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Surveillance life and the shaping of ‘genetically at risk’ chronicities in Denmark

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Abstract

Today, in the field of hereditary colorectal cancer in Denmark, more than 40,000 identified healthy individuals with an increased risk of cancer are enrolled in a surveillance program aimed at preventing cancer from developing, with numbers still growing. What this group of healthy individuals has in common is lifelong regular interaction with a healthcare system that has traditionally been geared towards treating the acutely and chronically ill. In this article, we explore how people living with an inherited elevated risk of colorectal cancer orient themselves towards their families’ and their own predispositions as well as the lifelong surveillance trajectories that they have embarked upon – what we call surveillance life. Unlike prior critiques of predictive genetic testing as generative of ‘pre-patients’ or ‘pre-symptomatically ill’, we suggest that for those enrolled in lifelong surveillance programmes in welfare state Denmark, the relevance of risk fluctuates according to certain moments in life, e.g. at family reunions, when a close relative falls ill, in the time leading up to a surveillance colonoscopy or when enduring the procedures themselves. As such, rather than characterising surveillance life in terms of ‘living with chronic risk’ we show how ‘genetically at risk’ chronicities take shape as persons come to terms with a disease that possibly awaits them leading them to recalibrate familial bonds and responsibilities while leading lives punctuated by regular medical check-ups.

Keywords
Risk, hereditary cancer, Lynch syndrome, surveillance, chronicity, Denmark
Introduction

“I do think I have a life like everyone else’s, so it’s not something I… well, just before the colonoscopy I do feel the weight of it all and this past summer I was weighed down by it. But, mostly that was because I was about to have the colonoscopy, but I don’t think about it on an everyday basis, I don’t think I have less of a quality of life. And it’s not like I think now I have to spend all my money traveling the world because I will die from colon cancer tomorrow.”

Louise is a 27-year-old, healthy woman who carries an inherited gene defect known as Lynch syndrome that significantly increases her risk for several cancer types, most notably colorectal cancer. Faced with a diagnosis of ‘at elevated risk’ and the prospect of lifelong recurrent medical surveillance, Louise recalls thinking: “If you were to have a gene defect, this is the lucky one to have drawn from the pool of gene defects because there are things you can do about it. It’s not like the Alzheimer genes where you might get demented by the age of 40, but really there’s nothing you can do about it. As long as I follow the programme, I ought to be in a safe-zone.”

Louise’s reflections on how it is to live with Lynch syndrome in Denmark reveal some of the ambiguous tensions that surround the personal and social ramifications of living with an inherited increased risk of colorectal cancer. As we will see, for Louise as well as other healthy at-risk individuals living in Denmark who have tested positive for Lynch syndrome and subsequently lead a life with lifelong recurrent medical check-ups, learning about an inherited elevated risk for colorectal cancer does not quite amount to the life-changing ‘biographical disruption’ (Bury 1982; Becker 1999) or ‘loss of self’ (Charmaz 1983) that a diagnosis of a chronic or degenerative disease can bring in its wake (see also Jauho 2019 & Lau 2018). Being
healthy yet at elevated risk is not everything, but it is not nothing either. And so, we might ask, if it’s not disruption, then what is it?

One of the central developments within 21st century biomedicine has been the stabilisation of what might be thought of as a ‘preventive healthcare complex’ within primary and secondary healthcare, which are otherwise geared towards treating the acutely and chronically ill. While efforts to prevent illness have long since been a part of national health policies and interventions in different parts of the world, in recent years, developments within the fields of biomarker research, genetics and related screening programmes have generated a parallel group of ‘at risk’ persons enrolled in secondary prevention and early detection programmes within hospital and general practice settings. Self-reported unhealthy lifestyles, elevated cholesterol levels, high blood glucose or blood pressure levels, genetic mutations, abnormal brain scans and more are now routinely used to identify persons ‘at risk’ of cancer, diabetes, heart disease, and more. In the name of prevention or early detection, such ‘at risk’ persons may then be encouraged to join lifestyle interventions, put on preventive pharmaceuticals ‘for life’, advised of the possibilities for preventive surgery and/or enrolled in lifelong surveillance programmes (Kenen et al. 2003; Greene 2007; Dumit 2012; Will & Weiner 2014; Jauho 2019; Lau et al. 2018).

