

Rethinking 'risk' and self-management for chronic illness

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Abstract Self-management for chronic illness is a current high profile UK health-care policy. Policy and clinical recommendations relating to chronic illnesses are framed within a language of lifestyle risk management. This article argues the enactment of risk within current UK self-management policy is intimately related to neo-liberal ideology and is geared towards population governance. The approach that dominates policy perspectives to 'risk' management is critiqued for positioning people as rational subjects who calculate risk probabilities and act upon them. Furthermore this perspective fails to understand the lay person's construction and enactment of risk, their agenda and contextual needs when living with chronic illness. Of everyday relevance to lay people is the management of risk and uncertainty relating to social roles and obligations, the emotions involved when encountering the risk and uncertainty in chronic illness, and the challenges posed by social structural factors and social environments that have to be managed. Thus, clinical enactments of self-management policy would benefit from taking a more holistic view to patient need and seek to avoid solely communicating lifestyle risk factors to be self-managed.

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Introduction

Over the last 30 years an abundance of sociological literature dedicated to the concept of risk has emerged, from perspectives that examine micro-level cultural constructions of risk (Douglas, 1986, 1992), the 'risk society' theory (Giddens, 1991; Beck, 1992), and perspectives that argue risks are socially-constructed discourses of regulatory power (O'Malley, 1996; Dean, 1999b; Galvin, 2002). Other critical commentaries have been concerned with the ontological



and epistemological status of risk, arguing that risk is in part constructed and historically localised within socio-cultural processes (Peterson and Lupton, 1996; Lupton, 1999, 2006; Lupton and Tulloch, 2002; Tulloch and Lupton, 2003). Another perspective is that calculating and controlling 'risk' is firmly embedded within the rationality at the heart of the modern project (Wilkinson, 2009).

More specifically, within the sociological health field, risk has been a rich topic of discussion, research and debate (Green, 2009). Broadly speaking two theoretical perspectives are prominent in conceptual pieces regarding health policies: first, literature has been concerned with broad theoretical understandings focused upon how risks are communicated via discourse and the impact they have upon individual discipline, moral self-regulation and conduct (Armstrong, 1995; O'Malley, 1996; Dean, 1999b; Galvin, 2002; Nettleton, 2006); second, they have explored the impact of living in a risk society where reflexive agents determine their life trajectories and manage their health (Giddens, 1998; Greener, 2008). Importantly, Wilkinson observes that the purely theoretical explorations of risk are not always borne out empirically, especially in relation to health behaviours (Wilkinson, 2009). Other scholars have also taken interest in understanding micro-social 'risk' behaviours (Zinn, 2004, 2005; Alaszewski *et al*, 2006), lay interpretations and enactment of risk (Monaghan *et al*, 2000; Hallowell and Lawton, 2002; Monaghan, 2002; Davis *et al*, 2004; Balfe, 2007a, b; Sear, 2009a, b), and healthcare professionals communicating risks more accurately to patients and their social networks (Alaszewski and Horlick-Jones, 2003; Alaszewski, 2005).

'Risk' is ubiquitous in general government policy discourse and at the same time, as Zinn (2005) notes, intimately related to healthcare policy in contemporary western societies. For this reason it is important to explore whether and how risk underpins and is embedded in specific policy initiatives. Self-management for chronic illness is one such high-profile policy initiative in a number of western countries. It has been introduced within the United Kingdom in the last decade (Kendall and Rogers, 2007; Greenhalgh, 2009) and we draw upon UK policy documents and related clinical recommendations (from bodies such as the National Institute for Health and Clinical Excellence) to demonstrate that notions of 'risk' shape self-management policy. We argue that the prominence of self-management policy is part of population governance in neo-liberal societies through the exploration of relevant theories of 'risk'. In this article the policy perspective of self-management is problematised by examining literature from the sociology of health and illness that offers a different perspective upon what constitutes 'self-management'. We then discuss work that explores the enactment of risk and management of health 'risk' entails from the lay agent's perspective. We argue that contemporary chronic illness self-management policy and its particular underlying rationale of encouraging risk management is problematic. Consequently a nuanced view of 'risk' and self-management is required.



Self-Management for Chronic Conditions: UK Policy

In the UK the last decade has seen self-management become embedded within policy and practice. The past Labour Government who held power between 1997 and 2010, first made the move to embrace self-management as a central plank of healthcare policy.

UK policy (in common with many other western countries) defines self-management as care that is led, owned and done by people themselves. Self-management is viewed as key to the development of patient-centred health services (Department of Health, 2005) and important for effective management of long-term conditions (Department of Health, 2004; Wanless, 2004). The terms self-care and self-management are often used interchangeably, with self-care being a broad concept that takes in a wide range of activities for upholding 'health' (Department of Health, 2005). The term self-management tends to relate to chronic conditions (Tomkins and Collins, 2005). As chronic conditions are the focus of our article we will use the term self-management throughout our discussion.

