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Translating and Transforming Care: People With Brain Injury and Caregivers Filling In a Disability Claim Form

Alex Gillespie[1] and Helen Moore[2]

Abstract

This article examines how the Disability Living Allowance claim form, used in the United Kingdom to allocate £13 billion of disability benefits, translates and transforms disability and care. Twenty-two people with acquired brain injury and their main informal caregivers (*n* = 44) were video-recorded filling in the disability claim form. Participants disagreed on 26% of the questions, revealing two types of problems. Translation problems arose as participants struggled to provide categorical responses to ambiguous questions and were unable to report contextual variability in care needs or divergences of perception. Transformation problems arose as participants resisted the way in which the form positioned them, forcing them to conceptualize their relationship in terms of dependency and burden. The disability claim form co-opts claimants to translate care and disability into bureaucratically predefined categories, and it transforms the care relationship that it purports to document.

Keywords

boundaries; brain injury; caregivers / caregiving; disability / disabled persons; communication; social constructionism

Form-filling has become central to institutions, evident in registering for services, booking facilities, making investments, obtaining mortgages, paying taxes, auditing accounts, and distributing resources (Frohlich, 1986; M. Power, 2000). It enables institutions to gather information, and, moreover, it makes form-fillers complicit in this surveillance (Bonnin, 2014). Perhaps because form-filling has become so routine, it has received surprisingly little research attention (Graeber, 2012). Yet form-filling deserves attention, not only because it has significant effects within society but also because ostensibly simple responses to structured questions conceal a complex process of social construction (Campbell, 2001; Mallinson, 2002; Shweder, 2008; van Oort, Schröder, & French, 2011; Wagoner & Valsiner, 2005). The aim of the present article is to examine this process of construction through an empirical study of people with brain injury and their caregivers filling in a disability claim form.

Disability Living Allowance (DLA) Claim Form

Completed DLA claim forms are used to disburse £13 billion per year among nearly 3.3 million people in the United Kingdom (Department for Work and Pensions, 2013b). The 55-page claim form purports to assess the degree of disability and the amount of care needed, and

thus calculate the claimant's eligibility for an allowance of between £21 and £134.40 per week. The political and economic context of pressure on welfare budgets means that decisions have to be made about who receives (and who will not receive) financial support. The aim of the DLA claim form is to attempt to ground such decision in seemingly simple and comparable facts.

The 55-page form is meant to be completed by the person with the disability; however, claimants often seek help with it (Salway, Platt, Harriss, & Chowbey, 2007). There is also an option to provide a statement from someone who can vouch for the extent of the illnesses or disabilities. Thus the form co-opts the person with the disability and their significant others into the process of documenting and reporting. Arguably, the process of filling in a disability claim form entails a process of self-examination, or even confession (Townley, 1996). Filling in such a form entails internalizing the criteria and language of the form, and then describing oneself in terms of that criteria and language. There is a shift of power, a

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"ruling relation" is established, in which the local is subordinated to the interests vested in the form (Campbell, 2001).

Claimants have been reported to find the DLA application both time-consuming and stigmatizing (Pudney, Hancock, & Sutherland, 2004). A survey in Scotland reported that 97% of claimants found the claim form difficult to fill in (Banks & Lawrence, 2005). Salway et al. (2007) interviewed claimants who "described the process of claiming DLA as complex, time-consuming and stressful; in some cases even citing the system as a factor exacerbating the seriousness of their health condition" (p. 294). These interviewees were particularly concerned about identity matters: Some feared that information about their disability would circulate in the community and/or resisted the way in which the claim form forced them to confront the full extent of their disability.

People With Acquired Brain Injury (PwABI) and Informal Caregivers

Acquired Brain Injury (ABI) is defined as an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma (Brain Injury Association of America, 2011). PwABI often have a mix of cognitive, behavioral, communicative, and psychological problems that can inhibit their resuming work, maintaining relationships, and engaging with people in a socially appropriate and meaningful way (Trudel, Tryon, & Purdum, 1998; Verhaeghe, Defloor, & Grypdonck, 2005; Wood & McMillan, 2001). Financial difficulties are common, with one study finding only 41% of PwABI employed 2 years post-injury (Van Velzen, Van Bennekom, Edelaar, Sluiter, & Frings-Dresen, 2009). When brain injury is severe, there is often a heavy reliance on informal caregivers to facilitate activities of daily living (Perlesz, Kinsella, & Crowe, 1999).

