting, because suitable explanatory models are already in place. Simply thinking of symptom awareness as a cognitive or informational act does not take into consideration that embodied experience is an assemblage of social processes, which flows back and forth through the social spaces of institutions and the body-self (Kleinman and Kleinman 1994).

Jenny

Jenny is 65 years old. She lives together with her husband and their adult daughter, Christina, in a small apartment in a poor suburban area in Jutland. The apartment seems cramped, perhaps because it is packed

with stacks of newspapers and large furniture and the TV is always on. During one of Merrild's visits, Jenny has a cast on her arm. She suffers from tenosynovitis, caused by the strain of carrying Christina up and down the stairs after she suffered a complicated fracture in her leg. Christina suffered brain damage during birth and she has ADHD and non-verbal learning difficulties; she still lives at home due to her disabilities. Jenny spends most of her time at home caring for Christina, the youngest of her seven children. Like Christina, Jenny's other children all suffer from physical and cognitive disabilities and all of them live on social benefits. Her husband is away at work all day and she has few friends. 'I have become lazy, and watch too much television', she sighs when Merrild asked her about her everyday life. There is a sense of stillness in her life, a sense of detachment and little motivation; she just manages to get through each day. Jenny has spent most of her life at home taking care of her children. She worries about Christina, who has attempted to take her life several times, and she is concerned about her if one day Jenny is not able to care for her.

Jenny worked as a social and healthcare worker for about 12 years, but due to her asthma and COPD (chronic obstructive pulmonary disease), her retirement pension kicked in when she was in her late 30s. This was long before it became so difficult to qualify for it. Much like Sofie, Jenny does not seem to complain. Almost to the contrary. When asked if she has other things that she struggles with, apart from her asthma and COPD, she replies, 'well, not more than other people are dealing with . . . high blood pressure, cholesterol. And then my ADHD of course.' As she talks, however, it seems that she has more to deal with than most people. She suffers from chronic pain stemming from her osteoarthritis. Some years back she suffered from a blood clot. 'Oh yeah, and I also have depression and get anti-depressants for that', she casually remarks. As a result of her many conditions, she takes a lot of medication, which comes prepacked from the pharmacy. She can name the different drugs she is taking and she is aware of their possible side-effects. The anti-depressants make her tired and the drug that keeps her blood pressure 'in the range of the normal', as she describes it, sometimes makes her dizzy and gives her a headache.

There is no doubt that life is hard for Jenny. She manages most things on her own and she is used to getting things done without help. When we talk about friends and family, she goes quiet, as if pondering. She has few friends. And she is often tired, so it is easier just staying at home. It is clear that she is trying to keep her life, and that of her daughter,

her health and her body, afloat and much of the time she does this while lying on her bed, alone in her apartment watching the TV.

Jenny tries her best to manage the many side-effects of her medications and she elaborately explains how much she can take and when it is best for her to take what drugs. When asked how she knows all this, she tells Merrild about a variety of Facebook groups and websites where there is considerable information about her conditions. Jenny is a member of several online groups where members share their predicaments, their knowledge of bodily experiences and new forms of treatment.

Jenny knows the healthcare system well. She regularly visits her GP and she sees a lung specialist three times a year. When she talks about the healthcare system, she seems frustrated, like Sofie. 'In the old days, when you went to see the doctor, they would take care of your problems, but now you can only bring one thing to each consultation', which is often the case in GP clinics who operate on tight time schedules. But for Jenny, 'there is never just one thing' and last time she saw her GP she also raised the concern that she might have cancer. Almost a year earlier she noticed a birthmark on her back, which was itching and annoying her. So the week before she met with Merrild, she consulted her GP: the pain in her arm was becoming unbearable and the combination of painkillers and anti-depressants were making her tired. Just as she was leaving, she asked the doctor if he would mind taking a quick look at her back. She knew quite well that this was not the proper process, 'they want you to make separate appointments for stuff like that, but usually they agree to take a quick look', she says with a sneaky smile. She continues to talk about her arm and how it is difficult to help Christina while it is in a cast. Merrild asks what happened with the thing on her back. 'He [the doctor] said it was fine. He could remove it another time, if I wanted him to. But you know there is all this talk about skin cancer and stuff like that so I figured I might as well ask. And it had been so annoying on my back, and also, you know, I was feeling tired due to the drugs and all.'