In 2001, the UK Labour government set out its vision for the management of long-term conditions in a keynote report: *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*. The document makes the argument that patient knowledge and experience is an untapped resource to be drawn upon and utilised when managing and caring for chronic conditions. This is in order:

... to ensure that a patient's growing knowledge of his or her condition is developed to a level whereby self-management, within the boundaries of a medical regime, becomes a real option. (Department of Health, 2001a, p. 6)

The underlying philosophy of the purpose and mechanics of delivering self care are revealed in strategy documents aimed at health-care organisations and professionals. One such document is *Self-care: A guide to developing local strategies and good practice* (the document conflates the terms self-management and self-care). It stipulates that

The NHS (National Health Service) cannot do self-care to people, but what it can do is create an environment where people feel supported to self care. This can be done through developing organisational structures and networks, appropriate information, Interventions and technology ... (Department of Health, 2006c, p. 2)

The Labour government devised guideline documents for operationalising their vision of supported self-management. A number of local and national initiatives to improve patients' self-efficacy and skill sets for managing conditions have been



implemented (Department of Health, 2005). One route to ensuring optimised self-management of chronic conditions is *The Expert Patient Programme (EPP)*. The EPP is deemed an essential tool for empowering patients to have the self-belief to be able to manage their condition effectively. The EPP was first developed in the United States by Lorig *et al* (1993). The focus is on enhancing self-efficacy through participation in a highly structured course, led by teams of trained volunteers all living themselves with a long-term condition (Department of Health, 2001a; Taylor and Bury, 2007). Another envisaged route for encouraging patient self-management is through primary care health professionals offering support, encouragement, education and advice. This involves drawing up individual care and action plans (Department of Health, 2005).

Providing support to self-manage and offering the correct information to 'empower' patients runs counter to the centrality of patient-centeredness, patient-knowledge and supporting patient needs, goals and interests. This is because implicit within policy documents a position is adopted where the patient has no agency, is disempowered or self-managing incorrectly (Kendall *et al*, 2011). In practice this can create paradoxical scenarios where a bio-medical approach to ensuring self-management is privileged and maintained in some instances and in others patients' subjective experiences are valued and acknowledged (Wilson *et al*, 2007). The endorsement given by the Department of Health to EPP and embedding patient-centred self-management in primary care is driven by a number of factors, including reducing the economic burden associated with chronic illness. This includes the forecasted economic strain predicted to overwhelm the NHS and the welfare state. Thus encouraging chronic illness sufferers to engage in structured self-management may lessen this load (Department of Health, 2001a, 2005, 2006a, b, c; Kendall and Rogers, 2007; Bury and Taylor, 2008).

With the election of the UK Conservative-Liberal Democrat coalition government the drive to reduce public spending has intensified and stimulated the desire to reform the NHS. However, in terms of self-management policy it seems little will change. The coalition's first White Paper (Department of Health, 2010) postulates some familiar themes of the NHS being patient-centred, focusing upon individual need and expertise, thus offering shared decision-making. This is twinned with communicating 'appropriate information' that will improve outcomes and adherence to treatments while simultaneously reducing costs (Department of Health, 2010). Running parallel to these themes is a drive to increase focus and resources upon operationalising clinically effective treatments and guidelines (from bodies such as NICE) as the cornerstone of how the NHS manages patients. The following quote exemplifies this:

We are also clear that increasing patient choice is not a one-way street. In return for greater choice and control, patients should accept responsibility



for the choices they make, concordance with treatment programmes and the implications for their lifestyle. (Department of Health, 2010, p. 16)

Thus, the current indications are that the focus of government self-management policy will continue to remain the same.

Self-Management Policy and 'Risk' Management

Self-management policy in the UK promotes the use of patient knowledge and empowering people to actively participate in chronic illness management. In turn, this is founded upon an economic imperative to reduce costs to the state and society. We now devote time to exploring how self-management policy is also underpinned by 'risk'. Zinn (2005) asserts that the concept of risk in health care has a discernable dominant characterisation. 'Risk', from the perspective of healthcare, is founded upon the need to manage the potential for negative healthcare outcomes on the basis of the calculation of probabilities. The bed-rock of policy is for lay people to rationally avoid objectively defined health risks (Zinn, 2005).

Wilkinson has noted the relationship between controlling risk probabilities and a deepening of bureaucratic control and management within contemporary western societies (Wilkinson, 2009). In the self-management policy documentation (discussed above), the calculation and prediction of economic outcomes collide with the calculation, prediction and control of morbidity potentialities. Self-management policy advocates providing the 'right' information and offering support and advice. The logic underpinning 'correct' self-management is managing lifestyle risk factors with view to ensuring 'correct' health outcomes with little reference to individual differences.

