

# 'In the meantime'

## Ordinary life in continuous medical testing for lung cancer

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### Abstract

Based on ethnographic fieldwork among Danes undergoing CT scans as part of follow-up testing for potential lung cancer, we explore how access to technologies generates diagnostic uncertainty and trends of continuous testing. Our research is set in the context of a welfare state that has cultivated forms of government whose public health branches focus on early diagnosis and cancer control. Many studies on biotechnologies emphasise subject-making and power relations. Inspired by the work of Veena Das, we adopt an approach that focuses on the entanglement of diagnostic investigations with everyday life. We argue that being followed establishes a mode of being which we call 'in the meantime'. Life in the meantime is equally characterised by a dramatic mode of being—that is, *waiting for death*—and an ambiguous mode of being: *feeling quite well*. As with any life crisis, it involves some sense of agency. We show in this paper how life in the meantime informs an ordinary ethics that encourages three ethical concerns in everyday life: firstly, how to inhabit life in the meantime? Secondly, what good is the testing for? And finally, what is a good death?

### Keywords

Closure, Potentiality, Uncertainty, Everyday life, Denmark.



1. Image of Jan sitting at the table. Photo by the author Michal Frumer, 2019.

## Introduction

In the telephone conversation, the doctor tried to explain to me what the lung change could be. 'It could be a lot of things,' he said. It could be former pneumonias, and Jan has worked with asbestos so it could also be due to that. It could be many things. But the doctor pointed out to me two or three times: 'It is not about cancer!' After a pause, he added, 'But Jan still needs to be followed.'

This statement by Bente about Jan's diagnosis shows how the diffuse entity of 'lung change' carries with it the diagnostic exercise of 'follow-up' and the experience of uncertainty 'in the meantime'. Through the case of Jan and his wife, Bente, we explore in this article the experiences of those who are tested and subject to follow-up CT scans for potential lung cancer in Denmark. Even with, and often because of, access to 'the best of technology' (a phrase often heard in Danish hospitals), diagnosing severe illnesses is an uncertain guessing game that can spiral into myriad uncertainties and searches for closure. As noted by Bente in the above, the doctor testing her husband, Jan, for lung cancer is both certain that Jan

does not suffer from a lung cancer and that Jan needs to be followed. The clinical impetus for follow-up is the small probability that an identified change grows into lung cancer. A change that remains stable over time (as detectable through CT scans) makes the likelihood of malignancy decrease considerably. In what follows, we explore the meaning and value of testing when it does not, and is often not expected to, lead to a definite diagnosis. What are the ethical implications for everyday living with regards to this form of testing, which is itself disconnected from diagnostic certainty?

In *Biomedicine in an Unstable Place*, Alice Street convincingly shows how patients in Madang Hospital in Papua New Guinea experience the chaos associated with a lack of resources in the public ward as an ontological crisis. They struggle to make themselves visible to others (i.e., doctors and nurses, their relatives that they have left behind in their pursuit of treatment, the state) 'as particular kinds of bodies or persons in the expectation of eliciting a productive relationship' (Street 2014, 24). This formulation is by itself a reason to explore care and diagnostics amid unstable biomedical infrastructures. Street persuasively demonstrates the materiality of inequality and the kinds of uncertainties that develop in a place where diagnostic technologies fail to work. In places with limited access to medical services and vital lifesaving drugs, she argues,

biomedical knowledge practices, and ancillary modes of relating to diagnostic technologies, do not bring about diagnostic closure. [...] In this clinical space, the contingency of medical fact becomes a productive end in itself and the open-endedness of the diagnostic process gives rise to more pragmatic forms of medical practice and more modest modes of expert personhood (Street 2014, 90).

Being well aware of the differences between the sociopolitical contexts engaged (Denmark and Papua New Guinea), we nonetheless suggest in this article that Street's merging of visibility and the production of uncertainty serves to unmask fundamental truths about biomedicine and hospitals in general. Biomedical technologies of today do not only seek to cure diseases when and where they have manifested; they also aim to reconfigure vital processes before pathologies ever develop (Rose 2007; Aronowitz 2015; Gibbon 2007). As testified by the research carried out by Sahra Gibbon and others (Gibbon 2007; Prainsack 2017), visualisation technologies and genomics (which we are coming to know as 'personalised medicine') are producing new languages and new categories of 'at-risk' patients, who must learn to live without closure. In privileged contexts, such as the Danish welfare state, diseases (and people) also 'fail to be made visible' (Street 2014, 18), and diagnostic work lingers on without a clear aetiology for

extended periods. But how do we understand what it is like to 'live under', as Emily Martin put it (2009), continuous medical testing and such lack of closure?

Within anthropology and beyond, there is a growing interest in the making of diagnostic categories (Bowker and Star 1999; Aronowitz 2001) and in the configuration of diagnostic processes and practices (Hadolt and Hardon 2017; Risør 2009; Risør and Nissen 2018). This literature testifies to how diagnostic work, including testing practices, is a process of 'making up' (Hacking 1999) people with diseases or in 'at-risk' states. It points to diagnostic processes as social events that not only name a condition (Brown 1995) but often also determine the hopes, expectations, treatment options, and cultural meanings associated with a given disorder or 'at-risk' status. In a recent collection, *Diagnostic Fluidity* (2018), Risør and Nissen present several contributions that point to the emotional work (Hadolt 2018) and the performative and intersubjective practices that go into testing and diagnostic work (Fainzang 2018; Tessier 2018). In exploring the generative role of emotions and affect in genetic cancer testing in Austria, Bernhard Hadolt (2018), for example, describes the affective rationales that organise genetic counselling. We learn how genetic counsellors operate a particular affective style that stresses rationality, client-centredness, and autonomous decision making, and how such emotional work shapes the intersubjective practices of genetic cancer counselling.

