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Studying the Study: Reflections on Exploring the Health and Disability Narratives of Long-Term Sickness Benefits Recipients in the UK

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Abstract

Researching sensitive topics such as sickness and disability can encompass a wide range of demands that must be continually negotiated throughout the research process by both the researcher and research participants. Therefore, a studying the study approach is important when exploring the quality and ethical practice in qualitative research on sensitive issues with vulnerable populations. This becomes especially important within a UK context when considering the negative discourse surrounding the sickness benefits process in the UK. Drawing upon semi-structured interviews with 25 long-term sick and disabled benefits recipients in the UK, the study sought to uncover the health and illness narratives of long-term sickness benefits recipients. Within the presentation of methods that were used, a discussion of the methods used in conducting a “study of the study” are considered, providing an illustration of how to do this and what to do with the results of such a reflective piece. The challenges of doing such research are outlined, and the need for a reflective process surrounding the research process is emphasised. Finally, the approach of studying the study is an example of an illustration of how to adopt this approach when considering qualitative research with hard to reach groups.

Keywords

Reflexive, Sickness, Disability, Sickness Benefits, Identity, Performance, Qualitative, Grounded Theory, Hard to Reach

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Studying the Study: Reflections on Exploring the Health and Disability Narratives of Long-Term Sickness Benefits Recipients in the UK

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Researching sensitive topics such as sickness and disability can encompass a wide range of demands that must be continually negotiated throughout the research process by both the researcher and research participants. Therefore, a studying the study approach is important when exploring the quality and ethical practice in qualitative research on sensitive issues with vulnerable populations. This becomes especially important within a UK context when considering the negative discourse surrounding the sickness benefits process in the UK. Drawing upon semi-structured interviews with 25 long-term sick and disabled benefits recipients in the UK, the study sought to uncover the health and illness narratives of long-term sickness benefits recipients. Within the presentation of methods that were used, a discussion of the methods used in conducting a “study of the study” are considered, providing an illustration of how to do this and what to do with the results of such a reflective piece. The challenges of doing such research are outlined, and the need for a reflective process surrounding the research process is emphasised. Finally, the approach of studying the study is an example of an illustration of how to adopt this approach when considering qualitative research with hard to reach groups. Keywords: Reflexive, Sickness, Disability, Sickness Benefits, Identity, Performance, Qualitative, Grounded Theory, Hard to Reach

Introduction

Currently within the UK there is a whirlwind of discussion surrounding sickness benefits¹ recipients. One of the fundamental reasons oft-cited for the interests in sickness benefits recipients is the large numbers of people who receive them. In the UK in May 2011, a total of 2.6 million people were claiming sickness benefits, of which around 700,000 people were claiming Employment and Support Allowance (ESA), 1.7 million Incapacity Benefit (IB) and 200,000 SDA (Department for Work and Pensions (DWP), 2011). As a result, the Coalition government and indeed successive governments have been committed to reducing the number of people receiving sickness benefits through welfare reform which requires all IB recipients to undergo a Work Capability Assessment (WCA) to determine their eligibility to remain on the said benefit. Surrounding the assessment process is the harsh re-emergence of a discourse that negatively labels sick and disabled people as “scroungers,” “work-shy,” “feckless,” and “lazy.” Headlines in the mass media regularly lament claimants who are “undeserving” of any help and support (Briant et al., 2011). Ongoing welfare reform means that not only are sickness benefits recipients facing uncertainty over their futures, but they are also finding themselves to be of increased interest to the mass media and wider public. A

¹ I follow the Department for Work and Pensions (DWP) in using the term “sickness benefits” as an umbrella term to refer to the range of benefits that are paid to people because their health limits their ability to work. The term will encompass Incapacity Benefit (IB), Severe Disablement Allowance (SDA) and Employment and Support Allowance (ESA).

wider narrative of suspicion and negativity is being attached to sick and disabled benefit recipients (Garthwaite, 2011), which in turn has caused fear and anxiety for sickness benefits recipients themselves (Garthwaite, 2013). Welfare reform is not just affecting sick and disabled people in the UK. In Australia sickness benefits for sick and disabled people have undergone similar trends to those that have been occurring in the UK, with increased conditionality, sanctioning and upheaval (Grover & Soldatic, 2012). Fundamentally, Grover and Soldatic (2012) note that for sick and disabled people a process of “reclassification” to restrict the access to sickness benefits has occurred in both the UK and Australia, with the intention that such benefits are only applicable to a newly-defined “truly” disabled group of people.