Embedded within *The Expert Patient* documents are references to managing risks and lifestyle to avoid longer-term health problems (Department of Health, 2001a). Another example comes from the implementation strategy document, *Self care – a real choice. Self care support – a practical option*, which emphasises the role of 'campaigns and training on lifestyle issues to change behaviours, promote good health and prevent ill health' (Department of Health, 2005, p. 3). The focus is upon prevention and control, or in short avoiding the *risk* (or probability) of future deleterious problems (Department of Health, 2005).

Consequently the initial policy focus upon the patient and their need, taking into account their individuality and variability, is further lost amongst the promotion of the 'right' way of self-caring for the purposes of economic rationales. As an example, *The Musculoskeletal Services Framework* (MSF) (Department of Health, 2006a) reveals a close association with encouraging



people to self-manage and avoid risk factors related to musculoskeletal problems via lifestyle modifications. Embedded within this broad ranging document is the government's plan for implementing 'supported self-care' (p. 20) within primary care. The rationale for encouraging self-management and asking patients to manage their own condition(s) is couched in the language of risk. It emphasises controlling lifestyle factors such as obesity, diet, exercise, alcohol consumption and smoking in order to restrict the possible exacerbation of existing osteoarthritic pain (Department of Health, 2006a). Concurrently, NICE treatment guidelines for musculoskeletal conditions recommend core self-management actions such as exercise, weight loss and information provision (National Institute for Health and Clinical Excellence, 2008), reflecting the concerns of avoiding bio-medically defined risks. Similarly the National Services Framework and NICE guidelines for Diabetes adopt the perspective of engaging with patients in order to encourage self-management of the risk factors (diet, alcohol consumption and exercise) that may aggravate/control their condition (Department of Health, 2001b; National Institute for Clinical Excellence, 2009).

Thus, encouraging self-management and the management of 'risk' factors are symbiotically entwined. Moreover, this may be interpreted as a manifestation of the government apparatus concerned with calculating and controlling costs, population health and in turn individual conduct. We now discuss theoretical perspectives to elucidate and embellish this argument.

Self-Management and Risk Theory

Useful insights can be drawn from work that uses a Foucauldian perspective to understand the drive to promote self-management. Dean (1996, p. 212) argues that it is important to question the ways that 'even the most mundane of governmental policies' relate to the shaping and forming of individuals and their actions. Rose's (1996) work charts how historically techniques of liberal government have shifted focus. In the early twentieth century a form of social liberalism existed in which the state and welfare provision was central to ameliorating the inequalities and social disruption that arose as a result of industrial society. The techniques of government employed at the time ensured people conducting themselves in accordance with reciprocal responsibilities they held towards fellow citizens and the state. Accordingly a set of norms and values for people to conduct themselves by as responsible 'citizens' were established.

In the UK context Joyce notes the shift to a neo-liberal style of government from the 1970s, arguing that variations of neo-liberalism have underpinned



all UK governments since. He contends that the heart of neo-liberal health policy is predicated upon 'individuals taking responsibility for their own health and not relying passively on the state' (Joyce, 2001, p. 598). Rose (1996) contends that the 'social-liberal' mode of government was replaced by a more market orientated model, one not predicated upon state welfare policies but one that embraced an individualistic ethos. He argues a situation arose where people are governed 'through the regulated choices of individual citizens, now construed as subjects of choices and aspirations to self-actualize and self-fulfilment (Rose, 1996, pp. 40–41).

Rose further states that neo-liberal governments use the knowledge systems available to them to ensure that people act in particular ways and within particular norms, boundaries, morals and responsibilities. At the same time liberal governments facilitate people's rights and freedoms and foreground the right to choose, although within a framework of normative standards decided by experts disconnected from government and mediated via managerial systems (Rose, 1996, 1999). This ethos has been shown to extend to regulating individuals' personal beliefs, sense of 'self-esteem' and ability to act responsibly (Cruikshank, 1996) or developing an attitude of 'prudentialism' with the mindset of pro-actively managing health and wellbeing, which in turn relates to being a morally upstanding citizen (O'Malley, 1996; Dean, 1999a).