The collection, however, as implied by the title, raises questions that extend beyond the practices and consequences of diagnostic work and testing. In discussing the presence of 'fluidity in several modalities of diagnostic work' (Risør and Nissen 2018, 22), Risør, Nissen, and the contributors to the collection point to the unstable and increasingly permeable boundaries of diseases or 'at-risk' states that characterise contemporary biomedical practices. As testified by Tessier (2018) in her work on dementia, lack of evidence and an increasing societal focus on making dementia visible and treatable in the US imply that clinicians must rely on an assemblage of more or less objectifiable forms of knowledge (brain scans and genetics) and affordances (speech, emotions, personality traits) informed by the social contexts when conducting diagnostic work. Thus, Tessier (2008) shows how diagnostic work calls on both professional and more mundane forms of judgments, sense-making, and assessments. This also illustrates what Nettleton, Kitzinger, and Kitzinger have called the 'diagnostic illusory', referring to the 'ambiguities and nuanced complexities associated with the biomedical imperative to name and classify' (Nettleton, Kitzinger, and Kitzinger 2014, 134).

The literature demonstrates how biomedical realities—themselves created through processes of visualisation and classification—have a history that follows the social and cultural developments of society as much as it does the developments in and processes of medicine (Armstrong 2011, quoted in Risør and Nissen 2018, 14).

The acceleration of technological innovation in the Global North, the cultivation of particular forms of government that emphasise early diagnosis and prevention, and current patterns of resource distribution are all dominant in shaping the development of diagnostic practices and testing cultures (Jain 2013). However, the examples also demonstrate that biomedical realities are bound to social realities and exist in parallel with the mundane and the everyday. There is a 'social life' to diagnostics and testing (Svendsen 2006). In order to emphasise this aspect, Monica Konrad and others (Konrad 2003; Svendsen 2006) have suggested engaging in terms of conceptualising peoples' experiences of test cultures that embrace the temporal and everyday dimensions created by the increasing use of biotechnologies. In her work on genetic testing for Huntington's chorea, Konrad shows how the prognostic repertoire of genetic knowledge becomes embodied in family relations as well as in everyday forms of bodily attention, producing a new kind of chronicity that she calls 'foreknowledge' (Konrad 2003, 43).

Departing from writings on 'the ordinary' by Das and others (Das 2007, 2015b; Stewart 2007; Hyde and Denyer Willis 2020; van der Geest 2015), we add to the literature on diagnostics by exploring the temporal, existential, and affective dimensions of being that the diagnostic work of follow-up introduces to everyday life. We situate 'the ordinary' by ethnographically focussing on everyday life. This allows us to explore how diagnostic uncertainty persists in the everyday and how, within the comforts of a privileged middle-class livelihood, it both interrupts and is absorbed by the ordinary. This is done through a detailed engagement with and portrayal of the case of Jan and Bente, whom the first author met during fieldwork carried out in two hospital outpatient clinics for lung cancer diagnosis in 2015 and again in 2018–2020.

We argue that follow-up as a form of continuous testing establishes a mode of being that we call 'in the meantime'. Life in the meantime is characterised in equal parts by a dramatic mode of being—that is, *waiting for death*—and an ambiguous mode of being: *feeling quite well*. Being in the meantime involves some sense of agency (Konrad 2003) and a moral striving in everyday life (Das 2015b, 134). We show how everyday life in the meantime, for Jan and Bente, informs an ordinary ethics where three distinct concerns become entangled with ordinary doings, hopes, and aspirations: how to inhabit life in the meantime? What good is the testing for? What is a good death?

## **Cancer testing in the Danish welfare state**

In Denmark, as in other parts of the Global North, the state's focus on early cancer diagnosis over the past two decades has generated a comprehensive restructuring of diagnostic and treatment trajectories. Through the implementation of national

cancer plans, an emphasis on standardisation and timeliness has cut hospital waiting lists for cancer diagnostic interventions as well as lowered risk thresholds (Vedsted and Olesen 2015; Tørring 2014). Early diagnosis, it is implied, minimises both the risk of missing a cancer and encourages the ruling out of cancer whenever 'a suspicion' arises. Despite these efforts, disparities in cancer incidence and survival persist between Denmark and other high-income countries such as Norway and Canada (Arnold et al. 2019). Cancer is the leading cause of death in Denmark, with new cases amounting to more than 40000 per year. The majority of these patients are diagnosed because they seek medical care due to symptoms. It is estimated that only about 10% of all patients with cancer are diagnosed through one of the three national screening programmes (Hansen et al. 2011).

As a small country of 5.8 million people, Danish citizens enjoy the comforts of expanded healthcare coverage. The Danish welfare state aspires to provide a free-for-all equal-access healthcare system. General practitioners (GPs) regulate access to specialised healthcare and are responsible for allocating and coordinating healthcare to those in need. In Denmark, 99% of people are registered with a specific general practice, which they consult for medical guidance. With a strong public health focus, state efforts accentuate the need to control diseases (and, ultimately, death) by detecting and taking action on incrementally smaller signs of potential disease. This is very much the case with regards to cancer control. For instance, the Danish Cancer Society encourages Danes to know 'The 7 Signs of Cancer'<sup>1</sup> and to 'Save Your Father' on Father's Day by reminding him of so-called 'alarm' symptoms of cancer.<sup>2</sup> As Andersen argues, cancer diagnostics have seen a general 'disease sensitisation' characterised by the representation of bodily signs of cancer as 'ever-present "what ifs"' (2017, 162).