In this article, we zoom in on one of these at-risk groups by exploring the shaping of what we call ‘surveillance life’ and the genetically at-risk chronicities it engenders in welfare state Denmark. We do so by unravelling accounts of how people with Lynch syndrome orient themselves towards their families, their predispositions, as well as the lifelong surveillance trajectories that they have embarked upon. Rather than characterizing their life in terms of ‘living with chronic risk’, we suggest that once lifelong surveillance programmes have become
a routine part of their lives, those who have inherited an elevated risk for colorectal cancer are reminded of this risk at certain moments in their lives - when meeting a partner, when starting a family, when a close relative falls ill, or in the time leading up to a surveillance colonoscopy. In Kenen and colleagues’ study of risk perceptions among healthy women with a family history of breast/ovarian cancer, they see ‘chronic risk’ as analogous to chronic illness, arguing that it can help us understand how informants “live with their heightened awareness of risk” (2003: 315). In shifting our attention away from ‘chronic risk’ which “involves perceptions—thoughts about potential body deterioration, rather than actual deterioration” (ibid.: 318) and towards what we are calling ‘genetically at risk’ chronicities as lived life, we show how lifelong surveillance trajectories intersect with life courses and vital conjunctures (Johnson-Hanks 2002) in unpredictable ways, not least since the age and life stage at which someone learns about their genetic predisposition for colorectal cancer can vary greatly, from adolescence through to later life. Leading a surveillance life forms around endeavours to stay healthy by adhering to a surveillance programme specifically targeted at identified Lynch syndrome families. In what follows, we show how surveillance life – as a new chronicity – in welfare state Denmark can be conceptualised through the analytical notions of coming to terms, care and control. But first, let us take a closer look at Lynch syndrome and what early detection and prevention of hereditary colorectal cancer entail in a Danish context.

**Prevention of hereditary colorectal cancer in Denmark**

Colorectal cancer (CRC) is the fourth most common cancer in the western world (Fitzmaurice 2018). Lynch syndrome, previously known as hereditary non-polyposis colorectal cancer (HNPCC), is the most common of the hereditary CRC syndromes caused by mutations in one of the mismatch repair genes (MLH1, MSH2, MSH6 and PMS2). It is autosomal dominant,
meaning that if one of your parents has the mutation your risk of inheritance is 50%. Lynch syndrome holds a lifetime risk of colorectal cancer from 20-80% depending on the gene, compared to 5% for sporadic cancer in the general population (Lynch et al. 2017). Though not as well-known as the BRCA genes which greatly increase the risk of breast cancer (Kenen et al. 2003; Gibbon 2007; Mozersky 2012), genetic factors are estimated to contribute to up to one-third of all colorectal cancers. The mean age of onset of hereditary colorectal cancer is 45 years, compared to 65 years for sporadic cancer, but cancer caused by Lynch syndrome occasionally strikes as early as in the 20s.

Denmark is a high-income country with just 5.7 million inhabitants and with universal tax-financed coverage of medical care and a range of other welfare benefits. Although some out-of-pocket expenses for pharmacy prescriptions and dental care are incurred, there is a high degree of social security overall. The Danish or ‘Scandinavian’ welfare model (Siiger 2009: 29) has been built around values such as equality and egalitarianism, which have in turn been adopted by Danish citizens by and large as defining characteristics of Denmark (Jöhncke 2010 [2007]: 37). Based on this self-identification with the welfare state, Danes are often described as accustomed to intervention by the state into personal matters (Høyer 2019).

In Denmark, a national surveillance program [kontrolprogram in Danish] targeting those healthy individuals at verified risk of hereditary colorectal cancer was established in 1991. The surveillance program is publicly financed and coordinated by the HNPCC (Hereditary Nonpolyposis Colorectal Cancer) register at Hvidovre University Hospital in Copenhagen. Distinct from the national colorectal cancer screening programme (offered to all citizens upon turning 50), the surveillance programme only includes persons with a confirmed inherited
elevated risk. When established in the early 1990s, the purpose of the registry was to reduce and prevent mortality and morbidity by tracing families with Lynch syndrome and other forms of hereditary colorectal cancer as well as to develop and streamline clinical practice. Today, the programme works by inviting persons with an inherited elevated risk of colorectal cancer for regular colonoscopies every second or five years (depending on risk status) with the aim of detecting potentially pre-cancerous adenomas and removing them before they grow into cancerous tumors or of detecting cancer in early stages. All adenomas detected during a colonoscopy are removed and sent to pathology laboratories. If a cancerous tumor is detected, the patient is assigned to a cancer treatment program. According to clinical studies, regular colonoscopies decrease the risk of disease and death by up to 60% (Jarvinen et al. 2009). As preventive devices, colonoscopies are invasive procedures that, other than causing discomfort and pain, carry certain risks such as perforation. The implementation of the register owes in part its results to an elaborate IT infrastructure and digitised health service system, containing structured data on all citizens from cradle to grave (Høyer 2019). This is possible since every Danish citizen is allocated a personal identity number at birth or upon emigration that is used in all interactions with public authorities (and for many private services as well).

