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Title

Getting what you deserve: how notions of deservingness feature in the experiences of employees with cancer.

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Abstract

This article extends deservingness debates in social welfare to a new domain by exploring how deservingness features in the experiences of people who are in paid work when diagnosed with cancer. In doing so, it explores the interrelationship between deservingness criteria and Parsons' sick role. Narrative interview data was collected from people with cancer who were employed when they were diagnosed (n=14) and line managers with experience of managing an employee with cancer (n=7). Semi-structured interviews were conducted with members of occupational health and human resources staff (n=3), health care professionals (n=5) and staff from a UK cancer support charity (n=7). Data was analysed thematically. Deservingness featured, and mattered, in how participants understood cancer in relation to work, and ensuing workplace interactions. Though cancer was generally seen as deserving; employees with cancer were perceived to be in need, and not blamed for their condition, this deservingness was subject to question. Employees with cancer were not necessarily considered equally deserving, dependent on their contribution as workers pre-diagnosis, and their efforts to contribute since being diagnosed. In a reflection of the fixed-term, time constricted nature of the sick role, work and welfare institutions required a definite timeline for employees to return to, or depart from work. The paper evidences an important gap between the fixed sick role as perceived by employers and the UK state welfare system, and the complex experiences of people diagnosed with cancer when in paid work.

Keywords

Cancer; Deservingness; Employment; Sick role; Welfare

Introduction

The application of deserving and undeserving as dichotomous categories for welfare benefit claimants is explored primarily in contemporary social policy literature (Baumberg, 2016). This article extends these deservingness debates to a new domain by exploring the concept within individual interactions in the workplace, in addition to reflecting on experiences of the UK welfare system. Unusually for work exploring deservingness, the paper has a condition-specific focus. Cancer incidence across the working age population is increasing, concomitant with an ageing workforce. Further, focussing on cancer allows for a more nuanced understanding of how deservingness is constructed in relation to health.

The paper begins by exploring key overlaps between Parsons' theorising for sickness and deservingness as conceptualised by van Oorschot (2000), before discussing whether people with cancer are categorised as deserving, and the relevance of research focused on experiences of cancer at work. It details the use of qualitative interviews from multiple perspectives and provides a summary of participant characteristics. Findings are structured around three themes; 1) how deservingness features in the workplace for employees with cancer; 2) how employees diagnosed with cancer are not viewed as equally deserving; and 3) how deservingness is constructed temporally, and consequently, is problematic for employees diagnosed with cancer.

The deserving sick role

To contextualise this paper it is important to explore how ill-health and deservingness are conceptualised in relation to work, and what material consequences these conceptualisations have for people with cancer. There are underexplored overlaps between contemporary understandings of deservingness in relation to the provision of social welfare and medical sociological framings of ill-

health, in particular, Parsons' Sick role (1951). Van Oorschot (2000) offers five criteria for how deservingness is gauged in public opinion for welfare distribution; control, attitude, reciprocity, identity and need. In more recent years these have been coined the CARIN criteria for deservingness (van Oorschot et al., 2017). Control means that the deserving individual is not in control of their situation, or responsible for their misfortune. Attitude is the expectation that those deemed deserving should be suitably grateful for the support they receive. Reciprocity as a criterion reflects the perceived responsibility of benefit claimants to earn the support they receive; the more reciprocation, the more deserving. Identity refers to someone being part of society, and not 'other'. The last criterion relates to need; the greater an individual's need, the more deserving they are (van Oorschot, 2000).

The reciprocal criterion above reflects the exchange fundamental to Parsons' sick role (1951), which features an exchange of obligations for entitlements for someone experiencing ill-health. The duties of the sick person are to seek out and comply with competent medical help, which subsequently functions to legitimise their diagnosis, and make all attempts to get better (Varul, 2010). The corresponding entitlements of the sick role are to be allowed temporary exemption from usual duties, for example, sick leave from work while recovering and to not be blamed for their ill-health. Thus, a condition of entering the sick role is to be deserving, and similarly, to be deserving in the context of ill-health requires that an individual have a 'genuine' illness that they are not responsible for (*ibid*). Fundamentally, both the sick role, and conceptualisations of deservingness in relation to ill-health, are subjective. In the context of welfare provision and/or workplace support this has important implications for people who are in work when diagnosed with cancer.

The sick role assumes illness to be responsive to treatment, and for the sick person to return to good health. This complements the notion of reciprocity, and the presumed intention of an ill person, and/or benefit claimant, to rehabilitate or recover, as is present in understandings of deservingness. The sick role has been critiqued for being limited to physical health rather than mental health, and for doing little to explain comorbidities (Gatchel, 2004; Gallagher, 1976). A connection can be drawn here between conditions not adequately accounted for within the sick role, stigma, and perceived lack of deservingness.