Jenny may be what is often referred to as a 'frequent attender' in public health terms, meaning that she has contact with her GP more than eight times a year ([Sundhedsdatastyrelsen 2020](#)). The frequent attender label is perceived negatively by the Danish public. Using the healthcare system in a sensible manner is culturally condoned. People are often eager to emphasise that they do not misuse the healthcare system and our interlocutors often maintained 'I rarely or ever go to see my doctor' or 'I only go when it is necessary.' However, an expanding medical semiotics, and the noisy body of Jenny, which bears the memories of pharmaceuticals and her depression, her respiratory illness and her hardships carrying

Christina around (figuratively and literally), makes it difficult for her to be sensible and to make the kinds of bodily distinctions that would ensure an 'early diagnosis' if cancer were growing inside her body. Jenny's noisy body is an assemblage of the ingestion of drugs and social and mental hardships, which stimulate her sensations 'concordant with cultural norms' (Nichter 2008: 163). Jenny is expected to be tired.

Jenny's hardships make clear how different life experiences enable and constrain different kinds of embodied experiences, actions and care-seeking decisions. If we follow the idea that symptoms may be the 'lived memories of past trauma' (Kleinman and Kleinman 1994: 716) and that the material body is contingent on environmental variables such as alcohol or drugs, then Sofie's pains and Jenny's tiredness are not just 'the symptoms that make up' their noisy bodies, but also the phenomenal point of departure from which they experience their worlds (Merleau-Ponty 2012: 100). How people engage in cancer diagnostics depends not only on how they interpret their bodies but also on the culturally embodied possibilities they have for distinguishing feeling fine from being sick (Hay 2010). The limitations of Jenny's and Sofie's (and their doctor's) possibilities to 'hear their body speak' (Frank 1995: 29) thus reveal the failed promise inherent in contemporary cancer semiotics and exemplify how medical disease representations may add to the production of inequalities in health. The vague and expanding medical semiotics that constitute contemporary cancer diagnostic infrastructures do not easily translate into useful sensorial distinctions for people living with noisy bodies. The noisy body is thus a poor phenomenal point of departure to detect an early cancer. This compounds the effects of a clinical culture that values efficiency (only one problem at a time operated in tight time schedules) in the cultural figure of 'the sensible patient' and, in the Danish context, a sensible middle-class patient (Offersen et al. 2016).

Conclusion: the failed promise of contemporary medical semiotics

In the late 1990s and early 2000s when cancer diagnostic infrastructures in Denmark were readjusted in order to avoid the long waiting lists that had long characterised the health system, symptom awareness was coined as a key strategy to accelerate diagnostic procedures. Since then, changes in diagnostic infrastructures have solved some problems: people do not wait for months before undergoing diagnostic investigations and patients

are increasingly diagnosed with cancers that are curable (Jensen, Tørring and Vedsted 2017). The social inequalities in cancer, however, have not been addressed; rather they seem to have widened (Dalton et al. 2019).

Within health promotion circles, in Denmark and beyond, inequalities in cancer survival are often explained with reference to lack of recognition of cancer symptoms and delays in care seeking (Davies et al. 2018; Ibfelt et al. 2013). In a recent report on early cancer diagnosis, the World Health Organization highlighted the importance of awareness of cancer symptoms as key to improving diagnosis: 'Patients must be aware of specific cancer symptoms, understand the urgency of these symptoms, overcome fear or stigma associated with cancer and be able to access primary care' (WHO 2017: 13). While such statements may work to encourage countries to improve access to care, they do not reflect the complex assemblage of biological, social and cultural dimensions that converge in the embodied practices of awareness and care seeking. This situation becomes infinitely more complex in local settings where the western scientific tradition of 'symptoms and cancer' has been imported and grafted onto local knowledge and forms of life (Livingston 2012). Simply thinking of symptom awareness as a cognitive or informational act does not take into consideration the way in which embodied experience is 'an assemblage of social processes that come together as a medium of interaction that flows back and forth through the social spaces of institutions and the body-self' (Kleinman and Kleinman 1994: 712).