Notwithstanding the existence of similar HNPCC registries in other parts of the world, having a national surveillance programme that routinely reaches out to Lynch syndrome families with an ‘offer’ of regular surveillance is quite unprecedented. As shown for instance in a study on preventive genetics in China, some health systems leave it to the individual to buy a genetic test and seek out options for medical surveillance on their own hand and out of their own pocket (Deleuran 2018; see also Zhu 2013). While clinical guidelines in most Euro-American countries have a directive stance towards familial responsibility of disclosing genetic information (Forrest
et al 2007), the extent to which the Danish health care system steers people’s preventive health is quite controversial. Thus, surveillance lives in Denmark are not only intimately tied to a Scandinavian welfare model but also to a well-organised surveillance programme and pervasive health imperative.

We begin our article by discussing how the bulk of hitherto social science engagements with genetic risk has had an empirical focus on the production, communication and/or sharing of knowledge about genetic risk, often through research involving observations of genetic counselling accompanied by interviews with clinical geneticists, counselees and counselee family members. It is through this research that the analytical notions of ‘pre-patients’, ‘perpetual patients’, ‘pre-symptomatically ill’ and ‘patients-in-waiting’ have been developed. We then go on to describe our methodology, which has allowed us to explore the surveillance life that begins in the months and years after counselling.

Predictive genetics and the new chronicities

David Armstrong has famously argued that 19th century Hospital Medicine was eventually joined by Surveillance Medicine in the latter half of the 20th century as extensive screening programmes and health promotion campaigns were rolled out across Europe. Surveillance Medicine, he argues, “turns increasingly to an extracorporeal space – often represented by the notion of ‘lifestyle’ – to identify the precursors of future illness” (Armstrong 1995: 401). Following up on his analysis, Joseph Dumit has argued that the rise of such a surveillance medicine has resulted in a shift from individual to ‘mass health’ especially when it comes to cardiovascular disease where the identification of elevated cholesterol levels as a ‘risk factor’ has led to preventive pharmaceutical ‘treatment’ on a massive scale (Dumit 2012; see also
Greene 2007; Will & Weiner 2014; Jauho 2019; Lau et al. 2018). While we in the field of hereditary cancer in Denmark may not speak of mass health, more than 40,000 healthy individuals with an identified increased risk of cancer are (or will be, for some as early as from the age of 25) enrolled in a surveillance programme, with numbers still growing.

These new possibilities for predicting, preventing and detecting disease have in turn shaped cultural and social understandings of illness and identity under a new ‘molecular optics’ (Novas and Rose 2000). At the same time, the new genetics have caused concern among several social scientists and bioethicists. A plethora of empirical studies has critiqued the new genetics for ‘genetisicing’ identity by delineating genes as ‘the cause’ of disorders at the expense of more socially grounded explanatory models (Lippmann 1992; Hallowell 1999; Finkler 2000; Svendsen 2005; Mozersky 2012; Aribas Ayllon 2016). Based on her fieldwork among British families affected by the late-onset neuropsychiatric condition Huntington’s Disease, Monica Konrad even argues that genetic foreknowledge shapes people as ill before they are diagnosed, couched through her concept of the ‘pre-symptomatically ill,’ which, she contends, makes “genetic prognostication itself a fundamentally chronic affair” (Konrad 2003: 27 See also Sachs 1997 and Konrad 2005). In a Danish context, Mette Nordahl Svendsen has shown how genetic counselling shapes social understandings and relations in ways that turns cancer prevention into a moral imperative (Koch and Svendsen 2005; Svendsen 2006). In America, Mara Buchbinder and Stefan Timmermans have argued that the routinisation of postnatal screening for genetic disorders has turned newborns into ‘patients-in-waiting’, requiring parents to take responsibility for their child’s uncertain health status while awaiting a potential metabolic crisis that might never strike (Timmermans & Buchbinder 2010, 2012). Others have been less worried about the potential impact of the new genetics. In their article on genetic risk and the birth of the somatic
individual, Novas and Rose for instance argue that “re-cataloguing illness and pathologies along a genetic axis does not generate fatalism. On the contrary, it creates an obligation to act in the present in relation to the potential futures that now come into view” (2000: 486). Bharadwaj (2002) suggests that learning that one is susceptible to genetic haemochromatosis does not seem to lead to radical transformations in identity or to impact relations amongst kin in profound ways (see also Lock et al. 2007). While these studies all share a focus on the production of genetic knowledge through genetic counselling and testing, and the psychological and social implications of receiving genetic test results, with the exception of a few studies (Sachs 1997; Caiata-Zufferey 2015) much less explored has been what happens after genetic counselling.