Around 4600 people per year are diagnosed with lung cancer in Denmark, a number evenly distributed between men and women. In terms of incidence, this makes lung cancer the second most frequent type of cancer in both men and women (prostate cancer being the most frequent in men and breast cancer in women). After five years, only about 18% of the men and 24% of the women suffering from lung cancer will still be alive. In total, lung cancer accounts for the majority of cancer deaths in Denmark for both sexes (Engholm et al. 2019). The 'recalcitrance' of lung cancer (Timmermann 2014) has directed efforts towards prevention, targeting cigarette prices and encouraging smoking cessation and early diagnosis. The CT scanning of lungs is part of this focus. Systematic screening for lung cancer is currently not endorsed by the Danish health authorities, and the vast majority of lung cancers are made visible because a person has sought care due to symptoms such as coughing or fatigue. Some

1 <https://www.cancer.dk/international/english/>.

2 [www.reddinfar.dk/](http://www.reddinfar.dk/).

people—including Jan—are offered follow-up testing if an indeterminate lung change shows up on their CT images. In a Danish study, a pulmonary nodule (a clinical term for lung change) was detected in almost one in four CT scans (Guldbrandt et al. 2014). Recent research reports an increasing incidence of pulmonary nodules per year in the US, from 150000 in 2003 to 1.5 million in 2015 (Gould et al. 2015); this is mainly due to the modification of diagnostic practices in terms of the increased use of CT modalities. It seems then that the surveillance of detected changes is becoming standard care in affluent settings. The same is true for other forms of predictive morphology that link specific changes in tissue to an increased danger of cancer in the future (Löwy 2008). For instance, in the management of bladder cancer, the detection of polyps implies five-year or even lifelong surveillance through follow-up testing. There is no national Danish count on how many people engage in such follow-up regimes, but numbers are increasing, as they are for people who have 'unspecific changes' made visible in the colon, cervix, or breasts (Danish Health Data Authority 2018).

Detected lung changes among Danes are currently monitored through a systematic follow-up schedule. Based on an algorithm, people are stratified into two groups according to their risk status (primarily their smoking status) and are offered follow-up at specific intervals according to the size and figuration of their lung changes. A person's intervals grow larger over time once their change has been deemed stable. Even though the schedule organises the experience of follow-up, the structure and its rationale are not obvious to the people being followed. This is certainly the case for Jan and Bente, whose story is the focal point of this article. In what follows below, we will introduce the empirical foundation of the article and then describe life in the Danish welfare state through the story of Jan and Bente.

## **Materials and methods**

Frumer's fieldwork began with follow-up consultations about sub-centimetre lung changes as well as with daily clinical work at lung clinics and CT conferences at hospital-based radiology departments. Diagnostic work in Denmark often unfolds like a pendulum; people arrive and leave again, with tests forming the pivot of the encounter. Often, results are shared via email; it is at home that people in follow-up regimes typically make sense of their diagnostic results and the signs and sensations of their bodies. Ethnographically, we approached the uncertainty of follow-up as something imbued with meaning through everyday life in Denmark.

A group of 13 people (seven women and six men) taking part in follow-up regimes for small lung changes agreed to participate in the project. In a few cases, the way into follow-up for our interlocutors was based on their GPs' (vague) suspicions of

lung cancer. Most of them, however, came to follow-up in more coincidental ways without suspecting cancer; for instance, after being CT scanned for heart trouble. Regardless, follow-up was still done with the intent of identifying potential signs of early lung cancer.

At the time of our field research, interlocutors were between 50 and 88 years old. Frumer visited each interlocutor at home soon after follow-up was offered and conducted semi-structured interviews. She kept in contact and conducted interviews while interlocutors waited for their first follow-up scans and after the first test results had been received. Frumer conducted between one and three semi-structured interviews with each interlocutor. These interviews covered issues pertaining to the interlocutor's experience of the follow-up regime and involved too more general health- and illness-related questions as well as questions about the interlocutor's life history more broadly. Spouses would sometimes be present, and interviews and home visits would sometimes involve garden walks and/or visits to the diagnostic clinic.

We base our analysis on all the ethnographic material available but, throughout the article, we engage particularly with the case of Jan and Bente (pseudonyms) to understand how they respond to being followed. With an emphasis on the ordinary, this approach allows us to accentuate the complexities, nuances, and minutiae of specific lives. We forefront 'what is at stake' through the slower pace of our detailed portrayal.

Before we engage more with Jan and Bente's story, a few general remarks must be made. Firstly, most of our interlocutors suffered from various illnesses, which were often unrelated to the lungs. None of the interlocutors perceived themselves to be ill due to lung changes. When they talked to friends or relatives about their follow-up, they spoke mostly about having an appointment at the hospital and the logistics of getting there. They did not consult websites for information, only (sometimes) their GP, and predominantly wondered 'is this something to be afraid of?' The vast majority did not make any dramatic life alterations but continued living as usual. With that said, the interlocutors who had not already stopped smoking did so during the follow-up. Six had never smoked in the first place. At one of the diagnostic clinics, a nurse several times told the story of a teacher, who—due to the follow-up—quit his job, sold his house, and called his family to come home (they were living abroad). This story was remarkable. Most people, like Jan and Bente, adjusted easily to being followed and articulated lightness despite the confrontation with potential suffering and death.

## Jan and Bente

We turn to the ordinary to ask questions about how the existential drama and uncertainty posed by continuous medical testing for lung cancer entangle with the everyday. This approach reflects the current movement within anthropology to turn away from the eventful and dramatic to instead foreground the ordinary as both the locus of ethical life and a site of those forms of vulnerability, suffering, and violence that appear quotidian (Das 2007, 2015b; van der Geest 2015; Gullestad 1984; Stewart 2007). From this perspective, critical moments and existential uncertainties are folded into the ordinary with its inconspicuous routines. In our usage, 'the ordinary' consists of everyday practices, affects, relations, and embodiments. We aim to show how the textures of uncertainty and ambiguity that are established during the diagnostic process become visible in the ordinary (see also Hyde and Denyer Willis 2020; Offersen et al. 2018). Interlocutors' experiences are often complex and incoherent and may conflict or conjoin at various moments and articulations (Throop 2010). When theory gets 'built into the ethnography itself' (Das 2015a, 15), the meaning of concepts and theoretical arguments 'emerge *in life*' (Das 2015b, italics ours), not outside of it, and do so without having been sorted for inconsistencies and ambiguities. This pattern allows us to explore how Jan and Bente are at once full of doubt (they pose questions, feel uncertain, etc.) and, at the same time, comforted and reassured. We suggest that their inconsistency expresses the struggle of leading ethical lives in the face of continuous testing.