In this chapter, we have explored the social life of medical semiotics and, specifically, how cancer symptom representations are produced and how people give meaning to bodily sensations within specific individual, social and biological contexts. This approach allows us to understand how disease representations bring new possibilities of perception and embodiment to social life. We have also shown how these fail to deliver useful distinctions for people living difficult lives at the margins of the Danish welfare state, illustrating the interconnections between health, institutions and bodily experiences. By viewing symptom experiences as embodiments of biological, social and cultural contexts, we have emphasised how (potential) failures to make distinctions between bodily sensations (as symptoms of underlying disease or as part of the everyday 'normal') are not merely attributed to errors of judgement but to aspects of local biology; or how culture and the biological body are interwoven (Kleinman and Kleinman 1994). Following Nguyen and Peschard (2003: 254), we suggest that 'the inequality – disease relationship is enhanced through the classificatory rationalities that dominates contemporary medicine'. Medical representations of cancer symptoms, and the promise

of embodied distinctions they bring into the building of diagnostic infrastructures, are thus imaginaries that augment the deepening of social inequalities in health in Denmark. By paying attention to the social life of medical semiotics, we are reminded that there exists what Rose (2007: 254) might have called 'a biopolitical vocation' to sensorial experience and bodily attention that adds to the production of differentiating social statuses and privilege.

The notion that culture 'unfolds into the body' (Kleinman and Kleinman 1994: 710), or the idea that the material body should not be left unattended when researching embodied experiences such as symptoms or sensations, is not new to anthropology. Scheper-Hughes and Lock (1987) used the concept of the 'mindful body' in their initial attempts 'to problematise the body' in anthropology and other social sciences. Recently, focus on violence and trauma, coupled with the subjectivity, has generated interdisciplinary conversations threading together the processes of individual experiences within specific cultural, social and biological contexts (Biehl, Good and Kleinman 2007; Hinton and Good 2009; Meinert and Whyte 2017; White et al. 2017). Hinton and Good (2009), for example, found that strong emotional states, including states of anxiety, are often re-experienced as a cascade of embodied sensations associated with evocative memories, triggered by particular spaces, times and breaches in social relations, as well as by states of uncertainty and threats to the future. Lock (2018: 458) has further conceptualised environmental and human entanglements through critical discussions with epigenetics, reminding us of the complexity of the questions raised once we take the material body seriously in anthropological analysis. As these insights gain momentum, a research agenda on the social life of medical semiotics will continue to improve our understandings of the relationship between social inequality and embodied experience. Overall, we know little about how social response and the experience of sensations are changing in socio-political cultural contexts exposed to new types of medical semiotics, produced and developed in response to new medical ideologies and technologies (Nichter 2008). If we glimpse into the future, the convergence of big data and vast resources to build artificial intelligence based diagnostic technologies will most likely result in diagnostic imaginaries where biographical and biological details, behaviours and sensorial experiences are transformed into new kinds of medical semiotics. How will such kinds of medical representations or visions of diagnostics transform into bodily experiences and how or when people ask themselves: Am I sick? Should I seek care? And, critically, how will they alter or exacerbate global inequalities in health?

