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## **Diagnosis, narrative identity, and asymptomatic disease**

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**Abstract:** An increasing number of patients receive diagnoses of disease without having any symptoms. These include diseases detected through screening programs, as incidental findings from unrelated investigations, or via routine checks of various biological variables like blood pressure or cholesterol. In this paper we draw on narrative identity theory to examine how the process of making sense of being diagnosed with asymptomatic disease can trigger certain overlooked forms of harm for patients. We show that the experience of asymptomatic disease can involve ‘mismatches’ between one’s beliefs about one’s health status on the one hand, and bodily sensations or past experience on the other. Patients’ attempts to integrate these diagnoses into their self-narratives often involve either forming inaccurate beliefs about bodily sensations and/or past experience, or coming to believe that feelings and experience do not necessarily track or predict health status, leading to an ongoing sense of vulnerability to ill health. These resulting alterations in self-understanding can sometimes be considered harmful, in view of their implications for ascriptions of responsibility and ongoing anxiety.

**Keywords:** diagnosis, narrative, personal identity, disease, illness, labelling

While there is a large amount of literature on the experience of illness, there is far less on the experience of disease per se. This is not surprising, of course: ‘illness’ is typically used to refer to the experience of ill health, and ‘disease’ to refer to the underlying medical condition.<sup>1</sup> Thus those interested in the experience of ill health will generally, by definition, be interested in illness, and not disease. Nonetheless, in this paper we seek to examine the experience of what we might call disease without illness, that is, of asymptomatic disease. Many patients receive diagnoses of disease without any symptoms, such as diseases detected through screening programs, as incidental findings from unrelated investigations, or via routine checks of various biological variables like blood pressure or cholesterol. Such diagnoses, indeed, have become increasingly common [11].

We use resources from narrative identity theory to clarify some features of the experience of asymptomatic disease. In particular, we argue that the experience of asymptomatic disease involves ‘mismatches’ between one’s beliefs about one’s own health status on the one hand, and bodily sensations or past experience on the other. As individuals attempt to incorporate these diagnoses into their self-narratives and resolve these ‘mismatches’, two strategies come into play. First, individuals may form inaccurate beliefs about bodily sensations and/or past experience. Second, they may accept that feelings and experience do not necessarily track or predict health status, potentially leading to an ongoing sense of vulnerability to ill health.

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<sup>1</sup> The distinction has been in use since the 1950s, such as in the work of Parsons [20, p 651].

Further, we seek to show how the process of making sense of being diagnosed with asymptomatic disease may trigger certain overlooked forms of harm. Diagnosis, of course, has many positive effects. It allows medical practitioners to intervene to avoid further morbidity and mortality (where effective treatments exist); to make predictions about future progression of the condition and likely outcomes; and where there is illness, diagnosis can help to explain the cause of symptoms or clinical signs. Diagnoses also have important social functions including: granting access to the ‘sick role’, legitimating suffering [23, p 793], and enabling access to medical resources and (sometimes) income support. Nonetheless, there is growing awareness that diagnoses can cause harm. The increasing diagnosis of asymptomatic disease is recognised to be potentially harmful in that it leads to various negative practical consequences, such as unnecessary treatments; and diagnosis itself is known to be associated with negative psychological outcomes [e.g., 12; 31].<sup>2</sup> Harm arises especially where there is *overdiagnosis* (the identification of non-harmful disease [11]), or overtreatment. Some people have their lives disrupted by a diagnosis that, it turns out, was unnecessary, or did more harm than good. Our analysis engages with the idea that asymptomatic diagnoses can lead to identity-related harms that are distinct from the recognised practical and psychological consequences. We argue that alterations in self-understanding can at least sometimes be considered harmful, in view of their implications for ascriptions of responsibility, inaccurate notions of our capacity to control our health, and the ongoing anxiety that can result.

In section one, we describe the rise in diagnoses, and hence experience, of asymptomatic disease. In section two, we draw on a range of qualitative studies exploring how a diagnosis of asymptomatic disease is likely to be experienced. We then, in section three, introduce ideas developed in narrative identity theory that are useful in analysing this experience. In section four we apply these ideas to show how having asymptomatic disease involves mismatches between individuals’ beliefs about their health and bodily experience, and these beliefs and past experience. In section five, we argue that some of these possibilities can be considered to harm some of those affected. As such, the potential identity-related harms from being diagnosed with asymptomatic disease can be considered a reason for additional caution in giving people medical labels.