Jan and Bente live in the countryside, just outside a small Danish city in which they can easily access grocery shops, a small commercial zone, and a public library. Like most Danes, they own a small single-family house, which they purchased and completely renovated back in 1984. They do not have children, but they have a dog, *Tøsen* ['Lassie' in English], a friendly Doberman. Before his retirement, Jan worked as a blacksmith, while Bente used to work as an intensive care nurse. Jan began his working life abroad, travelling between Norway, Sweden, and Finland. Bente primarily worked at a hospital in a nearby city. Today, they spend most of their time at home maintaining the house, garden, and their huge self-built conservatory. Bente takes care of the gardens, while Jan takes care of the house. Their favourite spot is by the old and now empty chicken yard. Here, the grapevine has grown into a roof, and they can watch their garden through the shifting seasons.

Like the rest of our interlocutors, all of whom were artisans, teachers, nurses, small business owners, or care assistants, Jan and Bente embody a form of Danish 'indeterminate "middleclass-ness"' (Jenkins 2012, 44). In this context, the ordinary is partly defined by an aspiration to 'manage well' and cherishes the recognisability

of everyday life. Such Danes are likely to put a coffee thermos on the table together with biscuits, and they might excuse themselves for not having vacuum-cleaned. They all expect public transportation to arrive on time and to be compensated if it is considerably late. They expect to be seen on time when going to consultations at hospitals and clinics, and they bemoan that medical professionals seem in a rush and have little time to properly care for patients in the ward. They have lived through different societal crises: traffic-free Sundays due to the oil crisis in the 1970s, for example, and the subsequent period of massive unemployment in the so-called impoverished 1980s. They have learned to get by and to expect help to be there when needed. Being born in post-World War II Denmark, they were raised on the ethos of the burgeoning Danish welfare state. They have all experienced the shifting of healthcare policies to the centre of the welfare state as well as its increasing reliance on ever more sophisticated biotechnologies.

Neoliberal policies and their accompanying welfare state cutbacks have also made their presence known in Denmark, but their consequences are unevenly distributed (Merrild et al. 2017). For Jan and Bente, the orchestration of the Danish welfare state is predicated on mutual trust: ideally, the central government trusts its citizens to act in accordance with principles of tolerance and to be socialised through the educational system until capable of 'critically thinking' (Gilliam and Gulløv 2017). In general, Danes trust the government to be open and honest and to safeguard the 'community' as a whole, both in terms of supplying common resources (such as drinking water and hospitals) and protecting the population against pollution and toxins in food and commodities. With a strong public sector and the progressive redistribution of wealth through taxes, Danes often emphasise that 'the broadest shoulders must bear the heaviest burdens'. Faring well in the Danish welfare state implies a delicate harnessing and balancing of rights and responsibilities (Offersen, Vedsted, and Andersen 2017). Danish citizens have a right to free education, free healthcare, and financial support in times of unemployment or sickness. Protecting 'the common resources' is considered a joint responsibility, and many Danes take that to mean that one must not take advantage of 'the system' and must dutifully 'pay one's taxes'.

In this 'little land of milk and honey [*lille smørhul*]', as Bente described Denmark, citizens benefit from parental leave with pay, child benefits, state education grants, support for childcare fees according to income, housing benefits according to income when renting, and state pension from the age of 66 years (now increasing to 69 years). This extended safety net is coupled with a strong public health focus, as described above.

All of this adds to the production of a (generally) long-living, well-educated population capable of contributing to the tax-paying workforce. Although recent

years have brought a call for the state to acknowledge and act upon growing inequality and polarisation (Vallgård 2016), most Danes live under relatively stable and predictable conditions that support their pursuit of the indeterminate 'middleclass-ness' that is manifest in the hopes, aspirations, and values of Jan and Bente, as well as their everyday lives. They hope to enjoy old age while they still have the strength to do so. Like other Danish welfare state citizens, Jan and Bente felt that, in their retirement, it was their turn to reap the benefits of their hard work and step out of the labour force; to enjoy the birds nesting in their garden with cups of warm coffee and the daily morning show on the radio. They hoped to be able to stay in their house, in which they had taken root and built their lives and from which they hoped to be 'carried out feet-first' when the time came.

## How it all began

In November 2018, Jan got very sick in his stomach. For three weeks or so, he could not keep any food down, and he lost all his energy. In Denmark, people can only access hospital investigations if they get a referral from 'their GP [*min egen læge*]', as they say. This means that some people, including Jan and Bente, have known 'their GP' (in this case, Henrik) for many years. Jan consulted Henrik<sup>3</sup> about his stomach trouble, and Henrik measured Jan's electrolytes and CRP. He gave Jan some pills containing lactic acid bacteria to stabilise his intestines and reminded Jan to drink plenty of fluids. However, Jan continued getting worse. On a day when Bente walked their dog by herself because Jan did not feel like walking, Jan complained about breathlessness. Bente checked Jan's heart rate on 'an impulse' and discovered an atrial fibrillation. Their GP hospitalised Jan immediately. This was on 5 December, Bente recalled. At the hospital, Jan was told he had pneumonia. The pneumonia was made visible by a chest X-ray, and Jan was put on oxygen and two different types of penicillin. The doctors also prescribed blood thinners due to the atrial fibrillation. Bente was unhappy with the hospital staff and especially the decision to put Jan on blood thinners. 'It is a treatment for life,' she commented harshly.