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References

- Andersen, Rikke Sand. 2017. 'Directing the senses in the contemporary orientations to cancer disease control: Debating symptom research', *Tidsskrift for Forskning i Sygdom Og Samfund* 26: 145–167. <https://doi.org/10.7146/tfss.v14i26.26282>.
- Andersen, Rikke Sand, Mark Nichter and Mette Bech Risør. 2017. 'Sensations, symptoms and healthcare seeking', *Anthropology in Action* 24(1): 1–5. <https://doi.org/10.3167/aia.2017.240101>.
- Bakah, May and Dennis Raphael. 2017. 'New hypotheses regarding the Danish health puzzle', *Scandinavian Journal of Public Health* 45(8): 799–808. <https://doi.org/10.1177/1403494817698889>.
- Biehl, João, Byron J. Good and Arthur Kleinman. 2007. *Subjectivity: Ethnographic investigations*. Berkeley: University of California Press.
- Bronnum-Hansen, Henrik and Mikkel Baadsgaard. 2008. 'Increase in social inequality in health expectancy in Denmark', *Scandinavian Journal of Public Health* 36(1): 44–51. <https://doi.org/10.1177/1403494807085193>.
- Dalton, Susanne Oksbjerg, Maja Halgren Olsen, Christoffer Johansen, Jørgen H. Olsen and Kaae Klaus Andersen. 2019. 'Socioeconomic inequality in cancer survival – changes over time: A population-based study, Denmark, 1987–2013', *Acta Oncologica* 58(5): 737–744. <https://doi.org/10.1080/0284186X.2019.1566772>.
- Davies, Hilary, Afrodita Marcu, Peter Vedsted and Katriina L. Whitaker. 2018. 'Is lower symptom recognition associated with socioeconomic inequalities in help-seeking for potential breast cancer symptoms?' *Psycho-Oncology* 27(2): 626–632. <https://doi.org/10.1002/pon.4557>.

- Dencker-Larsen, Sofie and Kjetil G. Lundberg. 2016. 'Depicted welfare-recipient stereotypes in Norway and Denmark: A photo-elicitation study', *Nordic Journal of Social Research* 7: 1–15. <https://doi.org/10.15845/njsr.v7i0.866>.
- Farmer, Paul. 1999. *Infections and Inequalities: The modern plagues*. Berkeley: University of California Press.
- Foucault, Michel. 1994. *The Birth of the Clinic: An archaeology of medical perception*. New York: Pantheon Books.
- Frank, Arthur. 1995. *The Wounded Storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.
- Hamilton, William. 2009. 'The CAPER studies: Five case-control studies aimed at identifying and quantifying the risk of cancer in symptomatic primary care patients', *British Journal of Cancer* 101(2): S80–86. <https://doi.org/10.1038/sj.bjc.6605396>.
- Hamilton, William. 2010. 'Cancer diagnosis in primary care', *British Journal of General Practice* 60(571): 121–128. <https://doi.org/10.3399/bjgp10X483175>.
- Hay, M. Cameron. 2010. 'Suffering in a productive world: Chronic illness, visibility, and the space beyond agency', *American Ethnologist* 37(2): 259–274. <https://doi.org/10.1111/j.1548-1425.2010.01254.x>.
- Hinton, Devon E. and Byron Good, eds. 2009. *Culture and Panic Disorder*. Stanford, CA: Stanford University Press.