### **1. Increasing prevalence of the experience of asymptomatic disease**

A range of (interrelated) factors contribute to the rise in experience of asymptomatic disease: expansive diagnostic definitions; reclassification of risk factors as diseases; advances in imaging and testing technologies; increased use of screening programs; and increases in incidental findings.

First, a number of diseases have been redefined in ways that expand patient populations, sometimes dramatically. This includes, in the last 20 years, type 2 diabetes, hypertension,

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<sup>2</sup> Some studies indicate that these outcomes can result from the receipt of the medical label itself, rather than the illness associated with it [10; 32]. Our discussion is consistent with these psychological findings but provides a way to understand the experience qualitatively.

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chronic kidney disease, high cholesterol, gastroesophageal reflux, and ADHD [41; 30; 35]. The 1997 change to the diagnostic threshold for diabetes created an estimated 1.7 million new cases of diabetes in the USA [41]. A 1998 redefinition of hypercholesterolemia resulted in an estimated 42 million new cases in the USA [41]. A 2002 definition of chronic kidney disease (CKD), has been estimated to classify around 12.5% of adults in the USA as having CKD, up from a prior estimate of 1.7% [30]. Perhaps the primary reason for these redefinitions is to decrease morbidity and mortality by earlier identification of cases or risk states. But in some cases, redefinitions aim to remedy underdiagnosis, or enable consistency in research and practice, or in diagnosis across different patient populations [30].

Second, some conditions previously regarded as risk factors have come to be counted as diseases. Osteoporosis, or reduced bone mineral density, was originally described as a risk factor, and applied to people with non-traumatic fractures. In 1994, the World Health Organization defined osteoporosis to include asymptomatic people with bone mineral density below a certain threshold. Osteoporosis is now generally accepted as a disease though in many cases it is and will remain asymptomatic [17]. Other ‘risk factor’ diseases are obesity, pre-diabetes, and pre-hypertension; and on some views, hypertension and hypercholesterolemia themselves.

Third, increasingly sophisticated tests and imaging technologies are able to detect diseases that, previously, would not have been detected unless or until they became clinically apparent [35]. For example, one study found that the prevalence of abdominal aortic aneurysm (in an ‘at risk’ population), when assessed using physical examination, was 2.5%, with 20% of aneurysms detected less than 5cm in diameter. Using ultrasound, the prevalence rose to 9%, with 72% less than 5cm in diameter [6, p. 117]. Similarly, the introduction of high resolution CT pulmonary angiography for detecting pulmonary emboli led to an apparent increase in incidence of 80% between 1998 and 2006 in the USA, while mortality from pulmonary emboli did not change significantly [19]. Such technologies allow us to find more disease, but many of the additional instances are asymptomatic, and in many cases, inconsequential.

Fourth, screening programs have expanded to new locations and populations, for an increased range of conditions, further contributing to the detection of disease that is not symptomatic or clinically apparent. For example, after the introduction of mammography screening programs, breast cancer incidence in a number of locations rose by an average of 2-10% per year [4]. The common use of ultrasonography screening of the thyroid has been associated with a 15-fold increase in thyroid cancers detected over the last 20 years in Korea [1]. Prostate-specific antigen screening programs are associated with increases in incidence of prostate cancer of between 22-70% [43, p 608].

Finally, due to the greater use and sophistication of various imaging technologies, it is becoming increasingly common for abnormalities to be found incidentally, when tests or interventions for other conditions are undertaken [28]. For example, the rate of diagnosis of

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cancers of the kidney and renal pelvis almost doubled over 30 years in the US, most likely due to increases in incidental detection associated with increased use of abdominal ultrasound and computed tomography [43, p 601; 5]. A significant rise in the rate of pituitary tumours over the last 20 years has been linked to higher rates of cranial MRI scanning, leading to increased incidental findings [45].

Not all of the additional cases of disease found as a result of these trends will be asymptomatic; however, the trends do mean that the experience of diagnosis of asymptomatic disease is becoming more common. And while many of the diagnoses reached by the pathways described above may be beneficial, enabling prevention of advanced disease, many are thought to be overdiagnoses; to be unnecessary medical labels [17; 41; 43; 35]. Since the additional diagnoses tend to identify trivial and/or less advanced disease, we may reach a point of diminishing returns regarding the utility of these diagnoses.