Jan and Bente framed the story of Jan's illness in the light of the diagnostic sequence they experienced: one test leading to another and new suspicions being raised with no clear end. For Jan, his suffering did not really relate to his lungs *per se*, but to his stomach. He could not understand why he needed more testing when the doctors had already taken care of his pneumonia. However, the X-ray led the doctors to focus on some small lung changes. Jan and Bente felt that these changes were detected purely by coincidence. The day after Jan's hospitalisation, a young doctor (Bente stressed his youth) told them about the prospect of doing a CT scan 'because something might be hiding behind'. Bente asked the doctor

3 All names are pseudonyms.

directly, 'Is it cancer that you are thinking about?' It was. When Bente told the story to Frumer, she paused for a moment and then explained that this was difficult: 'The heart, I didn't ... well ... well you ... you can easily live with that and get treatment. The other thing is more ... fatal, you might say, right?'

For the young doctor, the 'something' he mentioned was a possible growth sheltering in the depths of Jan's body. Two-dimensional X-rays visualise first that which is located closest to the skin's surface. A near-skin change may, therefore, muddy the image and shadow something deeper inside. CT scanning reduces the likelihood of this type of 'overlying'.

Due to Jan's hospitalisation, Bente experienced being alone in the house for the first time since 1984. She felt lonely and helpless. She could not manage their wood pellet heating system by herself. With her weak eyes, even seeing in the winter-dark became difficult. Reluctantly, she began to depend on their neighbours. She had their dog *Tøsen's* daily snoring to comfort her. When Jan returned home, Bente started talking to him about what the survivor would do when one of them died. Should they prepare for death now? Would they be forced by circumstance to sell their house? Every day Bente asked Jan, 'How do you feel?' After even the slightest change, her thoughts ran wild: was this a sign of deterioration? Would they soon be confronted with the horrors of cancer and its treatment? When talking to Frumer, Bente concluded that, 'I don't think that I whine, but I do think about it.' Jan then added, 'But you talk a lot about it.'

Back at the hospital in December, the lung changes seen on the X-ray were interpreted as related to Jan's infection. Jan was discharged after three or four days with no talk of a CT scan, Bente explained, but he had to continue taking penicillin at home. During an outpatient consultation at the hospital in the beginning of January 2019, the cancer suspicion resurfaced. According to Bente, the new doctor told them that everything looked peaceful and they should not worry. 'There probably wasn't anything behind,' he said. Still, it would be a good idea to come back for another X-ray at the end of January. After this last X-ray, Bente called Henrik, their GP, to get the result. In Bente's words, Henrik told her that 'something—they couldn't see what was—was still hiding behind' and that he had requested the first CT scan. Henrik wanted the scan to be without contrast so as to expose Jan to as little radiation as possible. Bente laughed when she told Frumer that the result from this scan was that 'there was still something they could not see'. In the clinic, in front of patients, doctors and nurses often describe lung changes in vague and euphemistic terms or through analogies. They commonly describe them as 'shadows' or 'spots' on the lungs and downplay their significance by emphasising that 'this is nothing', it is 'quite common', and that said changes are probably age related, 'like a mole on the skin or hair turning grey'. Even though

these analogies help people relate to the meaning of their lung changes, the nature of these changes is often not specified—either during consultations or in written communication. In official hospital letters communicating test results to patients, sentences stating that 'changes are unchanged' appear without further explanation of the sort of 'change' or how unchanged 'an unchanged change' is. As several of the people in follow-up reflected, the literal absurdity of 'an unchanged change' prevents people from understanding why they are being offered a follow-up in the first place. Importantly, it denies them a coherent language with which to share their experiences with others.

Due to the continuously indeterminate imaging results, Jan and Bente's GP, Henrik, requested a new CT scan at the beginning of February. This time he requested a CT scan *with* contrast in the hopes of gaining more clarity. After this second CT scan, Bente explained, they finally received a clear answer that 'this is definitely not cancer!' However, this CT scan's visualisation of tissue changes prompted a systematic follow-up testing of Jan's lungs to disconfirm a potential cancer growth in the future (this is sometimes called 'watchful waiting'). This meant that the hospital offered Jan a follow-up test with a CT scan in three months' time. Jan and Bente were not aware how long the follow-up would continue or how often Jan would need a scan.

The clear communication of 'not cancer' from the doctor made space for a story of insignificance through an emphasis on the tissue changes as expected signs of old age. In this space, the lung changes would not be the kick-off for Jan and Bente's lives to crumble; but at the same time, it engaged them in everyday ethical conversations about the potential threat of cancer to their 'ordinary life', hopes, and aspirations. In the following, we unfold three ethical concerns that 'descended into their ordinary', to use Das's expression of how crises and vulnerabilities are woven into everyday life (Das 2007). These concerns of 'ordinary ethics'—as opposed to normative ethics of rules and demands (Das 2015b, 2020)—pivot around our conceptualisation of the experience of testing and follow-up; being in the meantime is an explicitly existential and ordinary dimension entangled with everyday life. The first ethical concern revolves around how to inhabit life in the meantime. The second concerns the good the testing is for. The third ethical concern involves Jan and Bente explicitly facing questions of what is a good death.

## **Everyday life in the meantime of follow-up**

The meantime, we suggest, adds a temporal, existential, and affective dimension to being that is simultaneously ordinary and extraordinary; an experience of being in the middle of something without, for the time being, clear demarcation. Jan and

Bente's first ethical concern—of how to understand and inhabit this new ordinary life—illustrates how a crisis weaves into the everyday.