Charmaz (2000) notes that in contrast to the short-term (or terminal) conditions that are assumed as part of the sick role, people with long-term conditions do not necessarily recover (or die) from their illness. Parsons (1975) argued in a later paper that the sick role could be applied to long-term conditions, suggesting that a return to normal duties could result from the successful management of an individual's condition. There remains an implication here though, of a static and unchanging condition, rather than the long-term social process of many illnesses that can include degeneration, fluctuation and comorbidity (Nettleton, 2006), such as cancer. These more complex and dynamic elements of long-term conditions can be identified in the theorising of Bury (1982). Biographical disruption centres the perspective of the individual experiencing long-term ill-health. It can be seen to encompass the exchange that features in the sick role, situated within a functionalist framework and represents a description of role expectations, rather than personal experience. Being diagnosed with a long-term condition upsets the 'normal rules of reciprocity' (Bury, 1982, p.177), and arguably, replaces them with new presumed 'rules' of the sick role.

This paper does not seek to defend the sick role, but recognises how it complements other functions within society including work and employment (Bellaby, 1990; Gerhardt, 1979). Bellaby (1990) who observed factory workers in an investigation of how 'genuine' illness is negotiated in the workplace, described how Parsons' theorising resembled the employment contract by 'regulating temporary deviations' (sick leave) from work (p.63). The sick role is a single element in a 'much larger set of mechanics embedded in the social system: a 'window' effectively, on a broader set of motivational balances' (Williams, 2005, p.130). An important sociological critique then, of Parsons' thesis, is that it does not problematise the power structures that it describes (Johnson, 1972), nor does it imbue those within the sick role with any agency, instead presuming an element of passivity (Radley, 1994), something also central to being deserving (van Oorschot, 2000). It situates the ill person as someone subject to the decision-making of others, in this example, employers, highlighting the need to explore how employers understand and respond to ill-health in the workplace.

Are people with cancer deserving?

Literature exploring deservingness and welfare has not focused on specific conditions, but has only discussed sickness-related benefit claimants more generally (for example Baumberg, 2016; Garthwaite, 2015; Bambra, 2011). Experiences of cancer are of interest because it can be determined that the disease is considered deserving by continued support from the UK public for cancer related charities. Charity publications repeat the statistic that one in two people can expect to get cancer in their lifetime (Cancer Research UK, 2015), situating cancer as an illness anyone can get. Charity advertising regularly reflects on the level of need

experienced by people diagnosed with cancer and frames recipients of support as having little control over their illness. 'The 'worthy' client of charity is explicitly produced as *not responsible* for needing charity' (original emphasis) (Loseke 1997, p.428).

Reciprocity and attitude as posited by van Oorschot (2000) are also criteria for deservingness, and are apparent within charitable provision for people with cancer. This is achieved by focusing where possible on recovery and rehabilitation. A number of academic publications reflect the desire of people with cancer to return to 'normal' (Wells et al., 2013; Amir et al., 2010); resuming their normal duties, and continuing to contribute to society. These rehabilitative goals are reflected in published material from Macmillan Cancer Support, in which considerable focus is given to 'living with and beyond cancer' and which includes services related to improving employment outcomes (Macmillan Cancer Support, 2016).

There are observed differences between how the provision of charity is viewed in public opinion, in comparison to the provision of state welfare (Fong, 2007). This is relevant to people experiencing cancer, as they are likely to have recourse to both. Though recent British Social Attitude Survey data suggests increased levels of support for state welfare in the wake of UK government austerity measures (Clery et al., 2016), the stigmatised identity of benefit-claimant has been identified as an issue '…*even* for cancer related illness' (original emphasis) (Moffatt and Noble, 2015, p.1203). This implies that people with cancer could be perceived as either undeserving or deserving depending on how their situation is interpreted, and by

who. The stigma associated with receiving benefits can be explained by not meeting the criterion of reciprocity (Stuber and Schlesinger, 2006).

However, there are some specific legislative provisions for people with cancer in the UK. People with cancer who are eligible for the UK's main out of work sickness benefit; Employment and Support Allowance (ESA) are awarded it at the higher of two possible rates when receiving treatment (Gov.uk, 2012), endorsing the view that people with cancer are deserving of condition specific support. Cancer is also defined as a disability in UK law, meaning that employed people with cancer are entitled to workplace protections under the Equality Act (2010). One requirement is that employers make reasonable workplace accommodations to enable employees with cancer to participate in paid work and interviews on a level footing with their non-disabled peers, though there is evidence that these provisions are often only negotiated on an ad hoc, informal basis (Foster, 2007) and have done little to foster inclusivity or accessibility across the UK workforce.

Cancer and work

There are empirical and theoretical benefits to researching workplace experiences of cancer. It is often experienced as a long-term condition; half the people currently living with cancer in the UK have survived the disease for ten years or more (Office for National Statistics, 2018) resulting in long-term symptoms including chronic fatigue, cognitive dysfunction, pain and incontinence issues (Cancer Research UK, 2019a). People with cancer report comorbid conditions including mental health issues such a depression, anxiety and low mood (Mitchell, 2013). Over 100,000 working age people are diagnosed with the disease each year (Cancer Research UK, 2019b) and it is anticipated that this number will rise as a consequence of the

UK workforce ageing and the risk of cancer increasing with age (Cohen, 1994). For someone in paid work a diagnosis of cancer can result in extensive sick leave, during which people experience intense interaction with medical professionals, statutory services and charities.