Therefore, a studying the study approach is important when exploring the quality and ethical practice in qualitative research on sensitive issues with vulnerable populations. This becomes especially important within a UK context when considering the negative discourse surrounding the sickness benefits process in the UK. This article seeks to locate the narratives of long-term sickness benefits recipients within a wider framework that considers issues of the performance of both parties in the research process, drawing upon the theoretical framing of Goffman. The impact of stigma within the narratives is also central to discussions of identity and performance when talking about research with long-term sick and disabled benefits recipients. The findings presented here are taken from doctoral research carried out between 2009 and 2012 at Durham University, UK. The research builds on previous work I have carried out surrounding poverty, low-pay, welfare benefits, and how language is negatively used when discussing welfare benefits and those who receive them.

Methodology

Sampling and theoretical framework

The foundations of this research project are rooted within the realm of grounded theory. Yet whilst grounded theory assumes a lack of prior knowledge before embarking upon a research endeavour, this was not the case for this research project. Grounded theory relies on theoretical sampling, which involves recruiting participants with differing experiences of the phenomenon so as to explore multiple dimensions of the social processes under study. The researcher continues to add individuals to the sample until theoretical saturation is reached; that is, when the complete range of constructs that make up the theory is fully represented by the data. Although it is impossible to predict what sample size will saturate a given theory, typical grounded theory studies report sample sizes ranging from 10 to 60 persons (Starks & Brown Trinidad, 2007, p. 1375). In qualitative research, sample selection has a profound effect on the ultimate quality of the research (Coyne, 1997, p. 623). In contrast to other qualitative research based upon grounded theory, in most instances I had already spent time getting to know participants when completing health questionnaires with them. Often, the questionnaires could take almost one hour to complete as once people began talking, often they would digress from the questions being asked and begin telling me their wider narratives. These encounters allowed me to make notes of who could be a useful person to interview for a qualitative interview. Not only that, I had begun to form a relationship with potential participants; they already felt like they could begin to trust me enough to reveal personal information, and seemed to enjoy having someone to talk to. This is particularly important given that sickness benefits recipients are often referred to as a “hard to reach” group. Conducting questionnaires with people meant that they had already told me a lot of personal characteristics and information. For example, I knew their marital status;

who they lived with, if anybody; previous work history; when they began claiming benefits; their health problems; and their perspectives about returning to work.

Data Collection

An approach based on grounded theory methodology formed the methodological basis of the study. In grounded theory, the focus of analytical procedures is to locate relationships between concepts and themes across interviews through a process of constant comparative analysis (Charmaz, 2006; Glaser & Strauss, 1967). 25 chronically ill and disabled people narrated their biographies between March 2011 and August 2011 in County Durham and South Tyneside. Three people refused to take part in the study. All participants were initially recruited via Jobcentre Plus (JCP) "Choices" outreach events held between September 2009 and June 2010. Jobcentre Plus is a key welfare to work provider for working age people in the UK. The majority of interviews took place in participants' own homes. This decision was reached for two reasons: firstly, given the nature of the research often participants are experiencing debilitating health problems which limit their mobility. Interviewing people in their homes ensured that they did not have to worry about meeting me elsewhere. Secondly, I believe that carrying out interviews in someone's own home enhances the research experience for both the researcher and the researched – for the researcher, they are able to see someone in their own home and make sense of their narrative within the context it is situated. For people who are taking part in the research, they are likely to feel more comfortable in their own home and therefore might feel more relaxed. Less often, participants were keen to come to the university, perhaps out of curiosity regarding academic and university life, as Clark (2010) explains. Obviously, research in someone's home setting is accompanied by safety issues. Safety procedures were put in place and I always had to "check in" with a member of staff at the University before and after an interview. Interviews typically lasted between 45 minutes to over two hours and were transcribed verbatim and fully anonymised before thematic analysis was undertaken.