- Hinton, Devon and Susan Hinton. 2002. 'Panic disorder, somatization, and the new cross-cultural psychiatry: The seven bodies of a medical anthropology of panic', *Culture, Medicine and Psychiatry* 26(2): 155–178.
- Hinton, Devon, David Howes and Laurence Kirmayer. 2008. 'Toward a medical anthropology of sensations: Definitions and research agenda', *Transcultural Psychiatry* 45: 163–197. <https://doi.org/10.1177/1363461508089763>.
- Hvidberg, Line, Christian Nielsen Wulff, Anette Fischer Pedersen and Peter Vedsted. 2015. 'Barriers to healthcare seeking, beliefs about cancer and the role of socio-economic position: A Danish population-based study', *Preventive Medicine* 71C: 107–113. <https://doi.org/10.1016/j.ypmed.2014.12.007>.
- Ibfelt, Else Helene, Susanne Krüger Kjær, Claus Høgdall, Marianne Steding-Jessen, Troels Kjær, Merete Osler, Christoffer Johansen et al. 2013. 'Socioeconomic position and survival after cervical cancer: Influence of cancer stage, comorbidity and smoking among Danish women diagnosed between 2005 and 2010', *British Journal of Cancer* 109(9): 2489–2495. <https://doi.org/10.1038/bjc.2013.558>.
- Jain, S. Lochlann. 2013. *Malignant: How cancer becomes us*. London: University of California Press.
- Jensen, Annie, Jan Mainz and Jens Overgaard. 2002. 'Impact of delay on diagnosis and treatment of primary lung cancer', *Acta Oncologica* 41(2): 147–152. <https://doi.org/10.1080/028418602753669517>.
- Jensen, Henry, Marie Louise Tørring and Peter Vedsted. 2017. 'Prognostic consequences of implementing cancer patient pathways in Denmark: A comparative cohort study of symptomatic cancer patients in primary care', *BMC Cancer* 17: 627. <https://doi.org/10.1186/s12885-017-3623-8>.
- Jöhncke, Steffen. 2011. 'Integrating Denmark: The welfare state as a national(ist) accomplishment'. In *The Question of Integration: Immigration, exclusion and the Danish welfare state*, edited by Karen Fog Olwig and Karsten Pærregaard, 30–53. Newcastle upon Tyne: Cambridge Scholars.
- Kleinman, Arthur and Joan Kleinman. 1994. 'How bodies remember: Social memory and bodily experience of criticism, resistance, and delegitimation following China's Cultural Revolution', *New Literary History* 25(3): 707–723. <http://www.jstor.org/stable/469474>.
- Livingston, Julie. 2012. *Improvising Medicine: An African oncology ward in an emerging cancer epidemic*. Durham, NC: Duke University Press.
- Lock, Margaret. 1993. *Encounters with Aging: Mythologies of menopause in Japan and North America*. Berkeley: University of California Press.
- Lock, Margaret. 2018. 'Mutable environments and permeable human bodies', *Journal of the Royal Anthropological Institute* 24(3): 449–474. <https://doi.org/10.1111/1467-9655.12855>.
- Lock, Margaret and Vinh-Kim Nguyen. 2010. *An Anthropology of Biomedicine*. Singapore: Wiley Blackwell.
- Manderson, Lenore and Fiona C. Ross. 2020. 'Publics, technologies and interventions in reproduction and early life in South Africa', *Humanities and Social Sciences Communications* 7(40). <https://doi.org/10.1057/s41599-020-0531-3>.