For Jan and Bente, the experience of being followed spread beyond the concrete follow-up scan. Like the rest of our interlocutors, they described the actual scanning as 'no big deal'—almost a change without change, where they adjusted their everyday lives to encompass the regular CT scans. Being followed, however, accrued both dramatic and inconspicuous meaning through a less defined set of occurrences in a shared everyday life 'taut with moments of world-making and world-annihilating encounters that could unfold in a few seconds or over the course of a life' (Das 2015b, 54). The follow-up moulded Jan and Bente's shared everyday life by redefining it as something characterised by regular testing and the looming threat of cancer—that is, the threat that this shared life and future as imagined and hoped for could be suddenly destroyed. This threat introduced a sense of unease in Jan and Bente's lives and in their relations. They struggled to figure out the ways in which illness and its potentials were now present in their lives and questioned *how* they should be present. They jokingly quarrelled about the need to articulate a sense of illness. Jan described 'all that talk about illness' as 'whining [ynk]', whereas Bente explained that it was sometimes important to put one's distress into words. Jokingly, Jan quickly responded, 'I have a sore neck today.'

When asked about the future, Jan argued that there was 'no need to ponder that much about the future' since 'we live in the moment'. However, whether they liked it or not, in their shared everyday life in the meantime Jan and Bente were confronted with potential illness, suffering, and death, and an anticipated but open-ended future: will I die from this? Will I be left alone in this big house? As noted by Andrew Irving (2017) in his work on people living in the shadows of HIV and AIDS, there exists the daily challenge of how 'life and death are negotiated in specific moments as a particular kind of social, familial, religious, or moral being' (Irving 2017, 2). The prospect of death propelled Jan and Bente to ask questions about their moral commitments in life and blurred the lines between (potential) crises and the everyday.

The meantime, which Jan and Bente suddenly found themselves in, was a way of experiencing follow-up that might be particular to the affluent Danish welfare state—or, perhaps, to people accustomed to a certain level of protection from threats and dangers to ordinary life and wellbeing. It is difficult, Das argues, to 'see' the ordinary: 'depending on how we conjure the everyday, the threats to the everyday will also be seen in relation to this picture of the ordinary' (Das 2020, 15). How everyday life is experienced in this meantime (if it *is* even experienced as a meantime) and how people like Jan and Bente work to make the meantime inhabitable thus reveal notions of an ordinary ethics in the particular context of

welfare and 'middleclass-ness'. From here, people such as Jan and Bente continuously work for and achieve meaningful modes of being. Jan and Bente embody a specific form of ordinary ethics that exposes a particular form of Danish middle-class life. This form of life entails the privileges and aspirations of stability and predictability. As opposed to lives marked by struggles of financial instability and bodily chaos, which are also present in the Danish welfare society (Merrild et al. 2017), Jan and Bente's shared life offers them the space to attend to the sense of unease accompanying the meantime. Thus, it is (also) through this privilege that the meantime comes into being, and *in* this meantime that those same privileges are threatened. In this way, Jan's regular coughing became both the predictable outcome of a long life of smoking and welding, hardly noticeable, and a sign of potential cancer, threatening life as he and Bente knew it.

As a modality of being in relation to the threat of cancer, ordinary ethics in the meantime do not only involve managing ordinary hopes and aspirations of everyday life in the light of old age, but also the management of the concrete events of follow-up: driving to the CT scans, reading meaning into actual words in GPs' letters, deciding whether to continue follow-up testing or not. Most often, the experiences of the meantime are not particularly significant or dramatic. Life carries on. Time passes. The idea of lung cancer fades a little. New suspicions are not raised and new diagnostic tests are not added. For instance, Jan's body did not signal to him that anything alarming was under way. He did not lose weight or show any of the other signs of cancer that Bente had contemplated. 'We crawl on,' Jan noted.

## **Stuck in the meantime—grappling with closure**

When reflecting on the first CT scan, Jan explained that he thought, *Now we cannot go any further than this*. He said, 'Hopefully we can say that it is over and done with,' and coughed. '... We can get a clear answer. I was happy that now I couldn't be chased to any new places.' The notion of 'a clear answer' makes it evident that living without closure is challenging. In a move closely related to the second ethical concern, Jan and Bente reflected on how to meaningfully engage in the uncertainty of the meantime. Jokingly, Jan explained that he just wanted to know whether 'everything is in order or not ... that is the only answer I can use.' Later, he talked about his body, adding, 'Does it function or doesn't it?' It was almost like a plumber talking about a heating system in need of repair. When it comes to questions of illness, life, and death, people seek answers to questions of where a given illness leads and how they should act (Irving 2017). This is seen in Denmark as it is in Papua New Guinea (Street 2014). Contrary to Jan's expectations of biomedicine as exhibited in his plumbing metaphors, the Danish state's recent aspirations to make low-stage cancers visible produce additional forms of uncertainty. Therefore,

Jan and Bente's expectations of the healthcare system are not met when the welfare state provides additional uncertainty and ambiguity. Their aspirations of 'middleclass-ness' come into conflict with the efforts of the Danish welfare state to control cancer earlier still, and contradictory feelings come to colour how the meantime affects them.

Jan explained that it was frustrating to have to go to the hospital since he did not feel ill, and the decision to keep on testing was, he felt, out of his hands. At the same time, he did not worry because 'we are all done ... no need to keep on digging'. Here, he articulated the diagnostic process as being closed, even though the testing was continuing—Jan was regularly invited for follow-up scans. It is clearly difficult to understand, let alone express, the rationales for continuous testing as a layperson. On the one hand, Jan's lung change is 'nothing', and is hardly detectable in the images. In the absence of physical suffering and urgency at the hospital appointments, the straightforward interpretation is that his lung change is not alarming. On the other hand, it still needs to be followed; therefore, another concern faced by Jan and Bente in their everyday lives is how to ascribe meaning to life in the meantime and act according to this meaning. What is it all good for? And what are the right actions to take (or not to take)? Should Jan continue the follow-up and stay in this ordinary yet unsettling meantime?