To elicit the narratives presented here, a semi-structured topic guide was used which included questions around:

- 1) experience of receiving sickness benefits;
- 2) health and employment histories;
- 3) feelings of stigma and identity; and
- 4) perspectives on welfare reform.

Participants were chosen in order to reflect a wide range of different situations and backgrounds; I was keen to include variation by way of age, gender, employment history, length of time spent on benefits, educational background, household status, and differing health conditions, including how and why people had made the transition to receiving benefits. The age range of the sample varied greatly – the youngest participant was 32, and the oldest was 65, and had recently retired. Of the 25 people I spoke to, 15 were female and ten were male. In terms of marital status, most participants (19) were either married or had been married and were now divorced.

Interviews typically lasted between 45 minutes to 120 minutes and were transcribed verbatim and fully anonymised before coding and thematic analysis was undertaken. However implicitly, the researcher's definitions of reality clearly shape what categories he or she constructs. As such, coding and analysis was carried out alongside the fieldwork, in order to fulfil the following key aims:

- (i) to identify any emergent new areas of interest/ideas to ask participants about;
- (ii) to identify if certain types of participant are being overlooked, for example, if there is a paucity of older long-term IB recipients, then I can address this by actively seeking this type of participant;
- (iii) to identify when a saturation point is likely to have been achieved.

Data analysis involved open coding, axial coding, and then narrative analysis. Ideally, each interview or observation was coded before the next was conducted so that new information can be incorporated into subsequent encounters. Themes identified through the coding of initial interviews may also be explored in follow-up interviews. As I was not following a pure grounded theory approach, sometimes I did not adhere to these strict guidelines; however, I did always attempt to transcribe and code each interview before the next one was undertaken. This approach was ideal for pointing out areas that had thus far been under researched in the study, and also areas that do not need much further exploration.

First, a thorough reading of each transcribed interview was undertaken alongside NVivo 8 software to select and code quotations that referred to identity, stigma and lived experience. I developed the coding framework as I went through the transcripts, rather than trying to impose a pre-developed framework on the data (i.e. the approach was “bottom-up” rather than “top-down”). One drawback of this approach was that I continually had to return to earlier transcripts and consider whether new codes could be applied to previously coded sections. After coding the 25 narratives, NVivo 8 was used to connect the codes and quotations of each respondent to their story. I employed NVivo in a fairly basic manner, approaching the coding framework as a tool to aid the writing-up process rather than exploring the more complex analytical possibilities the programme offers. However, this combined analytical approach was considered useful for revealing the complex relationship between stigma, disability, identity development, and the ways in which participants story their experiences of living on long-term sickness benefits. The coded interview transcripts were explored and presented in a case-by-case format as opposed to issue-by-issue. Each of the condensed stories was then read and coded for themes related to the following three categories: constructing new dimensions of self; validating illness; and pursuing aspirations.

Alongside the process of data collection, a research journal where notes, thoughts, feelings and ideas could be documented allowed me to be reflexive throughout the research process. Memo writing is the pivotal intermediate step between coding data and writing the first draft of the analysis for Charmaz (1999, p. 376). Memo writing helps researchers to define and delineate theoretical categories and to focus further data collection. This analytic step is crucial because it keeps researchers in control of their studies. The following list describes the advantages of memo writing. Memo writing helps researchers to: stop and think about data; spark ideas to check out in the field setting; treat qualitative codes as categories to analyse; clarify categories - define them, state their properties, and delineate their conditions, consequences, connections with other categories; develop fresh ideas, create concepts, and find novel relationships; and discover gaps in data collection (Charmaz, 1999). All of these mentioned by Charmaz influenced the decision to begin a research journal where memos are noted and reflected upon. Journal keeping has allowed me a space to record my initial reactions and decisions and to be able to look back and analyse the factors behind those decision making processes, and to see how my thought processes changed throughout the course of the research. This approach was supported through numerous pieces of literature which argue that personal journals or diaries can be a valuable and relatively simple way for