Approximately two thirds of working age people who are in work when diagnosed with cancer return to work after completing treatment (Mehnert, 2011; Amir et al., 2010). Research exploring the employment trajectories of people diagnosed with cancer regularly present a maintained return to work as a broadly positive outcome (see Wells et al., 2013; Amir et al., 2010). Though there is no doubt that returning to work is experienced as positive by some people with cancer (Moffatt and Noble, 2015), the assumption that work is good for you sits at odds with a growing body of academic work critiquing the notion, and questioning changing conditions of employment (Frayne, 2015).

This paper explores how deservingness features in the experiences of people who are in work when diagnosed with cancer. Social policy structures in the UK, and to some extent Parsons, define ill-health, disability and deservingness by a person's capacity and willingness to engage in paid work (Finkelstein, 1993). It is important to explore how contemporary social and organisational policies, organisations and individuals frame, interpret and respond to ill-health in the workplace as these responses have significant material consequences for individuals with cancer, and implications for an ageing workforce more broadly.

Methods and participants

Participants to this study were recruited via a cancer specific employment service in North East England. This service offered one-to-one support to people with cancer

experiencing employment issues including advice by phone, workplace advocacy and referral to further services. It also offered free workplace training to line managers regarding managing cancer in the workplace. The study was conducted in partnership with service staff, who took on the role of gatekeepers for recruitment. The use of gatekeepers for this project was in compliance with the Data Protection Act (1998). Ethical and governance approvals from Newcastle University Faculty of Medical Science and relevant NHS Research Ethics Committees were obtained prior to fieldwork.

Being diagnosed with a condition such as cancer involves numerous interactions with a variety of new people and structures, as well as changed interactions within extant personal relationships. To address this, this study sought a range of perspectives on managing cancer in the workplace, including people who were in paid employment when diagnosed with cancer, line managers with experience of managing employees with cancer, human resources and occupational health staff, health care professionals and staff from a UK cancer support charity. Participants presented views shaped by personal experience, professional roles and wider public discourse. Some were in positions of relative power, able to make decisions with material implications for employees with cancer, some were subject to these decisions, others worked to ameliorate the impact, or to influence workplace decision-making. This multi-perspective recruitment resulted in data that provides insight into how deservingness is constructed for and by people with cancer.

Fourteen people who were diagnosed with cancer while in paid work and who had some engagement with the employment service responded to invitation packs

distributed by project gatekeepers and were interviewed. They represented a range of occupational classes, held positions at the time of their diagnosis that they had been in from between 1 and 34 years and had varied employment trajectories. They were interviewed between 1 and 8 years after (first) being diagnosed with cancer. Relevant participant information is available in Table 1. Narrative interviews were conducted with participants in order to access their working biographies (MacKenzie and Marks, 2016): '*tell me what you have done since leaving school*…'. Interviews took place in participant homes or in public cafes depending on participant preference and ranged from 45 to 90 minutes. As with all the interviews in the study, they were digitally recorded and transcribed verbatim.

Ten 'employers' were recruited to the study; seven line managers, two members of occupational health (OH) staff and one member of human resources (HR) staff. The initial invitation packs were responded to by OH and HR staff. These participants were invited at interview to recruit line managers (n=5) from their organisations who had directly managed an employee with cancer. Two further line managers were recruited via employee participants. Narrative interviews were conducted with line manager participants: '*tell me what happened from when your employee disclosed their cancer diagnosis*…', and semi-structured interviews were conducted OH and HR staff. The semi-structured interviews included questions relating to experiences of being involved in supporting employees with cancer, concerns about how to support employees and organisational issues related to providing support. Interviews took place at participant workplaces or in public cafes and ranged from 13 to 60 minutes. 17 employing organisations are represented across employee and employer participants.

Five healthcare professionals were recruited. They worked in services that had referred people with cancer to the employment service. They represented a range of healthcare services including general practice, community occupational health, end of life care and specialist oncology services. Interviews followed a semi-structured format, took place at participant workplaces and ranged from 25 to 45 minutes. The interviews included questions relating to participant experiences of referring people with cancer to employment and welfare services and their thoughts on the provision of welfare and workplace support for people with cancer.

Seven members of staff from a UK cancer support charity were recruited. All worked within employment specific services, including the recruitment site. Participants held roles that included providing support to people with cancer with employment issues and/or delivering training to employers about how to manage cancer in the workplace. A benefit of interviewing these participants was that they were able to relate the practices of a large number of employing organisations and a collection of work and welfare experiences of people with cancer. Data from these participants supported the arguments made in this paper. As shown in table 1, participants are denoted by their role and numbered; LM (line manager), OH (occupational health staff), HR (human resources staff) HCP (health care professional), CS (charity support staff), and employees with cancer are denoted by number and sex (eg. 4F).

Interview transcripts were read, re-read, compared and discussed with the author's supervisory team to develop a coding structure, which was then applied utilising NVivo 10 (McGowan, 2014). Interviews were coded line by line and examined

holistically to generate participant summaries and thematic memos. Repeated ideas and concepts became apparent in the data by comparing transcripts. These were then coded. Emerging data were coded as they were collected. Accounts from participants experiencing cancer included their work and welfare experiences since being diagnosed, and their experiences of the welfare system. Though not anticipating to code for notions of deservingness within data discussing the workplace, researcher familiarity with debates relating to social welfare allowed for the identification of deservingness as a theme. It lead to the development of three research questions responded to in this paper; 1) How did deservingness feature in the workplace experiences of people with cancer? 2) How was deservingness understood? and 3) What were the parameters to deservingness?