When trying to conclude, Jan said, 'For my part, I could do without.' He further explained, 'One needs to know so much about things today.' He paused. 'But if one didn't know, it wouldn't hurt ... I was actually feeling quite well.'

Bente agreed. 'Sometimes the doctors should hold something back. I could have done without.'

Jan nodded. 'Yes, so could I. I could have settled for pneumonia.'

In the absence of diagnostic closure, Jan and Bente grappled with the value of continuous testing. They desired the healthcare system to contain the indeterminacy, even to the extent of withholding information. Jan and Bente, as well as the others being followed, did not really like being involved in the ambiguous and provisional diagnostic process. Let us just settle for pneumonia—no need to keep on digging.

They reflected along those lines when Frumer asked if they considered stopping the follow-up. Jan found the whole thing quite irritating and laughed a little at his own response. Bente told us:

'Well, in some way, you are also reluctant to back out. Because ... everyone seems to think it's such a good thing to keep an eye on him, right? [...] He is probably the only one who thinks it's a little annoying. I don't want to be the

one who decides that now it stops there, right? Even our doctor thinks, "Let it just run every three months and accept it."

However, several times during our conversations, the dissonance of acting to safeguard against something that was being so heavily downplayed bothered Bente. She could not understand the reason for a three-month follow-up regime: 'Why do they want to keep an eye on it if it isn't anything? But, well ...' Bente here recalled Henrik, their GP, saying that the doctors at the hospital were now doing it 'for their own sake' as they were probably afraid of overlooking a growing cancer. Regardless, Jan and Bente followed Henrik's advice to accept the offer of a CT scan every three months. Yet Bente especially clung to the uttered message that the observed lung changes were not cancer.

Nevertheless, the indeterminacy continued and sometimes broke through, as when Jan and Bente received an appointment letter from the lung cancer diagnostic clinic containing the term 'lung cancer'. This surprised and even offended them—'As if that was completely evident,' Bente explained, 'very definite: this is why you need to go there.' The potential of cancer is difficult to hold at bay, and potential suffering still lurked in the shadows of their thoughts—and, perhaps, in the shadows in the images of Jan's lungs. Jan and Bente could not get away from this potential and were continuously confronted and chased around. They did not dare to take the responsibility of handling potential illness onto their own shoulders; they preferred the healthcare system to identify crises, themselves caused by 'something'.

## **Ending the meantime—notions of the good death**

As indicated by the two concerns already discussed, for Jan and Bente, the experience of being in the meantime carried with it existential questions of what a good life—and a good death—are. Jan and Bente's desire for closure and their efforts to manage the ambiguity of everyday life in the meantime as best as they could, grappling with what they considered a good life, mark an ethical aspiration in the ordinary. In recent debates on where to 'find' the ethical, Das and others argue that the ethical is immanent in the ordinary and resides in both practice and reflection (Das 2015b; Sidnell, Meudec, and Lambek 2019). The ordinary is continuously achieved and, as such, is at stake (Das 2007, 2015a; Offersen, Vedsted, and Andersen 2017). Notions of what exactly makes up a good life and a good death, especially as people get older, are inherent in more or less conscious reflections that are part of the everyday achievement of a desired ordinary. When the welfare state in the shape of a growing 'surveillance medicine' (Armstrong 1995) enters this ordinary and materialises in actual surveillance activities, notions of the good life and the good death more vividly manifest in

people's everyday efforts. For our interlocutors, this involves an explicit questioning of the entire practice of surveillance medicine in the name of welfare and protection from harm. For Jan and Bente, who are stuck in the meantime, this level of welfare and protection is both satisfying (because it is potentially lifesaving) *and* directly in opposition to their efforts to achieve a good life and a good death. To illustrate this: Jan and Bente perceived the idea of 'dropping dead' as a good death: Bente said, 'Because it is our one and all, this house, right? And we have, like everyone else ... a hope of being carried out of here, right?'

Jan added with a laugh, 'But that is not easy if we don't just drop dead, I suppose.'

'No, it isn't,' Bente said.

Frumer asked, 'What do you mean by that?'

'Well, I would rather ... drop dead,' said Jan, 'because then you don't have all those worries in the meantime. It surely must be the easiest way. Then descendants must take over ... then it's up to them. But I would rather just ... *duk* [Jan made a noise indicating a sudden and swift death].'

'Yes, yes,' Bente added, 'but we cannot drop dead at the same time. If only we were that lucky!'

Jan smiled. 'No. It's probably not that easy.'

This idealised notion of 'dropping dead' before one gets to worry, before one needs to contemplate the timing of death, stands in opposition to the state of 'being followed'. Without feeling ill, Jan—and Bente, as his wife—are confronted with the future prospects of having to sell their house and be alone. The image of a good death as one where you just 'drop dead' arose in all of our talks with Jan and Bente. It was also present in many of our conversations with other people involved in follow-up regimes. Death should come as a knockout punch, a clear strike—it should not lurk in the shadows.

A source of dread for Jan and Bente was the prospect of stalling death with technology well beyond the threshold of 'a good life', however difficult that term is to define. Both Jan and Bente reflected that they might not want treatment for cancer, if it should ever come to that, since they were not sure that the suffering connected to treatment would be worth going through 'at our age'. They also had reservations about attending national cancer-screening programmes. As Jan explained, the healthcare system 'has become quite pushy, keeping an eye on everything'. Thus, Jan did not adhere to the recommended colorectal cancer screening, and Bente deregistered from the breast cancer screening. They told Frumer stories about tests that find all kinds of 'trifles' that would never cause

suffering; people would die *with* these changes, not because of them. They also mentioned tests with thresholds so low that 'bleeding from a tooth will send you off for a colonoscopy'. Bente recalled that, according to a test taken during Jan's hospitalisation, Jan's PSA levels were marginally increased. Henrik checked them afterwards and spoke about prostate biopsies, which Jan had experienced before as painful. Jan did not schedule another visit to Henrik, and Bente explained, while talking to Jan, 'Well, you don't go down there by yourself, and I pretend that I have also forgotten.' She laughed.