researchers to work through and acknowledge their emotions, and the roles that they play within the research context (Darra, 2008; Glaze, 2002; Goodrum & Keys, 2007; Hewitt-Taylor, 2002; Hubbard et al., 2001; Smith 1999), and also as a way to manage distress, sadness and release emotions (Goodrum & Keys, 2007). Journals can therefore be viewed as an effective tool for reflexivity, as they can lead the researcher to a state of openness where prior assumptions, beliefs and attitudes are recognised and understood (Dowling, 2006). In particular, the journal allowed me to discover gaps in the data and developing and clarifying connections - enabling me to “*hear subjects’ voices more clearly and understand their tales more completely*” (Charmaz, 1999, p. 379).

Reflections on studying the study

The following section outlines the challenges of doing research with hard-to-reach populations such as long-term sickness benefits recipients, whilst emphasising the need for a reflective process surrounding the research process

Being the researcher

As those familiar with qualitative research methods will attest, internalising sensitive and distressing information can present a real risk for the emotional wellbeing of researchers. Often, I would finish an interview and experience a myriad of emotions – usually distressed, upset, privileged, guilty, angry, and lucky, amongst many others. Participants would tell me about their daily life, their health and illness experiences, and significant traumatic events that they feel have shaped them as people. I did often feel like participants saw me as something of a counsellor, although I am not trained for that role and nor would I wish to be. I did not offer advice other than to suggest they talk to a doctor, a trained counsellor or someone close to them if they wanted to discuss anything further. Indeed, some interviewees expressed concern for my emotions and often apologised for “burdening” me with their stories of battling chronic health conditions and disabilities. For example, Lisa, 54, suffers chronic back problems alongside mental health issues, comments: “*I have really poured everything out to you haven’t I, I’m sorry...I just don’t want you to think I’m burdening you with all of this.*” Mitchell and Irvine (2008) observe that they employed a range of strategies to enable participants to express, address, or manage their emotion. For example, allowing participants to set the pace and depth of an interview, or moving on from evidently distressing topics ensured there was a sense of personal control. I, too, adopted certain strategies to account for this, such as offering to switch the tape recorder off, suggesting we move on to another topic, and giving participants time to think about what they wanted to say next.

How participants viewed me as a researcher will unquestionably affect the response they gave me during the interview. I felt that my identity was characterised by me being a female 25 year old white PhD student from the North East of England. I had the same regional accent as they did, I possessed local knowledge of places they mentioned, and fully understood any local dialect that was used. Yet despite this common ground, I remained different to them in two fundamental ways – firstly, I was perceivably fit and healthy, and secondly, I was without any experience of benefits receipt, unlike them. Commentators have often questioned the ethics of a non-disabled researcher doing research with disabled people (Barnes & Mercer, 1997; Priestley, 1997; Stone & Priestley, 2006). For Stone and Priestley (1996, p. 700), when thinking about non-disabled researchers, they argue that the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider

world. Yet they also recognise that the researcher is required to bow in several directions: to research councils and to academic peers, to disabled people and their organisations. In this sense, the researcher both acts and is acted upon within these power relationships.

However, difference between researcher and participant is not necessarily negative and Vincent and Warren (2001) warn that too much researcher and participant symmetry could lead to assumptions on either side and misunderstandings can arise from either party on the basis of such shared assumptions. The points highlighted above, for example, participants' apparent surprise at the extent of their disclosures in an interview, and negotiating the boundaries of an appropriate researcher role versus that of a counsellor in terms of the responses and support that can be provided, cover already well-trodden ground by qualitative researchers. Therefore, this paper focuses more specifically on the experience of researching health, illness and welfare receipt, including reflections on how this shaped my interpretation of the accounts.