Findings

Deservingness and the employment experiences of employees with cancer

Across the data, participants evidenced how notions of deservingness featured in how they understood and responded to a cancer diagnosis in the workplace. They drew heavily on notions of deservingness while describing their experiences or thoughts on managing cancer in the workplace. Employees with cancer reflected on how they were not responsible for their illness. They explained that they had '*never smoked*' (12M), or engaged in other behaviours that would imply blame for their condition. One participant with cancer described herself as '*the most unlikely person… to get it* [cancer]' because she had a '*really healthy lifestyle*' (2F). Others were explicit that their cancer was not '[their] *fault*' (10M), and that they '*didn't ask for* [it]' (13M). Though not discussed in explicit terms, no other participant group implied individual blame for people with cancer, other than cancer support charity staff, who

in abstract terms, listed '*lifestyle choices'* (CS1) as one of many causes of the disease.

Participants also defaulted to describing the level of need experienced by people with cancer to establish deservingness. Cancer was situated as '*probably the worst thing in the world*' to be diagnosed with (HCP2). Line managers were distressed by the news of their employees' diagnoses, describing it as '*devastating*' (LM2) and '*a shock*' (LM1). Further to descriptions of personal distress employers immediately established in their interviews that cancer was a '*terrible*' illness that they would not '*wish on anybody*' (LM9). They were clear that when employees disclosed a cancer diagnosis to their employer, it was an employer's '*duty*' to '*support* [employees] *in any way* [they] *could*' (LM7).

Participants with cancer gave examples of the pain and discomfort they continued to experience after their diagnosis:

> *I'm tired a lot, I'm still getting the sweats…I canna run around* (13M)

Participants claiming sickness benefits used their medical correspondence to highlight the legitimacy and severity of their ongoing condition. Some read letters aloud during their interview, explaining how they were at '*a very advanced stage of the disease'* (13M) or '*in no condition to be working, or looking for work*' (10M). Their illness narratives featured justification, and drew on notions of deservingness. When employees discussed their physical symptoms they did so almost exclusively in relation to their continued capacity to work, often in the context of explaining continued sick leave or the receipt of state welfare. To this end, it is unsurprising that

in a number of interviews employees with cancer evidenced their level of need, utilising examples from welfare benefit assessments:

> …*it affects us down me right arm, I daren't pick a hot cup of coffee up with my right arm*… (13M)

This participant is clear that he is unable to meet what is deemed to be a basic requirement of work, and as such can frame himself as in need enough to deserve continued state support. Other examples given by employees with cancer included fluctuating levels of pain, hot flushes, chronic fatigue and uncontrollable mood swings. Participants were explicit in how their physical symptoms precluded them from returning to work.

The focus on need and severity of illness was reflected in some organisational policies, and in the interviews of line managers. It was most clearly articulated in relation to employees with a terminal diagnosis. Line managers evidenced '*pulling out all the stops*' (LM2) for employees who had been given terminal diagnoses, and this was supported in policy via the provision of ill-health retirement payments in the interviews of both public and private sector managers:

> …*for ill-health retirement… you've got a certain criteria that you have to fit and it's usually when you're terminally ill, so if you get ill-health retirement, you get your pension early*…' (LM7)

Participants also discussed financial need. People with cancer who are in work and rely on their income from work at the time of their diagnosis are particularly vulnerable to financial stress (Moffatt and Noble, 2015). Sometimes participants

related this to the provision of sick pay from employers, but it was most often described in relation to the provision of sickness related welfare benefits:

> *I'm on my own. I've got a house, a mortgage, council tax, everything, and I've only got six hundred pound coming in, and they* [Department for Work and Pensions] *said no to us!* (3F)

Other participants drew on the same logic of need to reach the alternative conclusion; that they were not in enough financial need to receive state welfare. This highlighted misconceptions about how UK state welfare is distributed, while also showing how in lieu of knowing what their actual entitlement was, or why, participants drew instead on criteria for deservingness to make sense of the support they did or did not receive. Deservingness, in this way, featured in the experiences of people who were in work when diagnosed with cancer. Both employers and employees drew on notions of need and severity of illness to situate employees with cancer as deserving of workplace and state support.

Not equally deserving

Despite cancer being constructed initially as deserving by participants, this was a relational process that continued to draw on further criteria than need and lack of responsibility. Both employees with cancer and employers made distinctions regarding deservingness based on the value and contribution of employees prior to them being diagnosed with cancer. One employee explained how her employers authorised sick pay over her contractual entitlement because she '*had never been on the sick in all the ten years*' she had worked for them (7F). Similarly, a line manager explained how she oversaw some small alterations to her employee's work

schedule when they returned to work after cancer treatment because prior to becoming ill, they had '*always given one hundred percent*' (LM5). This idea of some employees with cancer being more deserving than others was exemplified in the account of a member of occupational health staff. She described two employees she had worked with, who were both diagnosed with the same type of cancer. She extolled the virtues of one, who she said had been the type to "*stay late*", complete his tasks and had always "*given that little bit extra*". She commented on how she "*totally admired*" this employee. The second employee was held in contrast. She explained that he was involved in trade unions and had "*manipulated the system*" prior to being diagnosed with cancer. Her view was that he ought to "*get over it*" (OH1).