Armstrong discusses 'the rise of surveillance medicine' in which the focus of managing health is no longer based within the clinic, but operates at the level of managing the population and ensuring healthy 'norms' are maintained. This is related to the emergence of the 'risk factor', in which the probability of pathology rather than actual sign or manifestation of disease becomes the focus of medical management. Surveillance medicine, according to Armstrong, 'turns increasingly to an extracorporeal space – often represented by the notion of 'lifestyle' – to identify the precursors of future illness' (Armstrong, 1995, p. 401). Dean's work reflects and embellishes this argument and notes that population level risks are identified and acted upon by governments to implement systems of 'case management risk' (p. 189). These often take the form of the clinical encounter whereby people's health risks are assessed and managed (Dean, 1999a), something that can be seen in current health services framework documents (Department of Health, 2001b, 2006a). Dean maintains that the very concept of 'risk' is a way of categorising and organising the possibility of events for the purposes of governing conduct. Thus, nothing in itself is a risk, but knowledge is used to define the possibility of outcomes that in turn are used to govern. In other words, events or entities are deemed risks that can be managed. Risks, therefore, are a technique of governance that are used in political ways and used according to the politics they become attached to (Dean, 1999a). Thus, hazards and dangers exist, but discourses infuse certain



lifestyle risks as being more dangerous, worthy of attention or prevalent than others (Peterson and Lupton, 1996; Fischer and Poland, 1998). This view maintains that 'strict adherence to self-management regimes is seen as the only real means of avoiding cancers, heart disease and other afflictions that constantly threaten the integrity of the self' (Peterson and Lupton, 1996). Accordingly we are in an era with an ethos of self-responsibility and consumerism in which people then become 'risk managers' given to managing their own health and well-being rather than relying upon the state (Joyce, 2001).

Scambler (2002) highlights that the Governmentality perspective is useful and illuminates some of the mechanisms of governance, but it omits the role of economics and the role of capitalist power relations in neo-liberalism. He explicitly argues that under neo-liberal regimes individualising risks are forms of domination by those in power; 'the concept of risk, it might be said, has been expropriated to serve the ends of surveillance through the political promotion of technologies of the self'. (Scambler, 2002, pp. 129–130). Scambler maintains that neo-liberal regimes are actively promoting the techniques of managing self in order to satisfy the economic imperatives that underpin them (Scambler, 2002). Galvin suggests that the ultimate aim of self-management policy is to facilitate chronically ill people's re-entry to the labour market as 'self-reliant, independent, and responsible' citizens (Galvin, 2002, p. 108). As Galvin sees it, 'risks' and the discourses surrounding them are related to easing the economic burden that is frequently associated with the rise in chronic disease and impairment (for example, through disability or unemployment benefits and medical costs). Therefore, the modern patient is expected to be a reflexive self-helping citizen avoidant of 'risks' that they are told they are susceptible to (Galvin, 2002). Joyce notes this is not necessarily a one-way relationship: while citizens are encouraged to manage risks, the state has a mutual role in providing resources for citizens to do so (Joyce, 2001). Arguably, the plethora of NHS and state-funded self-management programmes are one such provision of resources.

This analysis offers an insight into the rationale for promoting the self-management for chronic illness agenda. The imperative to manage 'risks' is geared towards engaging the population in becoming self-monitoring subjects who care for and manage their own health in order to help maintain social order and reduce an economic burden. This view highlights the moral and economic rationale for governments' attempts to give legitimacy to the self-management policy agenda. However, dissonances occur between the theorising of risk and the available empirical evidence (Wilkinson, 2009). In particular, theories of governance are open to critique for not giving enough credit to agency in context (Lupton, 1999; Joyce, 2001; Tulloch and Lupton, 2003). This analysis describes the underlying process and the rationale of current policy. It does not necessarily account for what happens at the level of the socially situated agent



in terms of encountering, constructing and dealing with 'risks'. Nor does it offer insights into how policy can be translated into providing help and support to people's actual needs in relation to living with chronic illness.

A Viable Policy Perspective?

As discussed above, the elevated prevalence of risk discourses can be related to an increased promotion of self-management and lifestyle management to meet economic imperatives and maintain social order. The compartmentalisation of the health agenda and the lack of policy engagement with the complexity of how health is achieved (Hunter, 2003) feeds this individualised and decontextualised approach. Thus, current self-management policy can be critiqued on two grounds: first, there is abundant literature that diverges from a bio-medical/policy perspective of self-management. Second, an argument can be put forward that risk, as focused upon in policy and practice, is inadequate and disproportionately based on rational calculative action.

Turning to the first point, the 'lay' perspective of self-management challenges the dominant model postulated in policy. The 'lay' perspective is closely related to sociological work on living with chronic disease (Bury *et al*, 2005), which argues that self-care and self-management are primarily patient-centred concepts.