Taking up Atkinson and colleagues call for more “analyses of the intersection of genetic risk and family life” (2013: 1237), in this paper we ask: How might we think about life at elevated risk once routinised medical surveillance has settled in?

The fact that surveillance life has not been investigated more systematically is surprising, considering that genetic testing and medical surveillance are no longer cutting edge, rather they have become routinised throughout the world. So much so that, as noted earlier, a parallel group of ‘at risk’ persons – alongside the acutely and chronically ill – are now enrolled in prevention and early detection programmes within healthcare systems. While a host of new chronicities have now stabilised around such conditions as type 1 diabetes, chronic kidney disease and HIV involving regularised treatment regimens and rhythms of daily care (see Introduction, this issue; Manderson & Wahlberg 2020), ‘genetically at risk’ chronicities we suggest are forming around surveillance life. It of course remains important to study genetic counselling practices; however, it is what happens after a positive genetic test result that will have lifelong implications. It is to
this surveillance life – as a genetically at-risk chronicity – that we direct our attention in the analysis that follows.

The study

The article builds on a joint interdisciplinary research venture between the Department of Anthropology at the University of Copenhagen, where the first and second authors are affiliated, and the HNPCC register at Hvidovre Hospital, where the third author is based. The data on which our analysis of surveillance life is based, comes from over ten years of qualitative engagement with families with Lynch syndrome who follow the recommended surveillance program. Interviews with 12 persons with Lynch syndrome were carried out by the third author in the period 2009-2011 followed by a further 6 interviews with individuals with Lynch syndrome carried out by the second author in the period 2017 to 2019. Moreover, all authors have conducted focus group interviews with families (parents and their adolescents) with Lynch syndrome during 2019. All individuals came from families with mother, father and siblings, and the study is thus limited to heterosexual family forms. Moreover, observations of 15 genetic counselling sessions and follow-up interviews with individuals who had been referred for counselling based on a suspicion that they might have an inherited elevated risk of colorectal cancer were made by the second author. All authors have carried out observations of colonoscopies carried out at a gastroenterology unit. Finally, information evenings for healthy ‘at risk’ persons organised by the Danish HNPCC register were attended and observed, just as interviews with attending families were carried out. We connect these different spaces and interlocutors by focusing on the shaping of surveillance life and by attuning to the social experience of being healthy but at risk as it unfolds after the moment of disclosure of one’s medical category as ‘at elevated risk’. This category is, as Nordahl Svendsen (2006) reminds
us, not only a medical classification but also a social category as it carries certain ideas about responsible health preventive actions; in this case in the form of adherence to a surveillance programme of recurrent colonoscopies.

Coming to terms

Knowledge of genetic risk and the prospect of lifelong recurrent medical check-ups are catalysed at different life stages for people with Lynch syndrome. For some, genetic predisposition is disclosed during adolescence when parents inform their children of the possibility of inherited risk and they subsequently test positive for Lynch syndrome. For others it happens in adulthood or old age in the wake of discovering that a relative has inherited the defected gene. Still others are ‘caught’ following participation in a national screening programme for colon cancer offered to all Danish citizens upon turning 50. As noted earlier, medical sociologists and anthropologists have long highlighted the disrupted lives that often emerge out of a serious diagnosis, as individuals and their carers come to reorient and reshape their lives in the face of (anticipated) bodily limitations, discomforts, pain and unease. What is more, as Scambler and Hopkins argue in their 1986 article “Being epileptic: coming to terms with stigma”, receiving a diagnosis can also lead to the deployment of tools of negotiation and strategies of concealment as individuals and family members seek to ward off potential damage from the social stigma that surrounds a chronic condition. However, unlike diagnosis of a serious condition, the beginnings of surveillance life can in some ways be traced to the moment when a person learns that Lynch syndrome ‘runs in the family’. Regardless of what moment in a person’s life this happens, the question of whether to take a genetic test or not becomes an inescapable part of coming to terms with it, as we also know from numerous social studies of genetic counselling (Mozersky 2012; Hallowell et al. 2006). And while the personal and social
processes of coming to terms might never settle entirely, accepting that one carries a ‘faulty gene’ that necessitates being attentive to one’s own body in new ways stands as a crucial threshold for commencing a life under medical surveillance.