Employees with cancer also drew on their pre-diagnosis contribution to the workplace to make sense of what they deserved. They reflected on how they had '*worked* [their] *socks off*' (4F) for their organisations, managed to secure particular accreditations for their employers or evidenced a strong work ethics either to explain why they received more than their contractual entitlement, or to justify dissatisfaction when they did not. Some drew on their length of service. One participant described negotiating his redundancy package:

> *They offered us a deal of* [sum below £15,000 redundancy payment] *after twenty-four years of work, they had no chance*' (13M)

Though this employee had a different sense of what he deserved in comparison to his employers, he still used his pre-diagnosis contribution to make sense of what he should receive having since been diagnosed with cancer. What he was offered was

in excess of the legal minimum and what he was contracted, but based on his past service, this employee felt he deserved more.

This participant continued with this theme in how he made sense of what he deserved from the state welfare system. He compared himself to benefit claimants he considered less deserving. He suggested that he would be better off as an asylum seeker. He argued that he '*had to fight for what* [he] *got*' having '*paid into the system*' since leaving school (13M). This comparison spanned across much of the participant group. One healthcare professional stated that she was '*all for immigration and fairness*', but that there seemed to '*be an excess from European rules saying we've got to take everybody in and pay out all the benefits, yet Joe Public, who's worked all his life, you know, thirty or forty years, falls into no man's land* [trying to access welfare benefits] *because he's got cancer'* (HCP3). There was a sense from the participants that working people with cancer had more of a claim to state support than international immigrants and asylum seekers, people with health conditions deemed less deserving than cancer including '*bad backs'* (OH2) – always said with mimed inverted commas - and people who '*love living off the state, get whatever they can out of the system and still manage to get more*' (14M). Participants were able to categorise themselves as deserving in comparison to less deserving people, who they felt were still able to access support but had contributed, or were contributing, less.

Further to the pre-diagnosis work contributions required of employees with cancer, it was possible to surmise from the data that requirements were made of employees post-diagnosis. Employees provided examples of where their post-diagnosis efforts

had influenced the support they were offered. One employee with cancer who was nearing retirement age when he was diagnosed with cancer said that he had not wanted to return to work. He explained that the generous lump sum he received on his departure from the workplace was, in part, a reward because he '*didn't mess them* [employer] *about with tribunals and that*' (14M).

Line managers reflected on their employee's conduct post-diagnosis to ascertain what support they would provide. Here, a line manager explains on what basis she provided reasonable adjustments for an employee with cancer returning to work. She framed what is ostensibly a legal entitlement under the Equality Act (2010), as a reward:

> *You can't help yourself from doing it* [providing workplace accommodations] *and if that had been a different person who didn't try their utmost to come into work… and then when they come back, be really productive, I could imagine that I would probably struggle*… (LM5)

Another manager, also discussing an employee's workplace accommodations questioned whether she would "*feel differently towards somebody who wasn't as, you know, as keen to try and get on themselves*" (LM4). When calculating the potential ill-health retirement lump sum for an employee with cancer, a further manager described a collection of subjective measures to ascertain what the employee should receive:

> …*I have to compile a case over the years that I've managed her to say how well she has performed… what her behaviour's been like, how accommodating she's been, has she been keeping in touch, has she been trying always to come back to work*… (LM7)

She lists particular post-diagnosis actions and behaviours of her employee to take into account, alongside pre-diagnosis considerations. In particular, line managers valued and supported employees who kept in touch throughout their treatment, evidenced a desire to return to work, and, if returning, met their pre-diagnosis levels of productivity.

Employees with cancer had to engage in particular behaviours to access welfare support having been diagnosed with cancer. Communicating with the Department for Work and Pensions, as with keeping in touch with employers, required effort. It was incumbent on employees with cancer to proactively evidence genuine illness and seek the correct support:

> *I had a file like this* [gestures with thumb and forefinger] *from the Department of Work and Pensions, and I sent everything recorded delivery, and they were saying they hadn't got letters and I was saying I've got proof here that you have*… (1F)

Narratives from employees with cancer suggested that the welfare benefit assessment process required a performance of ill-health, and thus, deservingness. This performance would then be judged adequate or inadequate by assessors. One participant, during his assessment, having already been migrated from the higher rate of employment and support allowance (ESA) to the lower rate, showed symptoms of the mental health issues he experienced comorbidly with his cancer. He was found fit for work as '*the doctor said that he doesn't think* [10M]'*s got depression, because they said he didn't move, he um, he didn't sweat, which he did do all that*…' (wife of participant). Even when receiving the benefit, he was obliged to engage in work related activities (including CV writing and group employability

sessions) as a condition. He was placed in the position of needing to present convincingly as too ill to work, or prepare for a return to the labour force.

Though cancer was considered a deserving condition in general terms, it was apparent from the data that as time went on some employees with cancer were viewed as more deserving than others. Not only were their pre-diagnosis efforts drawn on, explicitly by employers and in general terms by a contributions-based welfare benefit system, but also their post-diagnosis efforts. Essentially, their ongoing deservingness was dependent on their ability to adequately meet the obligations of the sick role.

