

Abstract

This paper explores how employees and employers understand and respond to cancer in relation to work and post-diagnosis support. It draws on qualitative data generated from narrative interviews with people with cancer and interview data from employers, healthcare professionals and staff from a UK cancer support charity. Analysis was informed by constructivist grounded theory.

The paper shows how employers and the UK state welfare system assume a fixed term model of ill health that resembles Parsons' sick role by framing employees as deserving either when acutely ill, or when attempting to become more work ready. As the condition of employees with cancer transitioned from acute to long term, it became more challenging for them to meet employer and state criteria for deservingness. The assumption of a fixed term model of illness threatens to exacerbate the disruption represented by cancer, and has wider policy implications in an ageing UK workforce.

Keywords

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 is relevant to employees with cancer, many of whom access state welfare while taking temporary or indefinite sick leave from work. This article extends deservingness debates in social welfare to a new domain by exploring the concept in individual interactions in the workplace.

Parsons and deservingness

There are obvious, but perhaps under explored overlaps between understandings of deservingness and medical sociological framings of ill health.

The sick role is conditional on being viewed as deserving, and being deserving requires 'genuine' ill health.

Whereas biographical disruption has been widely heralded as an insightful theory that corresponds with contemporary experiences of ill-health in an ageing population (Locock and Ziebland, 2015), the same cannot be said of Parson's sick role (1951). According to the sick role, illness includes a reciprocal exchange of duties for entitlements (*ibid*). The duties of an ill person are to seek out and comply with competent medical help, which also functions to legitimise a person's condition, and make all attempts to get better (Varul, 2010). The corresponding entitlements of the sick role are not to be blamed for ill-health and to be allowed temporary exemption from usual duties while recovering.

Unlike biographical disruption, the sick role is characteristically time constricted. It assumes illness to be responsive to treatment, related to physical health rather than mental health and does little to account for comorbidities (Gatchel, 2004; Gallagher, 1976). Charmaz notes that in contrast with the assumptions that underpin the sick role, people with chronic (long term) conditions do not recover (2000). Parsons (1975) refuted that the sick role inadequately explained long term conditions in a second paper exploring the model, suggesting that a return to normal duties could result from the successful management of a person's condition. However, the implication here is of a static and unchanging condition rather than the long-term social process of some illnesses that can include degeneration, fluctuation and comorbidity (Nettleton, 2006; Gatchel, 2004).

Despite the criticisms of the sick role its impact as a model for illness should not be underestimated (Williams, 2005). The functionalist framework within which it resides continues to complement other functions within society, as it is 'basically economic' (Gerhardt, 1979, p.231). 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 model is a single element of 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).

This paper does not seek to defend the Sick Role, but instead recognises how structures and institutions still employ a functionalist model of illness. An important sociological critique of Parsons' thesis is that it does not problematise the power structures it describes (Johnson, 1972), nor does it imbue those within the sick role with any agency, instead presuming an element of passivity (Radley, 1994). Though these criticisms are valid, they do not alter the reality of power structures, nor is it necessarily inaccurate that people experiencing long term ill-health and/or disability might be forced into roles of passivity or be materially disempowered.

Bury

Deservingness in relation to sickness is negotiated and dynamic.

Biographical disruption is about the experience of illness from the perspective of the person experiencing it, Parsons is about the role expectations, largely of others. Deservingness arguably, relates to both of these, but work on illness narratives is quite separate to issues of deservingness.

Cancer has been framed within medical sociology as a biographical disruption (Hubbard et al., 2012). Though it is the primary cause of premature death in the UK (NHS, 2018) it is 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). It can result in a collection of long term symptoms including chronic fatigue, cognitive dysfunction, pain and incontinence issues (Cancer Research UK, 2018a). People with the disease also report comorbid conditions including mental health issues such as depression, anxiety and low mood (Mitchell et al., 2013). As a concept, biographical disruption has maintained longevity and durability with the sociology of health and illness by conceptualising illness as a particular type of disruptive event that highlights the resources available to individuals, provides modes of explanation for pain and suffering, as well as highlighting continuities and discontinuities between professional and lay thought, and the variety of individual experience (Bury, 1982).