- Martinez-Hernandez, Angel. 2000. *What's Behind the Symptom? On psychiatric observation and anthropological understanding*. Abingdon: Routledge.
- Meinert, Lotte and Susan Reynolds Whyte. 2017. 'Social sensations of symptoms: Embodied socialities of HIV and trauma in Uganda', *Anthropology in Action* 24(1): 20–26. <https://doi.org/10.3167/aia.2017.240104>.
- Merleau-Ponty, Maurice. 2012. *Phenomenology of Perception*, translated by Donald A. Landes. Oxford and New York: Routledge.
- Merrild, Camilla Hoffmann and Rikke Sand Andersen. 2019. 'Welfare transformations and expectations of sameness: Living on the margins in Denmark', *Nordic Journal of Social Research* 10(1): 66–84. <https://doi.org/10.7577/njsr.2858>.
- Merrild, Camilla Hoffman, Peter Vedsted and Rikke Sand Andersen. 2017. 'Noisy lives, noisy bodies: Exploring the sensorial embodiment of class', *Anthropology in Action* 24(1): 13–19. <https://doi.org/10.3167/aia.2017.240103>.
- Nguyen, Vinh-Kim and Karine Peschard. 2003. 'Anthropology, inequality and disease: A review', *Annual Review of Anthropology* 32(1): 447–474. <https://doi.org/10.1146/annurev.anthro.32.061002.093412>.
- Nichter, Mark. 2008. 'Coming to our senses: Appreciating the sensorial in medical anthropology', *Transcultural Psychiatry* 45: 163–197. <https://doi.org/10.1177/1363461508089764>.
- Offersen, Sara Marie Hebsgaard, Mette Bech Risør, Peter Vedsted and Rikke Sand Andersen. 2016. 'Am I fine? Exploring everyday life ambiguities and potentialities of embodied sensations in a Danish middle-class community', *Medicine Anthropology Theory* 3(3): 23–45.
- Offersen, Sara Marie Hebsgaard, Mette Bech Risør, Peter Vedsted and Rikke Sand Andersen. 2018. 'Cancer-before-cancer: Mythologies of cancer in everyday life', *MAT Medicine Anthropology Theory* 5(5): 30–52. <https://doi.org/10.17157/mat.5.5.540>.
- Ølholm, Anne M., Janne B. Christensen, Stine L. Kamionka, Mette L. Eriksen and Morten Sodemann. 2016. 'Hospital-based case management for migrant patients: A systematic review', *Public Health Panorama* 2(4): 515–526.
- Olsen, Maja Halgren, Trille Kristina Kjær and Susanne Oksbjerg Dalton. 2019. *Hvidbog: Social Ulighed I Kræft i Danmark*. Copenhagen: Kræftens Bekæmpelse.
- Rose, Niklas. 2007. *The Politics of Life Itself*. Oxford: Princeton University Press.
- Rosenkrands, Hanna S., Maria Kristiansen, Amalie Lipczak Hansen and Marię Norredam. 2020. 'Providing targeted healthcare services for immigrants with complex health needs', *Danish Medical Journal* 67(10). Accessed 15 September 2022. <https://ugeskriftet.dk/dmj/providing-targeted-healthcare-services-immigrants-complex-health-needs>.
- Ryter, Mikkel. 2019. 'Writing against integration: Danish imaginaries of culture, race and belonging', *Ethnos* 84(4): 678–697. <https://doi.org/10.1080/00141844.2018.1458745>.
- Scheper-Hughes, Nancy and Margaret Lock. 1987. 'The mindful body: A prolegomenon to future work in medical anthropology', *Medical Anthropology Quarterly* 1(1): 6–41.
- Seeberg, Jens and Lotte Meinert. 2015. 'Can epidemics be noncommunicable? Reflections on the spread of "noncommunicable" diseases', *Medicine Anthropology Theory* 2(2): 54–71. <https://doi.org/10.17157/mat.2.2.171>.
- Sundhedsdatastyrelsen. 2020. 'Udvalgte nøgletal for praksisområdet 2009–2019'. Accessed 17 August 2021. <https://sundhedsdatastyrelsen.dk/da/tal-og-analyser/analyser-og-rapporter/sundhedsvaesenet/noegletal-om-sundhedsvaesenet>.
- Tronto, Joan. 2012. 'Democratic care politics in an age of limits'. In *Global Variations in the Political and Social Economies of Care: Worlds apart*, edited by Shara Razhavi and Silke Staab, 29–42. London: Routledge.
- Udesen, Caroline Holt, Carina Skaarup, Maria Nivi Schmidt Petersen and Anette Kjær Ersbøll. 2020. *Social Ulighed i Sundhed og Sygdom*. Copenhagen: Sundhedsstyrelsen.
- Vallgård, Signild. 2019. *Hvordan Minder vi Uligheden i Sundhed*. Copenhagen: Informations Forlag.
- Vilhelmsson, Andreas and Per Olaf Östergren. 2018. 'Reducing health inequalities with interventions targeting behavioral factors among individuals with low levels of education: A rapid review', *PLoS ONE* 13(4): e0195774. <https://doi.org/10.1371/journal.pone.0195774>.
- White, Jarrod, Louise Newman, Glenn Melvin, Lenore Manderson and Katrina Simpson. 2017. 'Contextualizing posttraumatic stress disorder within culturally diverse groups: A comparison of Holocaust survivors and Sudanese refugees', *International Journal of Culture and Mental Health* 11(3): 321–331. <https://doi.org/10.1080/17542863.2017.1377271>.
- WHO (World Health Organization). 2017. *Guide to Cancer Early Diagnosis*. Geneva: World Health Organization.