A deservingness timeline

A feature of the sick role is that it is time constricted. Individuals are expected to return to health and normal duties having fulfilled the requirements of the role, and received the corresponding entitlements (Varul, 2010). This time restricted model was identifiable in how participants described their experiences of providing or receiving support in the context of a workplace cancer diagnosis. A responsibility of line managers, shown across the study data, was to predict and then enforce a timeline for employees with cancer to return to, or depart from work. One employee with cancer reflected on how this left returning employees such as herself with a seemingly binary option, whilst continuing to experience fluctuating and painful symptoms:

> …*I don't think they* [employer] *really know how to approach it… do we say this is the cut-off point, where we say you're either working full time* [or] *you're not working*… (3F)

This particular employee regularly experienced painful infections as a result of her cancer. She did not feel that she could take sick leave for these infections, as she exhausted her sick leave while receiving treatment for her cancer. The binary options she described regarding returning to work were reflected in the interpretations of managers, one of whom explained that his role was to '…*get that person brought back as quick as you can, or give that person the best support they can* [if not returning to work]' (LM2).

In this study, in which 17 organisations are represented across the employee/r participants, the sick pay offered by employing organisations varied from the statutory minimum to an employee's full salary for a year. The time allowed for sick leave was 12 months in almost all instances, with some discretionary increases. Managers were often under pressure to confirm an employee's intentions to return or depart from work before these twelve months finished, often at the conclusion of an employee's treatment:

> …*the difficulty tends to come once the treatment's finished, and then trying to establish a return to work date*… (HR1)

This was interpreted by both line managers and employees with cancer as '*pressure*' (4F) for employees to return to work, sometimes too soon, or before employees knew what the result of their treatment was. One line manager explained how her employing organisation requested that her employee with cancer return to work '*on the Monday after she's finished her treatment on the Friday*' (LM5).

Some managers identified that the pressures from their organisation for their employees to return quickly did not always reflect their employees' ongoing needs

519 and symptoms. Despite this, across the data there was evidence that managers
520 supported and rewarded employees who returned to work quickly:

521 …*I've never refused her* [early finishes] *because I think she was good enough*
522 *to come back in that short period of time, and I think as an employer, we have*
523 *to support that*… (LM1)

524 Employees with cancer were deemed deserving of workplace accommodations if
525 they took '*an appropriate time to get over cancer, basically*' (LM5).
526
527 The provision of welfare benefits mirrored the time constricted nature of the sick role
528 apparent in individual workplaces. Those that had recourse to sickness related
529 welfare benefits expressed fear and concern that their benefits would stop, or be
530 reduced over time:

531 …*somewhere along the line I'll have to sit in front of a board* [assessment
532 panel]. *If someone sat there and* [told] *me how I've got to feel, I'd blow my*
533 *fucking stack*… (13M)

534 This participant's concerns imply that the provision of continued welfare would be on
535 the basis of prescriptive post-diagnosis behaviours as mentioned previously, and
536 also highlights how over time the deservingness of employees with cancer is subject
537 to question.
538
539 Accessing state welfare featured disruptive insecurity. Employees with cancer
540 expressed concerns that the Department for Work and Pensions (DWP) '*would*
541 *eventually stop* [their] *money*' (10M). The withdrawal of state support over time, and
542 propulsion toward the labour market was even present in the accounts of employees

who did not have recourse to welfare benefit payments. One employee received unexpected, and unexplained correspondence from the DWP:

> *I went to my neighbours next door and I was crying, it* [letter from DWP] *says I've got to go back to work and I can't, I'm bad* [still unwell] (5F)

Others experienced an abrupt end to communication with the DWP at the conclusion of their benefit payments, leaving them feeling as though they had been left '*high and dry'* (9F). In all instances there was a fear, or reality, of access to welfare tailing off, and the expectation that people in work when diagnosed with cancer would return to work or, in the case of those who were terminally ill, die.

Discussion

Notions of deservingness featured in the employment experiences of people diagnosed with cancer when in paid work. Though participants all drew on notions of deservingness to make sense of cancer and the support that was made available to people diagnosed with the condition, these notions were dynamic, subjective and influenced by job roles, organisational parameters and social policy. Reflecting back on van Oorschot's work (2000), data from this study illustrates the explanatory potential of his deservingness criteria. In the first instance, across participant groups, there was tacit agreement that the people with cancer were not to be held responsible, or blamed for their condition. Employees did not blame themselves, though evidenced some awareness that others might by being quick to explain that they did not engage in behaviours known to cause cancer. Similarly, participants reflected on the need of those diagnosed with cancer. Employers were able to draw on common understandings of cancer as a dangerous and life threatening illness, subject to unpleasant and lengthy treatments, as did employees with cancer, who also drew on their actual experiences of physical symptoms. The essentially