A key feature of biographical disruption is that it allows for the exploration of relational and temporal aspects of long term conditions (Nettleton, 2006). It embeds illness within the social context of health, including the impact of illness on relationships, such as those in the workplace (Olliffe et al. 2013). Just under 120,000 people of working age are diagnosed with cancer in the UK each year (Cancer research UK, 2018b). It is anticipated that this number will rise as the workforce ages and long-term survival continues to increase (Maddams, 2012). There are numerous ways in which an individual's participation in paid labour might be disrupted by the onset of cancer. Research has indicated that sick leave from work varies widely, from a reported average of 27 days for prostate cancer patients (Bradley et al., 2006), to an average of 349 days for breast cancer patients (Roelen et al., 2009).

Disengagement from the workforce due to sickness can have serious economic implications for the individual employee (Moffatt et al., 2012), employing organisations (Young and Bhaumik, 2011) and the economy more widely (Luengo-Fernandez et al., 2013).

Disrupted work also has social implications. At work individuals engage in a myriad of relationships with colleagues, managers, subordinates and in many industries customers and clients (Grint, 2005). Being in good quality paid employment has been shown to have positive health outcomes (Taylor et al., 2017) and a positive impact on identity at both the individual (Hutton et al., 2012) and community level (Williams, 2010). Moffatt and Noble (2015) highlighted how for some employees with cancer returning to work is an important and significant way to repair the disruption represented by their diagnosis, in addition to releasing them from the stigmatised identity of welfare benefit claimant.

Cancer, CARIN, work, Britain

Cancer and how it relates to Oorschot's CARIN criteria and contemporary UK manifestations.

Contemporary social policy research has discussed the application of undeserving and deserving as dichotomous categories for sickness benefit claimants (Baumberg, 2016). This is relevant to the experience of employees with cancer in the UK, many of whom access state welfare while taking temporary or indefinite sick leave from work.

Being deserving

Van Oorschot (2000) offers five criteria for deservingness in relation to the provision of welfare benefits. The five criteria are: control, identity, attitude, reciprocity and level of need (*ibid*). Control means that the deserving individual is not in control of their situation and thus, is not to be blamed for it. Identity refers to being part of society and not 'other'. Attitude is the expectation that those who are deemed deserving should be suitably grateful for any support they receive. The greater the level of need, the more deserving someone is (van Oorschot, 2000, p.36). Reciprocity as a criterion reflects the perceived responsibility of the deserving recipients of state welfare to earn the support that they receive; the more reciprocation, the

more deserving. Effort, and therefore exchange, is associated with deservingness (Feather and Dawson, 1998). Though these criteria were generated from quantitative work exploring public opinion, their explanatory potential for understandings of deservingness can be demonstrated in their application to provisions of support to people with cancer.

Continued support for charities such as Macmillan Cancer Support suggests that there is a shared notion amongst the public that people with cancer are deserving of support. There are, however, observed differences between how the provision of charity is viewed in public opinion in comparison to the provision of state welfare (Fong, 2007). Though recent British Social Attitudes Survey findings suggest 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 a cancer-related illness’ (Moffatt and Noble, 2015, p.1203).

There are specific legislative provisions for people with cancer in the UK. The disease is defined as a disability in UK law, meaning that 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. Additionally, there are cancer specific caveats to the provision of the UK’s main out of work sickness benefit, Employment and Support Allowance (ESA) which means that people with cancer who are eligible and are awarded ESA receive it at the higher of two possible rates when actively receiving treatment (Gov.uk, 2012), endorsing the view that people with cancer are deserving of condition-specific support.

This paper explores how deservingness features in the experiences of people who are in work when diagnosed with cancer. It draws together concepts that have remained largely discrete in investigations of health and illness and have not been explored explicitly in relation to work and welfare. An omission from sociological work exploring ill-health using biographical disruption has been a focus on paid employment, with the notable exceptions of Garthwaite (2015) who explored a number of long-term conditions, and Moffatt and Noble (2015) who centred the work and welfare experiences of people with cancer. Social policy structures in the UK define ill-health and disability by a person's capacity to work (Finkelstein, 1993). Rightly or wrongly, a person's citizenship is inextricably linked with their employment status (Bambra, 2011). It affects their social class and the long-term health outcomes of themselves and their communities (Beatty and Fothergill, 2005). Furthermore, there are important and, thus far, unexplored overlaps between how contemporary social policies frame and interpret ill-health and disability via deservingness in relation to work and welfare, and what is largely considered an out of date sociological model for ill-health.