By telling these stories, Jan and Bente suggest that they preferred to avoid having their bodies regularly monitored for potential disease; that they could not make sense of a body always suspected of disease. The continuous offer of testing challenged their shared hope of a good death ('dropping dead'), especially when that testing related to a potential cancer (through, for example, the identification of lung changes and elevated PSA levels or through national screening programmes). Jan and Bente opposed the fact that they had to live in the meantime and had to accept being subjected to an (to them) incomprehensible surveillance regime, itself communicating to them in only an ambiguous manner the reasons for the investigations. The follow-up regime required them to consider how they were to interpret the mysterious messages received from the hospital, how to live a good life, and how to plan a good death.

## **Ordinary ethics in the meantime**

In this article, we introduced the concept of 'in the meantime' to describe the experience of living under continuous testing without closure. We argued that this experience resonates in 'the ordinary' by making people engage in ethical concerns about life, death, and the meaning of testing. The meantime reflects an ambiguous experience within which being followed stands out temporally, existentially, and affectively. Our interlocutors balanced the threat of potential lung cancer with a certain lightness of being, folding the extraordinary into the everyday. This lightness, however, contained an existential uncertainty that often presented itself through their emphasis on the benefits of being 'kept an eye on' (by the 'friendly' state).

Through the case of Jan and Bente, we described three specific instances of ordinary ethics as different ways of being *with* the potential crises. Thus, we foregrounded the quotidian and subtle transformations in the ways of being and vulnerabilities of everyday life: Jan and Bente reflected on their situation and engaged with ethical concerns while trying to find space to live. The first ethical concern was manifest for Jan and Bente through their attempts to figure out how to live in the meantime; testing had become part of their ordinary, entangling

everyday life and leaving traces of uncertainty behind. The second concern saw Jan and Bente desire closure, even going so far as to wish that the follow-up had never been offered. They pondered the conflicting value of the continuous testing. In the last, Jan and Bente critically distanced themselves from the whole testing regime by reflecting on forms of 'good death'. They questioned the welfare state's continual attempts to ever more comprehensive and detailed surveillance over Jan's body.

The Danish welfare state arose on the shoulders of World War II. Woven into the fabric of the welfare state is thus a fundamental story of post-war progress and improvement. Through the institutions and structures of the welfare state—the fine-meshed safety net, notions of mutual trust and responsibility, and generalised healthcare coverage—the state aspires to alleviate human suffering through initiatives of faring well in all phases of life. All these aspects, which form part of a privileged everyday life in Denmark, often fight off or postpone death. The regular testing of follow-up regimes generates existential drama, and yet this drama is quickly absorbed into the ordinary (Konrad 2003). It is, however, indicative of the uncertainty and ambiguity that arises when human beings must (re)visit their lives, ways of living, and future possibilities, and entangles everyday life with experiences under a system which prioritises the fundamental safety of privileged lives (Risør and Nissen 2018).

As human beings, we engage with cancer because it scares us (Jain 2013; Stoller 2004). But what are the consequences of mapping the body in such detail, as is regularly done in contemporary biomedicine? Should we embrace new technologies without asking how they 'descend into the ordinary' (Das 2007) and transform ways of being? Inspired by Street's merging of visibility and the production of uncertainty, we see how access to technology produces spirals of uncertainties that call for additional testing in the search for clarity, and how diagnostics become fluid (Risør and Nissen 2018).

Others have argued that changes in biomedicine and its technologies afford new moral subjects, each with its own uncertainties: for instance, (fore)knowledge, disclosure, and relatedness (Konrad 2003; Svendsen 2006; Hacking 1999). In our case, new subjects are not formed. Instead, we point to the possible modes of being, or 'forms of life' (Das 2015b), that are shaped. However, like Monica Konrad's concept of 'foreknowledge' (2003), our concept of 'in the meantime' points to connections between 'home', 'everyday life', and 'clinic'. It is in relation to the contours of everyday life that the meanings of diagnostics are moulded. By exploring continuous testing through an emphasis on both 'the ordinary' and on the question of how a potential crisis interweaves with the everyday, we learn how intruding predictive diagnostics that offer no closure may feel. In Konrad's case of

predictive genetic testing for Huntington's chorea—a so-called 'late-onset' inherited disease with no cure—'foreknowledge' is knowledge of an *anticipated* illness: you *expect* to become ill, but you do not know *when* the disease will show. Compared to this, 'in the meantime' describes an experience of *potential* illness: you *might* become ill, but you cannot know *whether* that will be the case. Attempts to deal with genetic foreknowledge also entail unresolved processes of moral striving, especially regarding kinship implications: who should know and who should not (Konrad 2003)? While follow-up regimes for lung changes do not raise questions of biological heredity, the ethical concerns raised by Jan and Bente remind us that being in the meantime is also defined as an experience that is social and shared. The meantime threatens Jan and Bente's *mutual* being. Their shared hopes and aspirations, and the life they have built together, are at stake. Thus, through our concept of 'in the meantime', we add another dimension to the forms of life possible for expanding groups of 'pre-symptomatic' (Konrad 2003) or 'at-risk' people. In relation to early cancer diagnosis and related kinds of continuous medical testing, we are encouraged to reflect on what desirable relationships between bodies, biotechnologies, the state, and disease surveillance look like. Furthermore, it reminds us that everyday ethical concerns in the context of what we consider to be privileged middle-class lives foster an ordinary ethics that is continuously achieved and moulded.

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