## **2. The experience of asymptomatic disease**

Though there has been little attention directed specifically to the experience of asymptomatic disease, there is some relevant literature. As well as two studies examining the impact of receiving a diagnosis in the absence of symptoms, we draw on studies on the experience of being diagnosed ‘at risk’, and of receiving a false positive diagnosis.

First, two qualitative interview studies provide information on the experience of diagnosis of asymptomatic disease.<sup>3</sup> One study reports experiences of diagnosis of colorectal cancer following screening, with asymptomatic individuals [29]; the other reports on experiences of women in recovery from early-stage gynaecological cancers, who were asymptomatic or had interpreted symptoms as normal occurrences [8]. Both studies show that patients receiving a diagnosis in the absence of any symptoms are more shocked by it than those with symptoms: without symptoms, there is no ‘preparation’ for a diagnosis, no alert that anything is amiss. “We search for a label when we experience bodily changes, and conversely expect to suffer symptoms when we feel ill” [8, p 515]. For asymptomatic individuals, the change from considering oneself healthy to considering oneself a patient, is very rapid [29, p 789]. Patients described their feelings of being well, fit, and healthy, which failed to match with the diagnosis [29, p 791-2].

The lack of symptoms can have long-term effects. Although the women in recovery from gynaecological cancers were successfully treated, they continued to report a heightened sense of vulnerability, anxiety, and uncertainty about their health; and to attend health checks long after their likelihood of relapse was, statistically, very low [8, p 516]. The authors argue that the experience of asymptomatic disease had taught these women that their bodily sensations were not a good guide to their health status. Even years later, “the perceived inability to

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<sup>3</sup> There have also been several studies that evaluated whether diagnoses of cancer from screening detection are more distressing than other diagnoses, using psychological assessment measures, though these have conflicting results [29, p 789].

ascertain healthiness causes health anxiety to elevate in the absence of indicative symptomatology” [8, p 518]. The sense of vulnerability and uncertainty was not limited to the index condition, but extended to every region of the body [8, p 516].

Studies into the experience of receiving a false positive diagnosis reveal some similarities.<sup>4</sup> With a false positive, an initial diagnostic test for a disease is positive, but later corrected by a more accurate or repeat test. Although the individual in question is given the all clear, there are variable retrospective interpretations of the experience and variable long-term effects. Participants in qualitative studies examining the experience of receiving false positive breast or ovarian cancer diagnoses often report shock, and loss of a sense of invincibility [38, p 8; 5, p 795]. Some participants report extreme distress: in one study, one woman reported losing twenty pounds through worry while awaiting follow-up [38, p 8]. But responses can differ significantly, with other individuals more sanguine [38, p 8; 5, p 797]. Similarly, on being given the all-clear, some people rapidly regained belief in their capacity to know their own health status, while others remained anxious and fearful, some for years after the event [6, p 800-1]. This again demonstrates the effect of becoming aware that bodily sensations may not match health status, such that silent disease is a constant possibility.

The experience of being diagnosed ‘at risk’ may also illuminate that of being diagnosed with asymptomatic disease, since most of those who are at risk have no symptoms – although here, the diagnostic label received is not one of disease.<sup>5</sup> Again, in such cases, patients are often shocked by the diagnosis, reporting fear connected to the unsuspected presence of the asymptomatic condition [24, p 439]. Many participants reported a changed perception of their body, regarding it as dysfunctional or not to be taken for granted [33, p 2727]; as inevitably deteriorating and vulnerable [15, p 19-20]; as being invaded or a source of danger [24, p 439-42]. Anxiety was increased by uncertainty about whether or not particular bodily sensations were or were not indicative of ill health [33, p 2725]. Some also reported a generalised fear of disease in parts of the body other than those that were the subject of the original risk diagnosis, leading to reliance on medical checks to manage anxiety [33, p 2727; 24, p 440; 39, p 809].