Methods and participants

As discussed in the previous section, cancer is experienced socially, with numerous actors able to make decisions and judgments which have social and material implications for those with the disease. To access some of the collective voices present in how cancer is responded to in relation to work and welfare, the decision was made to interview participants with differing roles in experiences of cancer.

Findings

Deservingness in the workplace

Deservingness features, and matters, in the workplace.

Cancer is generally seen as deserving, in terms of control (it's not their fault) and need (it impacts work ability, and particularly when it's terminal the need is seen at its highest level).

Cancer was situated by all participants as a horrible disease and '*probably the worst thing in the world*' to be diagnosed with (HCP2F). There was tacit recognition that employees with cancer were not responsible for their diagnosis. This lack of responsibility corresponds with a key entitlement of the sick role; not to be blamed for one's illness (Parsons, 1951).

Employees with cancer were quick to evidence this lack of responsibility over their diagnoses. They explained how they had '*never smoked*' (12M) or engaged in other

behaviours that would imply blame for their condition. One participant 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]'* (14M).

Part of the experience of being diagnosed and treated for cancer for employees was adapting to temporary or indefinite changes to their needs. Participants reflected on their level of need post-diagnosis to make sense of what they deserved, and whether that was commensurate with what they received. They gave examples of the pain and discomfort they continued to experience:

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 of their condition. Some read letters aloud, explaining how they had been informed that they were at *'a very advanced stage of the disease'* (13M) or how they were *'in no condition to be working or looking for work'* (10M).

When employees discussed their changed physical abilities, or increased level of need they largely did so to justify extended or indefinite sick leave and continued income from state welfare. To this extent, it is unsurprising that in a number of interviews employees with cancer evidenced their changed capability utilising examples that mirror questions 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 explaining how their physical symptoms precluded them from returning to work, situating deservingness and illness in relation to capacity to work, replicating the functionalism that underpins Parsons' sick role (1951).

Most of the employees with cancer experienced a financial shortfall as a result of their diagnosis and subsequent sick leave from work. They also drew on this financial need to make sense of what they felt they deserved in the way of recompense, especially from the state. Some were incredulous to find that despite their financial need, they were not eligible for 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).

Others used the same logic to reach the alternate conclusion; that they were not in enough financial need to receive state welfare. These assumptions were formed on the basis of a spouse's salary or property ownership. This highlighted some important misconceptions regarding participants' understandings of how welfare benefits are distributed. Two participants would not have been ineligible for the main income-replacement welfare benefit (Employment and Support Allowance) for the reasons given during their interview.

Cancer compared to 'bad backs'.

Not all people with cancer are equally deserving

Employers make distinctions about pre-diagnosis contributions, as do employees sometimes as they seem to say they deserve more because of it. Employers also differentiate on the basis of post-diagnoses contributions to the workplace.

In combination with their post-diagnosis need, employees with cancer drew on their pre-diagnosis contribution to both their workplace and the UK economy more broadly to frame their deservingness. Not only did their contribution set them apart from 'other', as explored above, it was also used by participants to make sense of the support they received having been diagnosed. They reflected on how they had added value, or built up their employing organisations and the length of time they had worked for their employers. They used their interpretation of their input to make sense of what support they received. In some instances, there was a perceived mismatch, when support (financial or social) was considered non-reciprocal, resulting in anger:

...they offered us a deal of [five figure sum below £15,000 redundancy payment] after twenty-four years of work, they had no chance... (14M)

Others felt that the support they were offered was commensurate with their pre-diagnosis contribution. One employee with cancer explained how she had been paid sick pay over her contractual entitlement because she '*had never been on the sick in all the ten years*' she had worked for her employer (7F), in addition to being considered a hardworking employee. She was paid six months full pay, instead of her contracted six weeks full pay.

Using the same reciprocal logic, but reaching an alternative conclusion, another employee with cancer was underpaid statutory sick pay. She justified this illegal underpayment on the basis that she '*hadn't actually worked for [her employing organisation]*'. Though she had been in her position for a number of years, the care organisation she worked for was subject to numerous mergers and take overs. The most recent takeover coincided with her cancer diagnosis. She felt the non-payment of statutory sick pay was reciprocal to the limited time that she had worked for her new management.