Children and young adults may come to learn that one of their parents has Lynch syndrome either following a conscious decision by parents “to have a talk” with their children or inadvertently by overhearing an adult conversation or when wondering why a parent is going to regular check-ups. Those adolescents and young adults who are aware that they might have inherited Lynch syndrome face a decision at the age of majority (18 in Denmark) about whether to be tested or not. Some genetic counsellors actively advise against this, arguing that since surveillance colonoscopies will only commence at age 25 there is no reason to burden these young people with knowledge of genetic risk until there is something to be done. But not everyone agrees with them, as one of our 18-year-old informants explained:

Mmmm, I have thought a lot about it, um, because it means quite a lot to me whether I’m walking around with this gene without knowing about it. Yeah, and so that’s why as soon as I turn 18 I’ll go in to have the test, while my sister on the other hand is totally different. She’s 21 years old and has no need to know… I was actually advised not to find out about it at such a young age, whether I had the gene, because I wouldn’t be able to do anything before I was 25 anyway, but um [sighs]… I just feel quite sure about it. [Bella, 18 years old]

Others did heed the advice of genetic counsellors:
I had been told that at around the age of 25 I would be able to find out whether I was a carrier or not. The closer I got to 25 the more I started thinking about it. So, in fact I ended up calling them myself to ask if I should come in. [Kasper, 35 years old]

For those, like Bella and Kasper, who do decide to have a genetic test, approximately 50% will of course learn that they have inherited Lynch Syndrome from one of their parents. There are many parallels to be drawn to the moment where genetic test results are given to a person with Lynch syndrome and a person who receives a diagnosis of a serious chronic or acute condition. Virtually all of our informants could vividly recall the moment they had learned of their elevated at-risk status:

The waiting time from having had the blood test until I went in to see [clinical geneticist] was tense. And I did feel like I had been hit by a freight train when I found out that I was carrying the gene. In that moment, it was as if my world fell apart. That’s how it was right at that moment. I didn’t really know where I stood. But, when it… I came to terms with it. If all I had to do was attend the colonoscopies every second year, then nothing could happen to me, you know? [35-year-old male]

As hinted at here, the more or less dramatic moment of disclosure is quite quickly surpassed by the exigencies of a daily life filled with work, school, chores and social engagements. Persons who learn that they have Lynch syndrome are after all healthy and so what they must come to terms with is related, on the one hand, to the potential that they one day may get cancer (and the surveillance program that is intended to prevent that), and on the other, that other family members (whether present or future) might also have Lynch syndrome. Since Lynch syndrome is genetic, those who bear its genes quite understandably orient themselves towards their kin,
worrying about their siblings and/or children who might likewise or might not have inherited Lynch Syndrome. This concern is at times construed in terms of ‘guilt’ that one has passed such a mutation on to children (see also Mozersky 2012). But it can also generate a new sense of belonging as suggested by one of our informants who exclaimed “oh we’re just the jolly mutation-carriers” to describe members of nuclear and extended family who bonded over having the “family’s gene”. Hence, one of the first aspects of coming to terms with having Lynch syndrome concerns a kind of lateral and vertical recalibration of bonds and responsibilities to one’s self as well as one’s kin.

**Pastoral, familial and self-care**

As already noted, in Denmark, preventive action for persons with Lynch syndrome entails enrolment in a surveillance programme, which configures a particular ‘chronicity’ characterised not so much by particular treatment regimens or the experience of bodily symptoms as by a preventive health-promoting apparatus targeting asymptomatic bodies. For people with Lynch syndrome, the regular interactions with the health care system are what turns their lives into surveillance lives. Once individuals have come to terms with carrying a disease-predisposing gene, leading a surveillance life continues to be fraught with ambiguities, since it entails heightened medical attentiveness at certain periodic moments and lack thereof in times in between. There is no question that the regular colonoscopies individuals with Lynch syndrome undergo stand out as rhythmic reminders of the cancer they must do uncomfortable bodily work to keep in check. However, those who attend their surveillance colonoscopies tend to be grateful that they live in a society that provides them with such an “offer”. Martin, a young man in his twenties explained:
Now that I know I have the genetic defect I’m just really happy that I have the possibility to be in a surveillance programme, and then, you know, I don’t really think about it other than when two years are up and I have to go for my next check-up. Really because since I do go for check-up examinations, then, well, the risk of dying from colon cancer, is… at least that’s what I’ve been told, that my risk is the same as the rest of the population. [Martin, 29 years old]