Several studies report that the mismatch between relevant bodily experiences and the diagnosis of being at risk seemingly led some subjects to reinterpret other experiences as symptoms of their condition. A study of women with lower than average bone mineral density found that some women interpreted various aches and pains as symptoms of their osteoporosis, despite knowing that the condition is asymptomatic unless fractures occur [33, p 2726]. A study of people at risk of diabetes or hypertension found that many regarded

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<sup>4</sup> While we focus on qualitative studies here, we note that psychological studies indicate that a false positive diagnosis is associated with measurable increases in anxiety and decreases in calmness [see 6, p 793; 10].

<sup>5</sup> Being diagnosed at risk is, however, often interpreted and treated similarly to being diagnosed with a disease, by both doctors and patients [33; 25; 3].

episodes of hypotension or hypoglycaemia as part of their condition, rather than an effect of its treatment [25]. One person reported developing what she understood to be relevant symptoms (lethargy and fatigue) after receiving a risk-factor diagnosis (for cervical cancer) [24, p 439].

An interview study with women diagnosed with an elevated risk of fracture reports that participants sometimes appeared to be cross about, or offended by, the diagnosis, stating that they had behaved in ways they took to mean that they *should* be healthy and safe from this condition, such as having eaten well and exercised diligently [39, p 811]. This was not always the case – some women regarded thinning bones as a normal part of ageing – but many appeared to regard the diagnosis as a direct challenge to their own self-care or lifestyle, implying that they had not looked after their health. Thus a risk diagnosis can involve not only a mismatch between bodily sensations and health status, but also between one’s own past behaviour and expectations about one’s health status. These mismatches may lead to reinterpretation of past behaviour in relation to health. A study interviewing women considered at risk of cervical cancer reported that individuals attempted to link the diagnosis to past behaviour, attributing their abnormalities to “a myriad of factors such as stress, poor diet, medications or pollution” (24, p 441).

This reinterpretation of the relationship between behaviour and health can lead to changes in behaviour (indeed, some risk factor diagnoses aim to motivate such behaviour change). In a study of people diagnosed with pre-diabetes, many reported making lifestyle changes to improve diet and exercise routines (to varying extents) after receiving this diagnosis, which sometimes led to improvements in health [18, 576]. But the effects are not always positive. Studies with women diagnosed at risk of osteoporosis reveal that while some respond to the diagnosis by following recommendations to increase physical activity to strengthen bones, others reduce their activity counter to medical advice, out of caution or feelings of fragility [39, p813; 33, p 2726].

A more insidious counterproductive effect relates to how a risk diagnosis plays into beliefs about responsibility for health. For some individuals, their newfound unhealthy status is a source of guilt, triggered by eating in the case of some lifestyle ‘pre-diseases’ [15, p 203]; others felt a responsibility to control their condition in order to avoid a worse outcome such as fracture [18; 39]. These judgements, as well as being themselves burdensome, may not lead to better health outcomes; although risk-factor diagnoses are often intended to facilitate preventive actions, these may not always be possible or effective. For example, some ‘pre-diabetic’ individuals who reported making lifestyle changes did not experience any commensurate changes in blood glucose levels [18, p 576]. Although this is consistent with the possibility that other factors such as age or heredity limited people’s capacity to control their condition, the phenomenon led to self-blame, and reduced trust in doctors’ advice. Medical practitioners regarded these patients to be noncompliant and dishonest [18, p 576-7]. Thus a risk diagnosis, in that it individualises responsibility for health, can encourage both

clinicians and patients to think they have more control over their condition than they do [see also 22].

### 3. Narrative identity

To provide a framework to understand these experiences, we draw on narrative identity theory, of which there are many versions in philosophy, psychology, sociology and other disciplines. Here we sketch some basic claims of narrative identity theory drawn from some of the most fully-developed philosophical accounts.

The basic claim of narrative identity theories is that people make sense of themselves and their lives by interpreting their experiences and actions ‘narratively’; that is, understanding each event in their lives in terms of its connections to other events. Each event is characterised by, and gets its meaning from, its role within a larger sequence of events. This claim explains the sense in which a particular event or action can be experienced very differently by different people, taking on quite dissimilar meanings. For example, attending one’s graduation ceremony might be experienced as a standard rite of passage by one person, a chore undertaken solely to please a parent by another, and a triumph over adversity by yet another. This reflects differences in the subjective quality of individuals’ experiences, which can be understood by articulating the role of the event in these people’s overall narratives, that is, in the context of other events in their lives and the connections between them [40, p 111-113].<sup>6</sup>