Performance and the research encounter

In his seminal work on performance and presentation of the self, Goffman (1959) remarks that “the individual will have to act so that he intentionally or unintentionally expresses himself [sic], and the others will in turn have to be impressed in some way by him” (1959, p. 2). Here, Jacqui wants to illustrate that she is different to other people receiving sickness benefits in that she is setting up her own business, thus distancing herself from a “spoiled identity” (Goffman, 1963, p. 3). Goffman (1981) observes that the performance of the interview encounter is fraught with risk for both the interviewee’s and the interviewer’s identity. In entering people’s homes and carrying out interviews, the researcher is bound to act and behave in a certain manner, as they are, after all, a guest in the person’s home (see Garthwaite, 2009). For Yee and Andrews (2006, p. 407) there is a paradox between the role of the researcher as a “good guest” and a professional researcher. They give the example of being offered refreshments and question whether “accepting an offer of tea or coffee can demonstrate that the researcher feels relaxed with the family and can be part of establishing a relaxed atmosphere. Participants clearly viewed me as a guest and wanted to ensure their homes were ready to be presented to me, as Joan indicates: *‘I thought ‘God I cannot let her come in here with the house like this’ so I got it Hoovered.*” Others, such as Sue, 50, were also keen to present themselves as good hosts. When I arrived at Sue’s home, she had baked a range of homemade cakes for my arrival – despite telling me in the interview of her difficulties preparing dinner for her husband every evening. These examples further hint at the dramaturgical notion of performance as suggested by Goffman (1959, p. 123) of front and back regions:

One of the most interesting times to observe impression management is the moment when a performer leaves the back region and enters the place where the audience is to be found...one can detect a wonderful putting on and taking off of character.

On occasions, participants attempted to seek similarities between themselves and my experiences, perhaps in an attempt to break down the “us” and “them” discourse created about sick and disabled people in populist discourse which characterises sick and disabled people as “shirkers” and “scroungers” (Garthwaite, 2011). The following quotation from Jacqui, 50, illustrates this: *“I’m setting up a business making costumes, you’re doing a PhD you’re wanting to do something with your life and that’s what I want to do.”* This encounter might point to what Goffman (1981, p. 5) terms a “face-saving” mechanism.

Whilst narratives can be shown through quotations from the transcript, the experience of interviewing people face-to-face and witnessing how their voice, expressions, and emotions change as they relay their story cannot really be replicated through transcribed text. Kirsty's interview was a pivotal moment for me in thinking about reflexivity in the research process. Kirsty, 32, was a prison officer for ten years until a chance accident at work – a heavy door fell on her neck in her workplace of a young offender's institution - that meant her future prospects of working were, according to her, "very restricted." I couldn't help but think that Kirsty was only seven years older than me, yet in one split second her life had completely changed. Kirsty said of the accident:

(Laughs) *Of all the things that can happen in a prison, a door fell off and hit me on the head. I pushed it open and the top hinge failed. It swivelled on the bottom hinge and fell onto me and I took the full weight on my head and it snapped my neck back and that's what caused the damage to my spine. It's a bit ironic of all the brave things that could happen to me in a prison – a door fell on my head.*

Although the transcript tells the tale, researcher encounters are embodied and situated events, and significant details are lost if we take away and preserve only the words people actually said (Warr, 2004, p. 579). For example, when Kirsty spoke of previously being given shopping vouchers to commend her excellent performance at work, the cruel irony of me offering her shopping vouchers as a gift for participating in the research because I wanted to hear about her experiences of health and illness was a sharp and unavoidable contrast. At that moment, I felt uncomfortable, frustrated for her, I felt like an intruder and I also felt frightened that something like that could happen to anyone - it could happen to me. As Warr (2004, p. 581) remarks, "*being present in the telling of these uncomfortable stories can heighten the capacity of the researcher to portray people's experiences with empathy and a deeper level of understanding.*"