Central to self-management is maintaining a sense of normality in the illness experience and a quest to reconcile a shift in self-identity (Kralik *et al*, 2004; Bury *et al*, 2005). Managing a chronic condition is heavily focused upon the ill person being able to continue as normal and 'cope' in daily life as well as continually adapt to circumstance in relation to contextual and disease-related issues (Rogers *et al*, 2007; Greenhalgh, 2009). For example, Rogers and colleagues found that patients with irritable bowel syndrome (IBS) developed their own routines and dietary patterns that were integrated within their own corporeal experience and knowledge. The management of IBS was often removed from the medical advice that they received (Rogers *et al*, 2005). Kralik *et al* (2004, p. 264) assert that 'self-management is not a linear consistent process; rather it is grounded in the personal and social context of people's lives'. As a result formerly stable environments have to be managed and re-negotiated or avoided for fear of causing pain, social discomfort or bringing on symptoms (Royer, 2000; Clarke, 2009). For the lay person, engaging in self-management is a process of experimentation, learning about bodily needs and information gathering contingent upon social context, lifestyle, perceptions of their condition and ability to act. Medical advice is used alongside self-management, and/or integrated within self-management practices. Self-management is a series of



negotiated actions framed by need and that can be both conscious and thought through or subconscious and intuitive (Paterson *et al*, 2001; Thorne *et al*, 2003; Kralik *et al*, 2004). Thus, patients do not solely rely upon medical expert involvement in order to be able to adequately self-manage their condition (Taylor and Bury, 2007; Wilson *et al*, 2007). Importantly self-management is conceived as being the 'mundane' reality of living with chronic disease, in other words, lay self-management strategies are not medicalised programmes aimed at gaining outcomes that can be measured to improve patient self-efficacy or function. Nor are they actions undertaken to avoid 'risks' as dictated by biomedical and policy discourse. The implication of the lay perspective is that no singular way of managing an illness exists, which in turn creates specific emotive challenges and strategies for the individual (Furler *et al*, 2008). Consequently, tensions occur between the lay model of self-management and the models promoted from the worldview of current policy and bio-medicine (Kendall and Rogers, 2007; Kendall *et al*, 2011), as the latter do not necessarily take account of people's sophisticated practice of self-management in the everyday.

Turning to the second point, there are a number of critiques of the enactment and conceptualisation of risk within health policy. Zinn (2004) contends that the view of risk management within the bio-medical paradigm equates to patients being made aware of probabilities of health outcomes. In turn they will rationally account for hazards to be navigated accordingly (Zinn, 2004). Self-management policy documents, and the musculoskeletal and the diabetes services framework are prime examples of how this is reflected in national policy (Department of Health, 2001a, 2006a). In contrast, a well-rehearsed argument has been presented that focusing upon calculable actions is inadequate for understanding the individual meaning and decision making of social actors. Wilkinson argues that one of the dangers associated with focusing upon effective risk communication is it contains an inherent view that 'risk', in whatever form, is a common cultural experience untroubled by social divisions (Wilkinson, 2009). Context, biography and social class mediate in people's perceptions of their health needs, how 'risks' are understood, and the decisions people make (Alaszewski and Horlick-Jones, 2003; Zinn, 2004, 2005; Alaszewski, 2005). In reality, a purely rational decision-making process is an untenable concept: everyday life, social context and emotion get in the way (Zinn, 2005). Wilkinson highlights that experiencing or being 'exposed' to risk can be emotional events related to embodiment and self-identity rather than solely related to future events (Wilkinson, 2009). Equally, as Zinn notes, the role of context, intuition and emotion is just as important in decision-making when people are confronted by 'risk' (Zinn, 2008). Further, as Seear states 'health and disease are random, unpredictable and uncontrollable events of life' (p. 54).



For Seear, comprehensively controlling ‘risk’ probability is a paradoxical endeavour due to the fact that ‘risks’ are probabilities and not certainties (Seear, 2009b). In summary, many sociologists point to the problem of privileging individual rational action and thus omitting social context, experiential meaning making, emotion and intuition. This leads to healthcare policy and its interpretation of risk discarding the experiential understandings and the needs of the ill person. The self-management perspective represented in dominant policy is insufficient for understanding the ways that people manage and take care of their chronic conditions in daily life. Understanding how risk, self-management and chronic illness inter-relate in the experience of the layperson is imperative. In the following sections we discuss how lay people may not always act upon public health risk discourses and how they may perceive ‘risk’ as a concern to be managed within their experience of chronic illness.

The enactment of Health Risks from the Lay Perspective

A broad field of literature highlights that the way people explain and account for illness can diverge from bio-medical explanations (Blaxter, 2004). Being necessarily selective for reasons of space, we highlight two examples of how lay people do not necessarily think in terms of causal risk factors. Research highlights that the meanings that people with osteoarthritis (OA) give to the condition are not related to external identifiable risk factors. A more complex interrelationship between people’s own expectations of ageing, perceived impact of pain on daily living and the dialectic of embodied self and social context circumscribe the experience of pain (Sanders *et al*, 2002). Rather than individuals identifying risks pertaining to their condition, they conceptualise OA as part of normal ageing and something they have ‘to put up with’. It is thus defined as an expected deterioration of the body, validated by social stereotypes. Similarly Higginbottom (2006a) has noted that lay meanings given to hypertension are mediated via life course, experiences of migration, ageing, ethnicity and social class, with people often citing the idea of stress as the main causal factor. This differs from the biomedical lifestyle risk markers associated with the condition, such as alcohol consumption, obesity, smoking, lack of exercise and diet (Higginbottom, 2006a). Arguably the ‘risk’ focus of the policy that we have highlighted is not sufficiently attuned to addressing the multi-layered experiences and needs of the person living with chronic illness.