Any particular event may thus take on different meanings for individuals over time because of the particular series of events in which it occurs. But sequences of events can also be connected up in a variety of ways. Narratives are selective and interpretive. In understanding our lives, we may emphasise some and not other events, pick out or emphasise some features of those events over others, present them in different lights, and so on. In interpreting ourselves over time, the way we form the events in our lives into a narrative reflects what our experience is like, what we take it to mean, and what attitudes we take up towards our experiences and actions. The selections and interpretations we make reflect our character, attitudes, values and perspective. Thus, we come to form a self-narrative that reflects how we think of ourselves, or what we can call a narrative self-conception.

Further, a self-narrative, and the self-conception that it reflects, feeds back into action and decision-making [44, p. 211-13].<sup>7</sup> In interpreting our lives, we come to form beliefs about ourselves, and these beliefs can become normative, and direct action in a range of ways. For

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<sup>6</sup> This feature of narrative is connected to its use in resisting what some have argued is a homogenising tendency of diagnosis, and medical understanding of patients more generally [e.g., 14; 37]. As the purpose of this paper is not to resist homogenisation but to begin to better understand this kind of experience this is not a specific issue for us, though we recognise that the generalisations we draw in section 4 will not apply to everyone.

<sup>7</sup> See also Hacking [16]. In Hacking’s terminology this is a ‘looping effect’ – a consequence of our practices of categorising or ‘making up’ people.

example, someone who considers herself deeply committed to environmentalism is likely to be motivated to act in ways consistent with this self-interpretation. Someone whose self-conception involves regarding her role as a friend, a teacher, a carer, or a soldier as important or valued is thereby motivated to act in ways consistent with those roles. Elements of one's self-conception are not, however, necessarily things one endorses or even approves of. We may disapprove of our own characteristics, and wish to alter them. Or we may take up various more complicated attitudes towards our characteristics, such as resignation, frustration, or alienation. It is thus not just recognition of a characteristic but the attitude one takes up towards it that shape its implications for action. Perhaps I come to interpret a set of my experiences to mean that I have trouble concentrating in the afternoon, and regard this characteristic as irritating or inefficient. I might first seek to change it, say by taking a refreshing break or doing meditative exercises after lunch, but finding this ineffective, seek instead to work around it by undertaking more difficult tasks in the morning. In this kind of case too, the self-conception guides and shapes actions and decisions.

Although people's lives generally lack the consistency and unity of literary narratives, there are two ways in which narrative self-understanding fosters coherence over time [34, p 158]. First, our actions and decisions are typically consistent with our self-narrative because of the way a narrative self-conception shapes action and decisions, as just described. Our self-conception is thus enacted. Since we will tend to act in ways shaped by our narrative self-conception, our actions over time are likely to fall into certain patterns and exhibit some level of consistency and coherence [34, p 157; 44, p 224-52].

But of course, we all experience contingencies which have no relation to what has happened before, and so will have no relation to an existing self-narrative: we lose jobs, are the victims of crimes or accidents, unexpectedly meet the loves of our lives, and have our plans blocked or altered in various ways that we can't control. Where a contingency is a very significant or 'life-changing' event (as a diagnosis of disease may be) it can cause dramatic change in a person's narrative and so in their identity. But even dramatic contingencies can be made consistent within a person's self-narrative. The contingency may be integrated into a self-narrative because self-interpretation is *actively* pursued, and this is the second way in which narrative self-understanding fosters coherence over time. Some narrative theorists argue that our activities of self-interpretation relate to a strong drive to understand our experiences and our own actions; we find a lack of such understanding aversive to the extent that we sometimes accept false explanations over having no explanation – we would rather be self-deceived than adrift [e.g., 44, p 260-5]. Thus, inconsistent, incoherent events are made consistent and coherent by narrative integration [34, 142-7].

This process might involve interpreting the contingency as expressing pre-existing features of one's life or character, or finding new sources of meaning in the contingency or one's response to it. An example of interpreting a contingency as an expression of a pre-existing feature of one's life or character is Spinoza's expulsion from the Jewish faith [see 27].