Employees with cancer drew on their work contribution prior to being diagnosed to make sense of the support they received since their diagnosis. To further establish their deservingness they reflected on their changed capacity and needs having been diagnosed and reflected on their worthiness as relative to those they considered less deserving in society. These understandings of deservingness reflect the disruption represented by a cancer diagnosis.

Line managers were required to manage their employee's absence and departure from or return to work. This sometimes resulted in employers having to calculate financial support offered to employees. Here, a line manager describes how she would calculate the ill-health retirement lump sum made available to her employee with cancer:

...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...
(EMP7F)

Further to representing a collection of subjective measures, this manager clearly states that she will take the post-diagnosis behaviour of her employee into consideration as part of these calculations. Post-diagnosis behaviours were also considered by employers managing an employee's return to work and subsequent workplace accommodations:

...I've never refused her [early finishes] because I think she was good enough to come back in that short period of time, and I think as an employer we have to support that... (EMP1F)

Employers, responsible for their employee's timeline for a departure from or return to work, rewarded employees who evidenced a desire to return. Particularly so if the employee appeared '*keen to get on*' (EMP4F) and returned to their pre-diagnosis productivity:

You can't help yourself from doing it [providing work place accommodations], and if that had been a different person, a 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... (EMP5F)

Reciprocity, therefore, was framed by employers as a criterion for deservingness. Unlike with employees with cancer, who focused explicitly on their contribution prior to being diagnosed, employers had expectations for employee behaviour post diagnosis. This requirement was reflected on by employees with cancer who returned to work. Some felt pressured to return before they were ready, and commented on the expectation that they would return to their pre-diagnosis shift patterns and/or productivity:

...I don't think they [employers] 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)

Employees with cancer were rewarded in the workplace for evidencing a desire to return to work and returning as soon as possible; by taking '*an appropriate time to get over cancer basically*' (EMP5F). The only exceptions to this were employees who were permanently departing from the workplace. One employee felt that he was offered a generous lump sum on leaving because he '*didn't mess them [employers] about with tribunals and all that*' (14M). Other deserving employees included those whose cancer was terminal, for whom sympathy and support was not questioned. This idea that those employees who were expected to die of cancer were deserving was reflected in terms of workplace policy:

...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... (EMP7F)

The presumption implicit in how employers discussed ill-health retirement is that employees with cancer would either return to work, to 'normal duties' (Parsons, 1951) after their treatment and were deserving, or would permanently depart from work. Despite the presence of legislation that recognises the long-term nature of cancer, employers did not respond to it as a long-term, fluctuating condition nor did they reflect on comorbid conditions.

Deservingness of cancer questioned by the system – response of participants is to compare people with cancer to migrants

Participants used othering and shaming discourses to situate people with cancer as deserving of support in comparison to undeserving others as has been identified in other research (Patrick, 2017). These comparisons were levelled at those who were considered to have less deserving health conditions including '*bad backs*' (EMP9F) (said with mimed inverted commas) or to be claiming disingenuously; people who '*love living off the state, get whatever they can out of the system and still manage to get a bit more*' (14M).

Immigrants were also utilised as an 'underserving' group for comparison. 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 his life, you know, thirty or forty years and then falls into no man's land [attempting to access welfare benefits] because he's got cancer*' (HCP3F). This same sentiment was expressed by a participant who asserted that he would have been better off as an asylum seeker. He argued that he had '*had to fight for what [he] got*' having '*paid into the system*' since leaving school (M4). These comparisons raise two

key issues. They highlight, again, a lack of knowledge and information about how UK state welfare is distributed, potentially resulting from misleading information in the media (Briant et al., 2013; Tyler, 2011). Secondly, they situate deservingness in relation to contribution and citizenship as the primary requirement made of the citizen is to contribute to society by means of paid work (Frayne, 2015).

The temporal structure of perceived deservingness is problematic

Employers and the UK state welfare system both want a definite timeline for return.

An important responsibility for managers was to predict and then enforce a timeline for their employees to return to or depart from work.