Medical surveillance is valued for the reassurance and safety it provides. According to Foucault, modern Western nations – different from the sovereign, oppressive power of the monarch in the Middle Ages – are characterised by a simultaneously individualizing and totalizing state ‘pastorship’, in which constant vigilance over both individual citizens and groups produces self-disciplining and submissive subjectivities (Foucault 1988; Rabinow and Dreyfuss 1982). The state’s proclaimed reason for exercising vigilance is its benevolent responsibility to provide and care for everyone, or to ‘shepherd’ them. One crucial way in which pastoral care is exercised, giving the surveillance programme its successes, is through what could be called ‘rhetorical persuasion’, to borrow a term from Dumit (2012: 62). For instance, a young woman who had lost several family members to cancer told that her geneticist had explained that as long as she followed the surveillance programme, her chances of developing cancer were “like zero percent”. Through a streamlined strategy of conviction and conversion, people with Lynch syndrome come to understand prevention as virtually bullet proof. This exchange took place between an endoscopic nurse and a young woman, aged 25, who had recently been enrolled into the HNPCC programme:

Woman: I think these exams are really painful, so the more sedation you can give the better.

Nurse: Is your mother also being followed?
Woman: Yes, my mom has Lynch as well.

Nurse: Do you worry before the colonoscopy?

Woman: Well, yes, the thought has crossed my mind.

Nurse: You shouldn’t be walking around feeling anxious. All cancer comes from polyps, but not all polyps develop into cancer. We are here to catch them before they grow. You should tell yourself, “I for one do not have to worry!”

Through conversations like these, health professionals not only convince individuals of the benefits of surveillance, but also that having a gene defect is almost a positive lot in life. In this sense, undergoing surveillance is endorsed by the biomedical system as a health-promoting enterprise that turns people’s fate around from disadvantageous to advantageous and through these communicative acts, people are encouraged to learn to live with surveillance as a necessary part of life. Thus, for pastoral power to be productive in relation to the ‘HNPCC flock’ it hinges on the condition that people assume individualised responsibility for surveillance and adhere to medical recommendations and guidelines, that is that they continue to show up for their colonoscopies their entire life. Yet, pastoral care equally depends on well-orchestrated coordination of the multiple elements, units, technologies and personnel that constitute the surveillance assemblage. The bond between the health care system and people with Lynch syndrome is moral and mutually dependent, thus, for surveillance lives to be meaningful, it requires a liaison with the health care system as a joint responsibility for health (see also Caiata-Zufferey 2015: 146).

Yet such pastoral care can be seen to break down at times when care is experienced as lacking. One woman explained how:
I’ve been a bit upset about how it is run now, after [doctor] stopped. In the past, we always got the good doctors that had carried out these examinations a million times. It’s not like they are very pleasant those colonoscopies. I’ve been lying there screaming in pain, so of course it’s not pleasant. Because we have to do it again and again.

It is far from only pastoral care that shapes the surveillance lives of those with Lynch syndrome. Interfamilial mutual care plays an equally crucial role for many individuals in the maintenance of a meaningful surveillance life:

The examination itself is the worst. The last time, I really considered quitting. I thought, fuck it, let me just get cancer and get surgery. I threatened to do that, but then I talked to my mother who got really upset, she cried and wanted me to reconsider, get myself together and say, okay, ‘I’m gonna do this every second year for the rest of my life, and I’m just gonna have to… endure’. I really can’t deal with the pain, but I do it, every second year.