The meaning that people give to chronic conditions is not the only factor that influences the way that the reality of living with a chronic condition diverges from the perspective of risk that is inherent with current policy. A broad field of



research reflects Tulloch and Lupton's (2003) assertion that health risks are understood and constructed within historical and cultural settings.

One example is literature concerned with health inequalities, which posits that structure and agency often intertwine. This then influences the ways that people understand and react to objectively identified health risks (Popay *et al*, 1998, 2003). Furthermore, when lay agents do take on board public health risk messages, they often measure them against contextual social knowledge and invoke the idea of 'fate' as an explanatory factor. The statistical risks underpinning epidemiological approaches do not necessarily chime with individuals' interpretation of their own risk because people quote examples of the exceptions to the rule: one person who smokes and drinks lives to be 90, whereas another person who never did so dies of heart disease (Davison *et al*, 1991, 1992).

What may be termed a risk or interpreted as a risk (or overwhelming negative probable outcome of ill health) for the lay person can differ from the bio-medical conceptualisation of what a 'risk' is. Graham's (1993) research on women who smoke is a good example. Her study participants knew at an abstract level that cigarettes were bad for their health. In the context of having limited economic resources for other treats or relaxation pastimes, smoking provided an opportunity for escape or time to oneself. The potential of future ill health from smoking was overridden by the contextual and currently felt 'risk' of not getting respite from hectic childcare duties and succumbing to fatigue and stress (Graham, 1993). Staying with the theme of gender; O'Brien *et al* (2009) elucidate the salience of negotiated masculinity and the association with heavy drinking and other activities that would be deemed risky by health-care professionals and policy makers. Conversely, engaging in health promoting behaviours is open to the same process of performative masculinity; weighing up masculine behaviour associated with heavy drinking was positioned against being marginalised by not drinking. This in turn is mediated by sub-culture, point in the life-course and social class. Here, maintaining an acceptable appearance of masculinity within a given social context influences the perceived 'risk' and risk behaviour engaged in (O'Brien *et al*, 2009). Other research has highlighted that activities deemed risky by biomedicine are often circumnavigated or repositioned by lay actors. Monaghan's work with body builders shows that steroid abuse is often defined to be an aid to being virtuous and developing a socially approved, muscular, externally sanctioned fit body while fitting into a particular sub-culture (Monaghan *et al*, 2000; Monaghan, 2002). Similarly Tulle (2008) demonstrates the musculoskeletal injuries of ageing athletes are open to contestation. Medics positioned injuries as age related and as a hazard due to the athletes' activity. For the older athlete injuries were defined as an occupational hazard and represented part of the maintenance of what Tulle



describes as embodied identity and habitus. Thus, for the athlete, the potential for loss of valued embodied self and symbolic capital is the dominant 'risk' (Tulle, 2008). Further, research shows that ethnic groups use herbal remedies to self-manage hypertension rather than relying upon bio-medical advice. Their understanding of 'risk' from hypertension was socially and biographically mediated and related to stress. The self-management strategies employed were drawn from their cultural background and self-learned. Thus their risk management strategies and risk interpretations stem from their immediate social context and cultural perceptions (Higginbottom, 2006a, b).

Managing Risk and Uncertainty in Illness

The important contribution sociology can make to the study of risk is to focus upon the issues and concerns that people face in everyday life rather than on their capacity for probabilistic thinking about 'risk' (Wilkinson, 2006, 2009). Zinn and Alaszewski conceptualise 'risk' as living with and managing uncertainty (Alaszewski and Brown, 2007; Alaszewski and Coxon, 2008; Zinn, 2009). Chronic illness is a time of uncertainty, both in terms of identity and biography (Charmaz, 1983; Bury, 1988; Zinn, 2004, 2005) and corporeality (Turner, 2008).