...the difficulty tends to come once the treatment's finished, and then trying to establish a return to work date...(EMP10M)

In this study the sick pay offered by employing organisations differed substantially but the time allowed for sick leave was 12 months in almost all instances, with some discretionary increases. Managers were under pressure to identify a timeline for their employees return, often before the conclusion of sick leave entitlement. One manager said that her employing organisation requested that her employee with cancer return to work '*on the Monday after she's finished her treatment on the Friday*' (EMP5F).

Workplace accommodations, a legislative protection made available to people with cancer precisely because of the long-term nature of their illness were often shown to be temporary. Public sector employers explained how employees with cancer had '*reasonable adjustment passports*' within their employee paperwork. They described how the passports were generally reviewed annually, but how in a context of numerous managerial changeovers, there were concerns that employees with cancer could be forced to go through their additional needs over and over again or that managers with differing opinions about employee deservingness might respond to employees unsympathetically:

...If I lose my senior officer and I put these things [workplace accommodations] in place with that person being fully aware of what I've put in place and I get a new boss, then if they don't feel the same way you have to go through all, all your evidence and what you want to put before them ... (EMP5F)

UK state welfare provision also appeared to default to a finite model of illness. Employees with cancer were subject to a process that promoted a move back toward the labour force after treatment. Some participants described 'giving up' (F7) on accessing welfare benefits in response to delays in assessment, difficulties in accessing adequate information and administrative errors. Healthcare professionals echoed the concerns of employees with cancer, describing the UK welfare benefit system as 'torturous and bureaucratic' (HCP1M) and 'wholly opaque' (HCP5M).

One participant received an unexpected communication from the Department for Work and Pensions, despite not receiving any out of work sickness benefits:

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

Participants who did have recourse to state welfare expressed dread and fear about being assessed for their continued payment of welfare. Though people receiving treatment for cancer are initially awarded the higher of two rates of the main income replacement benefit, Employment and Support Allowance (ESA), they are assessed at the conclusion of their fit note. One participant in particular had concerns that assessors would not consider his individual needs and capabilities and voiced anger and frustration:

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

People felt they needed to perform illness in expected ways to access their benefits, irrespective of how they feel.

These concerns were realised in the experiences of participants that did experience welfare benefit assessment. One participant received the lower component of income related ESA at the time of his interview having previously received the award at the higher level, until his fit note expired. He had developed depression, which is a common reported comorbidity of cancer (Mitchell et al., 2013). During his assessment, despite showing symptoms associated with his mental health issue he was found fit for work. The result of a subsequent appeal meant that though he was again awarded ESA, it was still at the lower of two available rates. He was required, as part of the conditions of his benefit entitlement, to attend work related activities, including fortnightly group talks and work focused interviews at a local employment support service. He explained that if he did not attend these activities '*they [the Department for Work and Pensions] would eventually stop [my] money*' (10M). More conditions were placed on him accessing welfare payments each time he interacted with the Department for Work and Pensions.

There is a gap between the fixed sick role as perceived by others (structure and policy), and the more complex experiences of individuals with cancer themselves. These represent overlaps between the sick role (as perceived by others) and biographical disruption: participants actively drew on the sick role to frame their illness narrative. To this extent, the sick role can be regarded, in this context, as a set of social practices which participants drew on. In this way, the sick role can be understood as a relational construct.

The whole concept of deservingness speaks to the sick role.

Though lacking the nuanced interpersonal relationships present in the workplace, the provision of state welfare in the UK for people with cancer mirrored the fixed-term model of illness present in individual workplaces. Both initially situate people who are in work when diagnosed with cancer as deserving of support, inclusive of cancer-specific policy regarding workplace protections and specific provisions of state welfare. However, in both instances, and despite legislation that identifies cancer as a long-term condition and/or disability the

conditions for deservingness alter and as a result compel some working age people with cancer back to work, before they are medically fit to return.

Discussion

There is, ultimately, something fundamentally and sociologically sound in Parsons' theorising. If we accept the many, valid critiques of the sick role, it remains a social trope that non-sociological lay people, such as the participants to this study, use to make sense of illness.

The sick role and biographical disruption do not exist in conflict.

This paper raises important questions about the enduring applicability of a key sociological construct, the sick role, and looks to question the nature of its enduring legacy and develop ways in which we might contemporaneously understand the concept.