568 economic framework to Parson's theorising and welfare deservingness was present
569 in how participants discussed their ongoing symptoms almost exclusively in relation
570 to their capacity to work.
571
572 The sick role is fundamentally an exchange (Parsons, 1951), which corresponds with
573 reciprocity as a criterion for deservingness (Varul, 2010). Employers and employees
574 with cancer considered the pre-diagnosis contributions of an employee relevant to
575 the support they received post-diagnosis. Some employers provided extra support
576 on this basis, and some employees felt they ought to get extra support. To some
577 extent, this could be interpreted as a nuanced and discretionary reflection of welfare
578 provision more widely, as employees with cancer who have recourse to state welfare
579 are usually in receipt of contributions based welfare in the first instance. This speaks
580 to wider debates about deservingness as it is largely understood that means-tested
581 provision of support opens up deservingness debates, while contributory-based
582 systems close them down (Larsen, 2006). Pre-diagnosis contribution was
583 demonstrated both in the description of length and perceived value of an employee's
584 service, as well as their work ethic, but also in the practice of 'othering' those
585 deemed to be less deserving, having contributed less. This is a phenomenon that
586 has been identified in other research relating to the provision of state welfare
587 benefits, stigma and shaming (Chase and Walker, 2013).

588 Employers, including line managers, did not only draw on employees' past
589 contribution. They made requirements of employees with cancer post-diagnosis,
590 rewarding those who offered clarity regarding their intentions to return to work, and if
591 they did return, for those who returned quickly. In particular, reasonable adjustments,
592 an entitlement under the Equality Act (2010), appeared to be offered as rewards for

speedy returns. To evidence deservingness, and fulfil the requirements of the sick role, employees had to behave in specific ways, largely needing to show a desire to return to work, and normal duties. It is necessary to point out that for some employees with cancer this would not necessarily represent a problem, as returning to work can help to ameliorate the disruptive influence of their diagnosis (Moffatt and Noble, 2015). However, for others it functioned to undermine the notion of legal entitlement, especially for those experiencing long-term symptoms that diminished their capacity to work or return to work in a short period of time. The alternative route to continued deservingness was to have terminal cancer, again reflecting criteria for deservingness relating to need (van Oorschot, 2000), and the sick role, as the more severe someone's illness, the more they are freed from normal social roles (Parsons, 1951). An issue with exchange though, especially exchange based on subjective measures, is that there is the opportunity for the exchange to become imbalanced. When one party in the exchange has influence of the material support for the other, an inability to meet subjective obligations can result in some employees with cancer being deemed less deserving than others.

The provision of sickness related welfare benefits for the employees with cancer also required specific post-diagnosis behaviours from claimants with cancer. To access state support employees with cancer were required to perform ill-health adequately enough to continue to access ESA at the higher of two available rates, or as time went on after treatment, evidence efforts to become more work ready (but not too work ready) to access a lower payment amount. A criticism of state welfare provision in the UK is its inability to accommodate more fluid or fluctuating health conditions (Riach and Loretto, 2009), which was evidenced in this study.

The requirements demanded by work and welfare institutions discussed in this paper illustrate how they uphold a fixed term model of illness reminiscent of Parsons' sick role, where by deservingness was a necessary feature of the sick role, and genuine illness was a necessary feature of deservingness (Varul, 2010). By focusing on experiences of cancer, with its common disease trajectory of acute illness and treatment through to long-term condition, the paper has been able to highlight the temporality of deservingness, both in interpersonal work place relationships, and at an institutional level. At the conclusion of treatment and/or sick leave, more requirements were made of individuals with cancer to evidence deservingness, and justify their continued identity as an ill person. Though there are specific entitlements for people with cancer in both the workplace and in relation to welfare benefits that reflect the long-term nature of the condition, these did little to challenge the fixed term model of illness assumed by employing organisations. Instead, in some instances they were incorporated and used to enable a fixed term model, particularly in the use of individualised reasonable adjustments as a reward rather than a recognition of long-term symptoms.

This has important implications for people who are in work when diagnosed with cancer, a demographic that is anticipated to grow in coming years. Though for some employees with cancer there might be no contradiction between how they understand their deservingness, and how their employers and the state support them, for others there will be, as has been shown in the data from this study. The impact in some instances is likely to exacerbate the disruptive influence of cancer. To perform sickness and deservingness adequately requires work; fulfilling the requirements set by individual line managers, employing organisations or the UK welfare state. To fail to be deemed deserving could potentially result in limited

material and social support in the workplace and/or financial insecurity. In circumstances where employees do not feel that the support they receive is commensurate with what they received, there is a risk of interpersonal relationship breakdowns in the workplace and the consequent implications of such a breakdown.

Bury's notion of biographical disruption highlights the resources available to, and social and embodied experiences of, people experiencing long-term ill-health, as experienced by them (1982). This paper highlights how Parsons' model of illness has explanatory potential for understanding how their experiences are interpreted and responded to by others, as well as how individuals understood their own deservingness. Participants used, and were driven by the sick role as a collection of social (and material) processes. Employees with cancer used them to make sense of their situation, while employers and the state utilised them to inform decisions about support.

In relation to the design and purpose of organisational and social policy, deservingness is directly linked with the ability to work. Though research has explored how the biographical disruption wrought by cancer is further impacted by changes to social policy that stigmatise sickness benefit claimants (Moffatt and Noble, 2015), notably little research explores the experiences of people who are employed when diagnosed with cancer explicitly in relation to deservingness, or related experiences of cancer to the sick role (Parsons, 1951). It is apparent from the data that there is a gap between the fixed sick role as perceived by others and manifest in organisational and social policy, and the more complex experiences of being diagnosed with cancer.