Certainly, these feelings of concern can "*be experienced at a more intense level if the research topic is highly sensitive*" (Johnson & Macleod Clarke, 2003, p. 425) as can be the case when a researcher delves into narratives concerning health and illness whose ultimate subject matter might be hidden from view. Yet the disability studies community suggests that any portrayal of "pity" should be avoided (Barnes, 2001). As the extract above suggests, evoking feelings of pity and sympathy might be unavoidable when looking at the narratives of long-term sickness benefits recipients. The narratives tell stories of chronic pain, disruption, loss of self and a struggle to reconcile an identity that was once shaped by something other than illness. Whilst Barnes (2001) and other disability rights scholars see such views as having the potential to make the lives of disabled people tragic, portraying the realities of living on sickness benefits for the people who receive it crucial in order to avoid people receiving such benefits from being branded as simply another group of the unemployed. A moral obligation then exists for the researcher to ensure that there is sound justification for the investigation and research method, which extends beyond intrusive curiosity and achieves more than the "*telling of sad stories*" (Thorne & Darbyshire, 2005). This point can be extended by reflecting on how the feelings researchers themselves experience and convey or "perform." It is useful to frame this discussion in terms of the responsibilities a researcher chooses to prioritise, and how these might shift over different stages of a study. For example, not to convey sympathy during an interview might seem callous, but as has been noted here, researchers may have an ethical obligation to go beyond simply evoking sympathy when representing participants' lives in their written outputs.

Again, this links in to notions of performance during the interview process both from participants but also myself.

For some participants, the research encounter was described as having made them feel useful, worth something and as a therapeutic encounter. Whilst this finding may not be wholly unexpected, it is perhaps more surprising when thinking about the stigma, suspicion and anxiety attached to receiving long-term sickness benefits in the UK. For many, being out of the labour market due to health reasons resulted in a loss of self and identity, and a loss of purpose. Taking part in the research was viewed not only as helping me as a researcher, but also as giving people something to do and helping them and was described as therapeutic – something also reflected on by Birch and Miller (2000). It could also suggest a desire within long-term IB recipients to attest that they were “genuine” and were legitimately receiving sickness benefits. Other participants felt that they had never been given the opportunity to talk honestly and openly about what it was like to experience chronic health conditions and disability and how it affected them. Here, Ray, age 53, who suffers health problems due to his alcoholism, explains why he decided to take part: “*Doing stuff like this, I think if it wasn't for stuff like this I'd be stuck in the house a lot more. It's given us a bit purpose to get out and I'm grateful for that.*” Several participants also expressed appreciation that someone was giving recognition to their situation and to their lives. Research by Johnson (2009, p. 35) found that many participants had spent so long trying to fit into what Heidegger refers to as “the they world” and present themselves as “normal,” that they never had the chance to authentically “be” and reveal their true experiences. However, it should not be naively assumed that the research process is one sided. As Miczo (2003) observes, it cannot be ignored that the first answer of the interview encounter is going to depend on the motives that led that person to be in the role of interviewee in the first place – perhaps in the case of this research, participants were keen to convey that they were, in fact, a “genuine” case.

Summary and Conclusions

Health and disability narratives are inherently complex and multifaceted, evoking both the researcher and participants to occupy certain roles. This paper has provided an example of how “studying the study” is important when thinking reflexively about the research process. By utilising the conceptual framing of Goffman’s work on performance, this article has demonstrated how the researcher-researched relationship is embodied by identity and the presentation of self for both parties involved. Being the researcher involves many different aspects, including the management of identity and emotion. Overall, the paper has demonstrated the importance of accepting that the researcher’s role is certainly not one that can be pushed to one side at the end of the day – participants and their narratives remain long after the digital recorder has been switched off.

References

- Barnes, C. (2001). “Emancipatory” disability research: Project or process? Public Lecture at City Chambers, Glasgow. Retrieved from <http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/glasgow%20lecture.pdf>
- Barnes, C., & Mercer, G. (1997). *Doing disability research*. Leeds, UK: Disability Press.
- Birch, M., & Miller, T. (2000). Inviting intimacy: The interview as therapeutic opportunity. *International Journal of Social Research Methodology*, 3, 189-202.
- Briant, E., Watson, N., & Philo, G. (2011). *Bad news for disabled people: How the newspapers are reporting disability*. Project Report. Strathclyde Centre for Disability Research and Glasgow Media Unit, University of Glasgow.