Family is what people with Lynch syndrome turn to when a life under medical surveillance becomes unbearable, and relatives mobilise themselves as supporters in times of doubt. Through the kind of lateral and vertical recalibrations of bonds and responsibilities that a positive test can catalyse, family members who share Lynch syndrome form family ‘cliques’ of emotional and practical relatedness:

Perhaps it’s something that has generated a kind of solidarity and unity among us. Well, of course based on something rather unpleasant… You know, every time one of us has been in for a check-up [kontrol] we ask “how did it go this time?” [Woman in her 50s]
In many ways, it is unsurprising that familial care should play such a central role in the lives of the genetically at risk, as the care they receive from the health care system is periodical. As already noted, in between colonoscopies persons with Lynch syndrome are basically on their own, thrown into an everyday life of uncertainty and watchfulness for signs of a disease that potentially will strike, which in turn generates certain practices of self-care. As explained by one of our informants:

I’m no saint, but I am conscious about what I eat. So, I’ve made a note of those things where when it’s colorectal cancer, then broccoli is good for you, so I guess we do eat more broccoli in my family […]. It’s the doctors’ responsibility to examine me carefully, I have to trust they do that, but in between check-ups it’s my responsibility, it’s my body, it’s my life.

Others insisted that their way of life was unchanged by their at-risk status, stating that they continued to for instance smoke, consume alcohol or eat red meat, even though they recognised these as generalised risk factors. However, for most, knowing about an elevated risk of cancer generated a heightened awareness about life-style. Adjusting lifestyle in terms of healthy eating or exercising was a way in which they could assume their own responsibility in keeping cancer at bay. Thus, while we might all be more or less susceptible to an imperative of health (Lupton 1995), being at elevated risk for many comes with an intensified consciousness about one’s own responsibilities in cancer preventive endeavours. In these ways, self-care can be viewed as an extension of the moral and mutually constitutive link between individuals, families, health care professionals and a welfare state that secures a healthy HNPCC flock.

*I kontrol* (in control)
Not only does living a life with a high risk of cancer imply practical actions that need to be taken to prevent cancer, it also implies managing and coping with the anxieties that the luring risk of cancer can actuate. For persons with Lynch syndrome, the notion of being in control has a dual meaning, perhaps especially so in Denmark where the word for surveillance is *kontrol*. And so, being ‘in control’ (*i kontrol*) represents *being under the control of* the preventive apparatus of surveillance medicine and *being in control* (of their life and situation) as an experienced, embodied sentiment, in the phenomenological sense. As we have seen, a positive genetic test result initiates a life under surveillance where an invasive, unpleasant and sometimes painful procedure becomes a prerequisite for staying healthy and alive. As such, for those who follow the recommended surveillance programme, the colonoscopy acts as the foundation for the feeling of having control of their lives, albeit very ambiguously so:

Hmmm… it does trouble me, but, well, it doesn’t trouble me that much any longer, you could say. It troubles me every time I have to go for some of the medical examinations, otherwise no. You can’t really go around feeling down about it all the time, can you?  
[Birgit, 50 years old].

Like Kenen and colleagues (2003), through our interviews we found that to tackle being at elevated risk, people used different ‘coping strategies’. Some seemed to take on a certain positive attitude to life, deciding not to let it affect their life negatively, as was the case with Louise in the opening vignette of this paper. For others, avoidance was the appropriate coping mechanism, as Camilla, a young woman whose father was diagnosed with cancer recently stated: “And when people around you get cancer, even though it’s not the same cancer as ours, you just go “oh, no”. I just can’t handle it and I shut down. I can’t bear to look at someone with cancer on the telly”. Yet another approach was that of having a mind-set that cancer would
inevitably come at some point. If they were prepared, it would not come as a shock, seemed to be the logic, as Karina expressed: “Yes, I think it will come. But, I am not nervous about it. Because, I believe it will be found in time”. While different, these sets of coping strategies can be read as our informants’ attempts to stay in control and “get on with their lives” (Kenen et al. 2003: 315).

During a colonoscopy, anxiety, pain and a lack of trust in healthcare professionals can create a sense of loss of control, with some informants attempting to regain control over these situations – by requesting a specific form of anaesthesia, an appointment that would fit into their schedule or a specific doctor – in a sense exercising agency upon a system that follows its routines and temporal structures and upon which one is also highly dependent if health is to be secured. Our informants’ approach to their colonoscopies was primarily formed by personal experiences from previous examinations and/or by anecdotal insights from other family members. When feeling they were not taken seriously when reporting symptoms or worries to doctors and nurses, this could increase a feeling of not having control.