Reventlow *et al* (2006) examined the experiences of people who recently had a scan for osteoporosis. Their participants merged the expert healthcare message of osteoporosis risk into constructing a new culturally influenced perspective, namely that osteoporosis is a condition that is frequently associated with old age and confers fragility. As a result the people who were diagnosed with the condition altered the way that they engaged with everyday activities on the basis of the notion of risk that they had co-constructed: people took more care doing usual activities of daily living that they thought were likely to damage their bones that were now perceived to be weak (Reventlow *et al*, 2006). Alaszewski *et al* (2006) investigated the ways that stroke sufferers' negotiation of risk involved. In this study stroke sufferers discussed that they were conscious of the risks posed by certain behaviours and activities. Balancing the risk of exacerbating health problems against the risk of social isolation or losing a sense of self became key issues for the participants (Alaszewski *et al*, 2006).

Balfe (2007b) has noted the salience of engaging in activities that allow moral performance and the establishment of normality when living with diabetes. Being able to act in an appropriate way is influenced by the management practices of those with diabetes. Eating healthily and avoiding risks from poor diet can be conducive to being normal and having a masculine sporty body for



some diabetics. For others, especially women, maintaining a particular diet to minimise 'risks' sits counter to maintaining a slim body due the need to take on starchy foods. Further examples show that people would avoid eating particular foods or eat unhealthy foods when in company in order to minimise the social 'risk' of being seen as abnormal or strange (Balfe, 2007b). Balfe further highlights that engaging in risky behaviours in diabetes represents an ambivalent practice mediated within the contextual spaces that identities are enacted. Thus for students, university life entails 'risky' drinking as an aspect of a normal identity in particular spaces and places central to student life – bars and clubs (Balfe, 2007a). Student's self-management practices were finely balanced between maintaining their identity and mediating the effects of alcohol 'risks' to their diabetes. For participants in these studies, the management of 'risks' encountered while living with a chronic condition relates to the way they adapt to maintain a sense of self in a particular social location. Again, the concept of what a risk is to the lay person is constructed within micro-context (Tulloch and Lupton, 2003), but also relates to managing and constructing a sense of certainty within the life course (Zinn, 2004, 2005).

Embodiment, Emotions and Risk

Another perspective from which to understand how people live with 'risk' in chronic illness is to look to the corporeal nature of illness experience (Kelly and Field, 1996) while remaining with the concept of uncertainty as a key component of experiencing risk (Zinn, 2004, 2005). Williams and Bendelow have been influential in developing an argument that calls for an embodied sociology in the realms of pain, emotion and chronic illness (Bendelow and Williams, 1995; Williams, 1999; Bendelow, 2009), with Bendelow latterly calling for 'risk' to be investigated in these areas (Bendelow, 2006). Managing self, social relations and emotion is positioned as central to living with and managing chronic illnesses, such as cancer remission or diabetes (Garrett, 2001; Furler *et al*, 2008).

Embodied experience and bodily changes such as the onset of chronic illness and potential impairment shape the way that social relations are enacted and how risks are navigated. As Turner (2008, p. 229) states 'when the body loses some of its mobility and dexterity, then the world presents itself as a problem', which has been highlighted in the examples of joint pain (Sanders *et al*, 2002) or stroke (Alaszewski *et al*, 2006). Staying with Alaszewski's work, the corporeal risk and uncertainty that is engendered through stroke survival equates to individuals re-negotiating taken for granted scenarios and everyday situations. Situations that were considered normal prior to the onset of the chronic disease become ambivalent, uncertain or hazardous (Alaszewski *et al*, 2006). Yu and



colleagues note that a recurrent theme in qualitative studies of coronary heart failure and its aftermath is dealing with the negative emotions that people experience when coming to terms with altered physicality, social relations and sense of self (Yu *et al*, 2008).

Managing the negative feelings that come with changed physicality, altered social role and changes in interactions with the social environment are what Wilkinson has called the 'risk' of social suffering of living with such uncertainty (Wilkinson, 2006). This more accurately encapsulates the immediate lived concerns of people over and above a focus upon understanding how they deal with the likely probabilities of 'risk' in daily life (Wilkinson, 2009). The process of negotiating the impact of chronic illness with the possible change in 'embodied habitus' may be emotionally charged through confrontation with feelings, self and social relations shaped by ambiguity, uncertainty and 'risks' (Edwards and Imrie, 2003; Galvin, 2005). Thus, engagement with altered embodiment, the social environment and immediate social relations has to be managed alongside the emotional consequences of impairment.

Can Risks be Controlled by Lay Agents?

A final point should be made about 'risks' and the policy focus upon controlling lifestyle risk factors. As can be seen in the examples provided above, 'risks' are constructed in terms of agent's social location and cultural lifeworld. Scambler observes that a fundamental flaw of the neo-liberal approach to risk management is that they ignore issues of social class and structural factors (Scambler, 2002). Graham (1993) and Seear (2009b) demonstrate that social class and gender relations play a role in the 'risks' that people are exposed to, and Flynn (2006) argues that risks are not just the products of meaning making, but also occur from generative social structural factors, which then have to be managed by people. Seear has noted the underlying philosophy of individualised control over 'risks' promotes the rational self as able to have complete control over the body, a view that is fundamentally flawed (Seear, 2009b) missing the dialectic between agency and structure.