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Although this event was a contingency in the sense that it was out of his control, and inflicted upon him from outside, it could be regarded as consistent with his self-narrative, an external expression of his departures from orthodox Judaism. In such a way, an event that is out of one's control might nonetheless come to be regarded as reflecting truths about oneself. As a more prosaic example, if I routinely break traffic rules, it is out of my immediate control whether or not I am caught, but if I do eventually lose my license and have to deal with the resulting difficulties, I can make sense of this as a reflection on my own behaviour.

Of course, some contingencies affecting our lives – earthquakes, political upheavals, and so on – may not reflect on us at all. Nonetheless, we may integrate these into our narratives by finding meaning in the events, or in our response to them. The loss of my home due to unpredictable conflagration may be integrated into a previously separate element of my narrative involving remaking aspects of my life, for instance. Or one might find meaning in a traumatic experience by helping others who have undergone similar traumas, or undertaking advocacy on their behalf [e.g., 9]. In the case of receiving a disease diagnosis, one might come to identify oneself as a patient of (or battler with, or some other construal) that disease. Integrating a contingency into one's narrative may thus involve coming to find elements of one's self-narrative in the contingency, or might involve giving the contingency meaning by responding to it in certain ways such that it comes to form part of one's narrative, while still recognising its contingent nature.

#### **4. Identity and the experience of disease**

There are several ways in which this framework illuminates elements of the experience of asymptomatic disease. First, to make a very general point, we cited research demonstrating that a diagnosis can change the ways in which a person interprets themselves or their experience. Someone who has been diagnosed with cancer is more likely to notice and emphasise mentions of the disease, or indeed other diseases, in a range of other contexts, given that they now connect it to an experience in their own self-narrative. Someone diagnosed at risk of diabetes is more likely to think about what they eat and how they exercise, or to recall the diagnosis when they undertake those activities. That is, having been diagnosed with a disease may cause someone to undertake the selection and interpretation that goes into their narrative self-interpretation in different ways – and this would reflect an alteration in the subjective character of their experience, affecting individuals to varying degrees. This point also applies to diagnoses where there is illness. Given the generality of this point we will not focus on it in what follows. But it is worth at least noting that receiving a diagnosis, a medical label, will play into people's self-conceptions in a range of complex ways, which are articulated in their self-narratives.

More specifically, narrative theory can help us to understand strategies people use to manage the two 'mismatches' (described in section 2) that occur in asymptomatic disease. First, as there are no symptoms, the information given in the diagnosis does not match bodily sensation; there is nothing in experience that indicates that anything is wrong in the body.

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The diagnosis is not only not predicted by, but not consistent with previous expectations, where ill health is heralded by changes in bodily sensation. Second, where a diagnosis is sudden or unexpected, and has no accompanying symptoms, the diagnosis itself requires, rather than provides, explanation. Individuals find nothing in their previous lifestyle or behaviour that explains or anticipates their having the disease.<sup>8</sup> Thus receiving such a diagnosis involves receiving information about one's health status which fits with neither one's experience of bodily sensation, nor with past behaviour, in the ways that we normally expect. The diagnosis is a contingency. Narrative theory predicts that those receiving such a diagnosis will tend to try to make it coherent or consistent.

Consider first the mismatch between beliefs about health status, and subjective bodily sensations. Making sense of this mismatch often appears to result in a new reliance on the diagnostic tools of medical science, as well as triggering ongoing anxiety and feelings of vulnerability. Patients explained the mismatch by accepting the new belief that bodily sensations are not a good guide to health status, and this belief directed future action. Alternatively, however, some patients attempted to reconnect their new knowledge about their health status to bodily experience in a variety of ways: by interpreting some experiences (either likely to be unrelated to disease, or perhaps the results of treatment) as symptoms, or even by developing what they took to be relevant symptoms. This is an example of the self-conception feeding back into action (or in Hacking's terms, a 'looping effect'). By altering their self-interpretations in these ways, patients may be able to retain a sense that their subjective experience matches the knowledge about their health provided by medical science, but at the cost of reducing the accuracy of their beliefs. By doing this, subjects may avoid the belief that bodily sensation is not a good guide to health status and so avoid feelings of vulnerability and anxiety that often accompany this.