Conclusion

Experiences of long-term ill-health in relation to work require further sociological examination. Cancer is a long-term condition that is often experienced comorbidly with other long-term conditions. Whereas employees with cancer were able to articulate the long-term and fluctuating nature of their condition, institutional responses from employing organisations and the UK welfare system assumed a fixed-term model of illness. As time went on, employees with cancer were expected to exit the sick role, or required to present as in-need enough to maintain their deserving/ill status. Despite relying on subjective and evaluative measures, deservingness featured in how decisions were made regarding the support offered to working people diagnosed with cancer. Dependent on pre- and post-diagnosis worker efforts, some employees with cancer could be categorised as deserving of additional support, transcending entitlement via workplace discretion. The resultant workplace hierarchy in deservingness – that might well have implications for employees experiencing other conditions - runs the risk of replicating the hierarchy of deservingness between welfare benefit claimants, most clearly articulated in this paper in relation to immigrants and asylum seekers. An ongoing issue arises when perspectives of deservingness have material implications, as with the provision of workplace support and the distribution of sickness benefits. Decisions based on deservingness are arbitrary, and by their subjective nature unfair. This paper recommends that researchers and policy makers seek to explore ways in which long-term conditions can be better accommodated with regard to both work and welfare, especially in the context of an ageing workforce.

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806 Tables and figures

807 Table 1: Participant summary

Participant	Participant information
Employees with cancer	*Work contract when diagnosed, return to work outcome, state welfare receipt*
1F	Part time work, returned to work after sick leave, temporarily accessed disability related state welfare.
2F	Part time work, returned to work after sick leave and then took voluntary redundancy, did not access state welfare.
3F	Part time work, returned to work after sick leave, did not access state welfare.
4F	Part time work, returned to work after sick leave, did not access state welfare.
5F	Two part time contracts (full time hours), returned to work after sick leave, and did not access state welfare.
6F	Part time work, returned to new position after sick leave, accessed disability related state welfare temporarily.
7F	Part time work, on sick leave indefinitely and accessing disability related state welfare.
8F	Part time work, on sick leave indefinitely and accessing disability related state welfare.
9F	Part time work, returned to work after sick leave and then took voluntary redundancy, temporarily accessed disability related state welfare.
10M	Full time work, on sick leave indefinitely and accessing disability related state welfare.
11M	Post-retirement zero-hour contract, did not return to work after treatment, accessing age related and disability related state welfare.
12M	Full time work, did not return to work after treatment (reached pension age shortly after treatment), temporarily accessed disability related welfare, and transitioned to age related state welfare.
13M	Full time work, on sick leave indefinitely and accessing disability related welfare.
14M	Self-employed full time, job seeking since concluding treatment and accessing a disability related state welfare.
Employers	*Job role, experience of managing employee with cancer and training*
LM (line manager)1	line managed employee with cancer to return to work, attended workplace cancer training
LM2	line managed employee with cancer through ill-health retirement, did not attend workplace cancer training
LM3	line managed employee with cancer to return to work, did not attend workplace cancer training

LM4	line managed employee with cancer to return to work, did not attend workplace cancer training
LM5	line managed employee with cancer to return to work, did not attend workplace cancer training
LM6	line managed employee with cancer to return to work, attended workplace cancer training
LM7	line managed employee with cancer through ill-health retirement, did not attend workplace cancer training
OH (occupational health staff) 1	occupational health staff, did not attend workplace cancer training
OH2	occupational health staff, facilitated and attended workplace cancer training
HR (human resources staff) 1	human resources staff, facilitated and attended workplace cancer training
Healthcare professionals	*Service*
HCP1	Hospice care
HCP2	Cancer specific
HCP3	Cancer specific
HCP4	Community care
HCP5	General practice
Cancer Charity staff	*Client group*
CS1	Employers
CS2	Employees with cancer
CS3	Employers
CS4	Employers
CS5	Employers
CS6	Employees with cancer and employers
CS7	Employees with cancer and employers

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8F	Part time work, on sick leave indefinitely and accessing disability related state welfare.
9F	Part time work, returned to work after sick leave and then took voluntary redundancy, temporarily accessed disability related state welfare.
10M	Full time work, on sick leave indefinitely and accessing disability related state welfare.
11M	Post-retirement zero-hour contract, did not return to work after treatment, accessing age related and disability related state welfare.
12M	Full time work, did not return to work after treatment (reached pension age shortly after treatment), temporarily accessed disability related welfare, and transitioned to age related state welfare.
13M	Full time work, on sick leave indefinitely and accessing disability

	related welfare.
14M	Self-employed full time, job seeking since concluding treatment and accessing a disability related state welfare.
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HCP5	General practice

Cancer Charity staff	*Client group*
CS1	Employers
CS2	Employees with cancer
CS3	Employers
CS4	Employers
CS5	Employers
CS6	Employees with cancer and employers
CS7	Employees with cancer and employers

Research highlights

- Employee/rs draw on deservingness to understand cancer in relation to work
- Deservingness undermines entitlement in the work experiences of employees with cancer
- Employers and the UK state welfare system default to a fixed term model of illness
- Employees with cancer experience a disruption to their working biography
- Conflicting models of illness can exacerbate the disruptive influence of cancer