Lupton argues that socio-spatial configurations can influence the way that risk is encountered and constructed (Lupton, 2006). From a disabilities studies perspective, the social structural factors influencing a built environment are seen to favour the able bodied (Gleeson, 1999). Experiencing physical impairment within the built environment is argued to produce difficulties and hazardous or uncertain situations (Clarke, 2006; Thomas, 2007). This view resonates with findings from research into musculoskeletal conditions (Sanders *et al*, 2002; Ong and Jinks, 2006) and can be witnessed in Alaszewski *et al*'s



study into stroke survival (Alaszewski *et al.*, 2006). We contend this perspective overlaps with and further strengthens the above argument that somatic and painful experiences are central to understanding the experience of chronic illness (Kelly and Field, 1996; Williams, 1999; Bendelow, 2006) and is an arena for exploring how 'risk', suffering and uncertainty intrudes into people's lives (Wilkinson, 2006; Zinn, 2009). The external social forces and constraints that people encounter influence the way that risk is experienced and, in turn, their experience of managing risk, suffering and uncertainty. Seear argues that the sheer volume of hazards, risk factors and risky scenarios that people are recommended to avoid or control is implausible. Few people have the required level of control in their lives, especially in relation to environmental factors, social class position and availability of resources (Seear, 2009a, b).

Concluding Comments

Using relevant sociological theories of 'risk', we have critically explored the concept and enactment of 'risk' in current self-management policy. Our article seeks to contribute in two ways. First, to think about the application of theoretical perspectives of 'risk' in relation to understanding lay self-management practices. Second, to help re-orientate current healthcare policy and the development of clinical practice.

Turning to the first point, we contend that while Governmentality perspectives of 'risk' offer a useful way of understanding some of the mechanisms of government and how 'risk' is subsequently enacted in policy. However, it does not allow us to understand the lay perspective of managing chronic illness. This includes the reality of when people may need to use health services when dealing with the corporeal consequences of their illness as well as managing their sense of self and micro-social concerns (Williams, 1999; Bury, 2000). Thus, we argue that it is important to understand the socio-cultural and historically situated nature of risk (in the sense of how 'risks' are defined and encountered at both macro and micro levels) (Tulloch and Lupton, 2003). Further, it is important to explore how the experience of health risks can emanate from social structures that the laity can also interpret and give meaning to (Flynn, 2006). In summary, the literature highlighted above defines 'risk' not as an external category that is rationally acted upon by lay actors; rather it is, at least in part, constructed within the actor's contextual social structure and on the basis of the embodied, emotive element of the illness experience. Thus, it will vary according to time and circumstance and a dynamic understanding is more appropriate to explicating the ways in which individuals with chronic long-term conditions give meaning to 'risks'. If health related



'risks', when viewed from the lay perspective, are related to socio-contextual factors that may influence social participation, preferred roles and self-identity, an overlap with the lay-view of self-management can be identified with its focus upon maintaining normality, experimenting and managing embodied needs, and re-evaluating social roles (with the associated emotional factors). Kendall and Rogers argue that self-management for individuals is founded in resistance to professional and state mechanisms of trying to engender compliance and dictate what is a safe and recommended self-management activity. Thus, what is deemed a 'risk' by bio-medically sanctioned self-management activities can actually be considered a fruitful and useful pursuit by lay actors (Kendall and Rogers, 2007).

We now turn to our second consideration. If healthcare policy is to maintain risk management as a central tenet then it needs to address and incorporate the lay view of risk, something that Alaszewski and Horlick-Jones have already called for (Alaszewski and Horlick-Jones, 2003). Wilkinson has also noted the danger of concentrating risk research upon policy and government agendas that can be to the detriment of recognising fundamental human problems and concerns (Wilkinson, 2009), such as the emotional fall out of chronic illness and the challenges that people face in daily life. In relation to self-management, this is directly linked to the concept of health risks. An attempt to broaden out the understanding and application of 'self-management' has been developed by Kennedy and colleagues through the WISE model that seeks to incorporate both the lay and professional perspectives into a supported self-management approach (Kennedy and Rogers, 2001; Kennedy *et al*, 2007). We contend that current self-management policies privilege educating and informing patients of health risks that run counter to efforts to integrate lay and professional knowledge in consultations. As we have shown, what may be termed a 'risk' can be very different from the patient perspective. Therefore, integrating the varied ways of viewing health risks into a shared perspective would provide a more nuanced and productive way of supporting existing self-management strategies and, address more holistically, the concerns and needs of those with chronic conditions.

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