The second mismatch, between knowledge of health status and individuals' past behaviour, led some to believe they should have had better health. Again, patients might simply accept that contingencies such as disease happen, which some appeared to do. But having this belief, too, may be uncomfortable, leading to a general sense of vulnerability, and the belief that one cannot influence future health by attempting to live well now. And most people instead attributed the cause of the disease to some past behaviour, such as poor diet or stressful experiences. In explaining their current experience by reinterpreting their past in such a way, individuals may be able to reconnect their previous behaviour with their health status, again lessening the new sense of vulnerability. This potentially enables a sense of continuity with one's past, such that the diagnosis is not experienced as such a disruption. This response,

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<sup>8</sup> Some similar points can be made about a diagnosis of disease where there is illness, of course, especially where the symptoms experienced are minimal or sudden; in the cases we focus on, the discontinuity would be even sharper. See [26] for a discussion of this idea in the literature on the experience of illness.

while enabling the contingency to be explained by past behaviour and so overcoming the apparent mismatch, again seems to reduce the overall accuracy of patients' beliefs.<sup>9</sup>

With both mismatches, people may take either of the routes described above for integrating a contingency into a self-narrative. Some avoid the mismatches by reinterpreting either bodily sensation or past behaviour such that the contingency, the diagnosis, comes to be regarded as explained by or consistent with these. That is, they come to regard the disease as somehow fitting with their narrative: a result of stresses they have experienced, or lifestyle factors that have affected their health, consistent with bodily sensation. The contingency comes to be understood as something that, while strictly speaking out of their control, reflects some elements of their lives. Others, however, retain a sense that their diagnosis *is* contingent and a matter of chance, and cannot be made to fit with their bodily experience or their past in such ways. This seems to be more psychologically difficult, since it involves accepting that disease can be unknown to us and can occur at any time (though of course, most of us would agree with this statement if explicitly pressed). These patients may still find meaning by allowing the contingency to shape other experiences, in the way they respond to the diagnosis, in order to maintain narrative integrity. Such patients might for instance seek to help others with a similar condition, or simply allow the new sense of vulnerability to influence how they interpret and make decisions about their lives.

## **5. Diagnosis of asymptomatic disease as an identity-mediated harm**

In this section we argue that receipt of a diagnosis of asymptomatic disease, considered apart from its practical consequences, can be considered to harm patients in some cases, in ways identifiable using narrative analysis.<sup>10</sup> Where patients take on inaccurate beliefs about their capacity to know or control their health status, this can increase burdens on them, and encourage faulty ascriptions of responsibility for disease, such that in at least some cases we could consider patients to be harmed. In cases where patients instead accept the possibility of unknown and uncontrollable ill health, the resulting psychological discomfort could be considered a harm. Of course, such harms need to be balanced in different cases as part of a broader consideration of the harms and benefits of giving a diagnostic label (including the risks of not identifying or treating a condition).

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<sup>9</sup> As noted above, this second mismatch may also occur with symptomatic diseases, and people's responses to it might also follow the strategies we describe here. We think the drive to explain the occurrence of disease may be stronger in cases where there are symptoms, because an absence of symptoms leaves the diagnosis more in need of explanation: the lack of symptoms can make the transition to thinking of oneself as unwell, and finding a way to identify oneself as such, more difficult.

<sup>10</sup> It is worth noting that changing the subjective quality of experience in the general ways described at the start of section 4 could be considered a harm, if, for example, the alterations increase distress. Changing the subjective quality of experience in such a way might also be considered a matter of social concern if it is widespread, with regard to the way it changes power structures in relation to medicalisation more generally, for instance [see, e.g., 2]. As these claims seem to require further argument, however, we mention them in order to leave them aside.

In the previous section we showed that when people experience the contingency of being diagnosed with an asymptomatic disease, they may integrate it by finding ways to make it cohere with their bodily experience and/or past. This option can allow patients to avoid taking on uncomfortable beliefs about the insecurity of their health, but reduces the accuracy of their beliefs regarding their ability to know about their own health status, and their ability to control it. In doing this, patients sometimes reinterpret their experience in ways that involve taking responsibility for having caused the disease.

Assumptions and beliefs surrounding responsibility for health are complex. In the past, disease has sometimes been considered a deserved retribution or punishment, and sometimes a matter of chance (such that medicalising a problem is occasionally a way to destigmatise it [see, e.g., 13]). Sontag argued that there is still a tendency to regard patients to deserve their suffering and diseases [42, p 46]: “Patients who are instructed that they have, unwittingly, caused their disease are also being made to feel that they have deserved it” [42, p 67].