It is in these different ways that being under control and attempts to regain or be in control shape the lives of persons living with Lynch syndrome, or what we are calling surveillance life. Everyday life filled with work obligations, family duties and daily routines are interrupted at different points in time and at vital conjunctures like getting married, passing an exam, having a child or losing a family member. These important moments, which are not related to risk as such, can often change a person’s life into new directions, evoking feelings and new ways of thinking and perceiving the world. Hereditary risk is perceived and understood in a familial and relational context (Petersen 2012; Svendsen 2005) and some of the most important moments in
life in many ways influence not only the individual but also family and family relations. At the same time, in surveillance lives, everyday life interacts with the health care system (through regular medical check-ups), clinical guidelines (which outline the kind and frequency of check-ups that are relevant) and research (which can give rise to hope for a new ‘fix’).

Conclusion
During the 20th century, surveillance medicine emerged through the spread of lifestyle interventions and mass screening programmes aimed at identifying an ever-growing group of persons ‘at risk’ of a future disease that could be prevented. In this article, we have examined not so much the spread of surveillance medicine within the Danish welfare state as we have the shaping of the surveillance life that increasing numbers of Danes with an inherited elevated risk of colorectal cancer are leading. Surveillance life is a palpable consequence of the discovery of highly penetrant genetic mutations that carry with them a risk of cancer and the consequent embedding of predictive genetic testing within a preventive, health-promoting apparatus in a welfare state that was founded on a principle of equal access to healthcare. While there are parallels to be drawn between genetically at risk chronicities and the chronicities that have more or less stabilised around long-term conditions like HIV or type 1 diabetes, there are also important differences. The chronically ill and genetically at risk share lifelong, regular interaction with the healthcare system in the form of medical check-ups that punctuate their lives, yet surveillance life forms around systematic efforts to prevent rather than treat disease. As such, surveillance life centres on healthy individuals who through recurrent colonoscopies strive towards staying healthy rather than living good lives in spite of disease. Moreover, hereditariness introduces lateral and vertical recalibrations of bonds and responsibilities to family members as well as to oneself. In some cases, of course, cancer is not prevented, instantly
transforming the healthy person who had been leading a surveillance life into a colorectal cancer patient (see Arteaga 2019).

There are also important differences between the different chronicities brought on by a ‘gene mutation carrier’ diagnosis. Thus, while colorectal cancer caused by Lynch syndrome can be prevented through regular colonoscopies without invasive surgery, surveillance and prevention of hereditary cancer is a contested terrain (Brodersen et al. 2010). At present, removal of breast tissue is the only effective but highly invasive way of preventing breast cancer from developing, while less invasive measures such as regular mammograms only help to discover the disease as early as possible. Furthermore, whereas hereditary breast cancer often befalls women, carrying a defected gene increasing your risk of colon cancer is a risk equally carried by both men and women. It is a highly stigmatised burden as the bodily parts implicated symbolise dirt and defecation. This does not mean that the burden of leading a surveillance life is not stratified across gender and social status, as the endeavours of staying healthy as mutation carriers naturally intersect with roles, responsibilities and exigencies of daily living.

While we have focused on the surveillance life that forms around Lynch syndrome families in welfare state Denmark, we would suggest that ‘at risk’ chronicities have come to play (increasingly so) a significant part in healthcare provision. Within outpatient and general practice settings, there is now a parallel group of ‘at risk’ persons enrolled in secondary prevention and early detection programmes alongside the chronically and acutely ill. Such developments are already placing healthcare providers under pressure as they struggle to keep up with the strain of increasing outpatient flows. At the same time, we as social scientists need
to ceaselessly attend to the consequent surveillance lives that a routinized surveillance medicine has brought in its wake.

References


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**Ethics Statement**

Research for this article has taken place according to the ethical requirements for qualitative research of Hvidovre Hospital and the University of Copenhagen governed by Danish law. Recruitment of interviewees and storage of interview data took place in compliance with national data protection requirements and all participants provided their oral or written informed consent to participating in interviews following clear information about the purpose of our
research. Having said this, while essential, formalized ethical procedures have played a relatively minor role in our ethical approach which has been ‘situated’ throughout as we always debriefed following interviews and ensured that interview participants were able to speak with relevant healthcare professionals in case their participation gave rise to any questions concerning genetic risk or medical surveillance. We took care to allow interview participants to reflect on their answers during interviews and during observations made sure not to interfere with ongoing medical procedures.

Biographical note

Laura Louise Heinsen is a PhD fellow at Aalborg University. She is the co-author of Selective Reproduction in the 21st century (eds. Ayo Wahlberg and Tine Gammeltoft) based on her former research on routine prenatal screening in Denmark.

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