- Charmaz, K. (1999). From the “sick role” to stories of the self: Understanding the self in illness. In R. D. Ashmore & R. A. Contrada (Eds.), *Self and identity, Vol. 2: Interdisciplinary explorations in physical health* (pp. 209-239). New York, NY: Oxford University Press.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, UK: Sage Publications.
- Darra, S. (2008). Emotion work and the ethics of novice insider research. *Journal of Research in Nursing, 13*(3), 251-261.
- Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher, 13*(3), 7-21.
- Garthwaite, K. (2009). What a performance! Exploring the reflexive roles of the researcher and the researched within health and illness narratives. *ENQUIRE, 4*, 110-133.
- Garthwaite, K. (2011). The language of shirkers and scroungers? Talking about illness, disability and coalition welfare reform. *Disability and Society, 26*(3), 369-372.
- Garthwaite, K. (2013). Fear of the brown envelope: Exploring welfare reform with long-term sickness benefits recipients. *Social Policy & Administration*. Advance online publication. doi/10.1111/spol.12049
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Glaze, J. (2002). PhD study and the use of a reflective diary: A dialogue with self. *Reflective Practice, 3*(2), 153-165.
- Goffman, E. (1959). *The presentation of self in everyday life*. Harmondsworth: Penguin.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Harmondsworth: Penguin.
- Goffman, E. (1981). *Forms of talk*. Oxford: Basil Blackwell.
- Goodrum, S., & Keys, J. (2007). Reflections on two studies of emotionally sensitive topics: Bereavement from murder and abortion. *International Journal of Social Research Methodology, 10*(4), 249-258.
- Grover, C., & Soldatic, K. (2012). Neoliberal disability restructuring in Australia and the UK. Presented at Disability – Spaces and Places of Exclusion, April 16–17, Lancaster University, UK.
- Heidegger, M. (1969). *Identity and difference*. New York, NY: Harper and Row.
- Hewitt-Taylor, J. (2002). Inside knowledge: Issues in insider research. *Nursing Standard, 16*(46), 33-35.
- Hubbard, G., Backett-Milburn, K., & Kemmer, D. (2001). Working with emotion: Issues for the researcher in fieldwork and teamwork. *International Journal of Social Research Methodology, 4*(2), 119-137.
- Johnson, B., & Macleod-Clarke, J. (2003). Collecting sensitive data: The impact on researchers. *Qualitative Health Research, 13*, 421- 434.
- Johnson, N. (2009). The role of self and emotion within qualitative sensitive research: A reflective account. *ENQUIRE, 4*, 23-50.
- Miczo, N. (2003). Beyond the “fetishism of words”: Considerations on the use of the interview to gather chronic illness narratives. *Qualitative Health Research, 13*, 469-490.
- Mitchell, W., & Irvine, A. (2008). ‘I’m okay, you’re okay?’: Reflections on the well-being and ethical requirements of researchers and research participants in conducting qualitative fieldwork interviews’. *International Journal of Qualitative Methods, 7*(4), 31-44.
- Priestley, M. (1997). Disability, values and quality: A case study in Derbyshire. PhD thesis. University of Leeds: UK.

- Smith, B. (1999). Ethical and methodologic benefits of using a reflexive journal in hermeneutic phenomenologic research. *The Journal of Nursing Scholarship*, 31(4), 359-363.
- Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47(4), 699-716.
- Thorne, S., & Darbyshire, P. (2005). Land mines in the field: A modest proposal for improving the craft of qualitative health research. *Qualitative Health Research*, 15(8), 1105-1113.
- Vincent, C., & Warren, S. (2001). 'This won't take long ...': Interviewing, ethics and diversity. *International Journal of Qualitative Studies in Education*, 14(1), 39-53.
- Yee, W.C., & Andrews, J. (2006). Professional researcher or a 'good guest'? Ethical dilemmas involved in researching children and families in the home setting. *Educational Review*, 58(4), 397-413.

Author Note

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