Such an ascription of responsibility is unlikely to be either fair or productive, and as such, we claim, can be considered a harm. Increasingly, epidemiological knowledge allows us to connect diseases to a range of behavioural and other factors, but this does not prove causation. That is, we might know that eating a diet high in red meat is associated with colon cancer, but this does not establish that eating red meat caused this individual’s colon cancer; such causation is likely to be multifactorial. Even if one has all the various factors that are statistically associated with getting a condition, and one gets that condition, it is not necessarily those factors which caused it [21]. Further, even if we could show that someone was causally responsible, through previous lifestyle and eating choices, for getting a disease, this would not establish their *moral* responsibility for having the disease. There might be mitigating or excusing factors, such as that the person did not know that some behaviour was likely to cause disease, or lacked control over their actions. Thus where patients, as part of narratively integrating the diagnosis with their other experience, come to take responsibility for having caused their disease, we may consider them to be harmed in that this self-ascription of responsibility, and any accompanying guilt or blame (from self or others), are unfair.

Further, this ascription of responsibility is unlikely to be productive. It involves (and may be partly motivated by) connecting one’s disease to factors that are under one’s control, such that one can attempt to alter the progression of the disease, or avoid future disease, by changing these factors. While this strategy allows patients to alter behaviour in ways beneficial to their health, in some cases (where the causal connection made is tenuous or overstated) the sense of control will be illusory. It has been argued that the view that we should take responsibility for our health can have negative effects like obsessive dieting or exercise, and can lead to “punishment and social exclusion” of those who do not undertake such measures [31, p 392], which could ultimately lead to victim-blaming, or discriminatory policies. The belief may also have counterproductive effects such as diverting attention away

from needed treatments, or lead to greater contingent shocks in the future, should preventive efforts fail.<sup>11</sup> Medical labelling that is motivated by preventive aims, in particular, needs to take these potential unintended consequences into account.

Not all patients responded to the mismatches described above by coming to regard the disease as a reflection of their past choices or by finding symptoms. Some instead accepted that disease can be a matter of chance, and not discernible via bodily sensations. In these cases, patients integrate the contingency into their narrative in other ways, finding strategies to accept uncertainty. Though this kind of response is likely to be more accurate regarding our capacity to control our health, it may also cause heightened anxiety, a changed (perhaps more alienated) relationship to one's body, and increased seeking of surveillance and testing. These patients seem to take on, if not responsibility for having the disease, responsibility for how they choose to respond to it, including whether and how to treat it. Though some may experience this choice as an additional burden, some may not, and indeed many patients may welcome or even demand this responsibility (though this could lead to increased self-blame if the chosen treatment is ineffective, or to choosing more aggressive treatments to prevent such regret).

Of course, putting someone in a situation where they might become aware of the unpredictability of future disease, or where they take on responsibility for their response, are not necessarily harmful. Some may accept these implications of their diagnosis with equanimity, and adjust to their new beliefs about bodily sensation or the relationship between health and behaviour without considering themselves harmed. Indeed, perhaps we should accept uncertainty about health and come to terms with our constant vulnerability to ill health [36]. Insofar as any new beliefs may be true, it might be inappropriately paternalistic to try to prevent people from forming them, even if the process has potential for harm. And certainly in cases where the diagnosis of asymptomatic disease has benefits, such as enabling effective treatment, we would not want to avoid diagnosis out of concern that it might have these effects. But in cases of overdiagnosis, where the disease is insignificant or trivial, these burdens caused by diagnosis are not offset by any potential health gains. In these cases, the potential for people to respond in ways that can increase anxiety, lead to surveillance-seeking, or take on responsibility for choices that are difficult but unnecessary, is, if not always harmful, at least a reason for additional caution in medical labelling.

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<sup>11</sup> Some of the trends described in section 1 are likely to encourage patients to respond to such diagnoses in this first way, and not the second. The implication of diagnoses made with preventive aims is that patients can influence future disease progression, but this is not the case for some or many patients or diseases. When disease occurs, patients will be more likely to narratively integrate the contingency in a way reflecting this belief about control, rather than regarding it as a contingency.

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