Informal caregivers are defined as people operating outside of an institution who provide daily and long-term support to a person with disability who is living at home (Turner & Catania, 1997). Although caregiving is a heterogeneous activity with variable outcomes (Carnes & Quinn, 2005), it often has a negative impact on health (Braun et al., 2009), subjective well-being (McPherson, Pentland, & McNaughton, 2000), and quality of life (Greenwood, Mackenzie, Wilson, & Cloud, 2009). Caregivers may even experience more distress than care-receivers (Badr, Acitelli, & Carmack-Taylor, 2007). Caregivers frequently report reducing their own hours of work (Carers UK, 2007) and financial difficulties (Jacobs, 1988). Accordingly, caregivers often have a significant stake in the DLA claim, because success increases formal support, thus reducing the demands on informal support.

Form-Filling: Translating and Transforming Effects

Forms are boundary objects because they exist in two or more social worlds (Bowker & Star, 2000; Star & Griesemer, 1989). Specifically, forms entail self-report information being produced in one context but then being interpreted and used in a different context. As information entered into a form moves from one context to another, it can have unexpected effects. Consider, for example, Garfinkel's (1984) analysis of the good reasons for keeping bad hospital records. Record keepers are aware of how the records might be used in the future (e.g., for an audit or a negligence case), and thus, what is "bad" record keeping in the immediate context might be "useful ambiguity" in a future context. Thus, form-filling, rather than mirroring reality, is a constructive process.

The constructive effects of form-filling, we propose, can be conceptualized as comprising two distinct types, namely, translating and transforming effects. Translating effects relate to the problems of moving meaning out of the social world being documented and into the social world of administration. In our research, translation effects relate to moving lived experiences of disability into bureaucratic indicators that facilitate resource allocation. Transforming effects refer to the way in which the act of form-filling requires form-fillers, not only to orient to an administrative, but to author themselves through that alien discourse. In our research, transformation effects are evident in the way that form-filling forces caregivers and care-receivers to write-up and author themselves and the minutiae of their relationship using the conceptualization of disability provided by the claim form.

First, let us consider the translation effects arising on the boundary between form-fillers and administrators. Forms are a peculiar technology of communication that enables information to move from the form-fillers to form-administrators. While prototypical human communication entails each party orienting to the orientation of the other party, addressing the specificity of the other (Gillespie & Cornish, 2014; Mead, 1934), forms entail a strikingly asymmetrical interaction (Frohlich, 1986). The form asks questions, makes assumptions, and puts the onus on the form-fillers to translate their own experiences into the discourse of the form. Rarely can the form-filler ask questions about the questions. Accordingly, uncertainty about the meaning of questions (van Oort et al., 2011), the frame of reference (Wagoner & Valsiner, 2005) and the context referred to (Mallinson, 2002) are widespread. Form-fillers often struggle to fit complex experiences and understandings into simple responses to ambiguous questions (Mallinson, 2002; McLean & Hoskin, 1998; Shweder, 2008). We conceptualize all of

these reported problems as translation effects because they pertain to problems of moving information from one social world into another via a form. Our first research question will further explore these translation effects:

> **Research Question 1:** How do claimants translate local understandings of disability and care into the language and assumptions of the claim form?

Second, let us consider the way in which forms can transform the way people think about themselves and their relationships. PwABI usually enlist the support of a caregiver to fill in the 55-page DLA claim form (Headway, 2012). However, getting PwABI and their main caregivers to jointly report on the disability and care needs is complex. First, PwABI may overestimate their own cognitive functioning (Schmitz, Rowley, Kawahara, & Johnson, 2006), and thus, caregivers tend to perceive greater levels of disability and care needs (e.g., Yeates, Henwood, Gracey, & Evans, 2007). Second, caregivers sometimes conceal the full extent of support provided to prevent the care-receiver feeling positioned as a burden (Moore & Gillespie, 2014; A. Power, 2008). Furthermore, denial is a common coping mechanism for both PwABI and caregivers (Ponsford, Sloan, & Snow, 1995). Making caregiver and care-receiver confront these issues is likely to change, or transform, the way each party thinks about themselves vis-à-vis each other.

We use the concept of positioning to conceptualize the transformative effects of form-filling. Positioning refers to the way in which people are located, described, and implied within communication (Davies & Harré, 1990); it is a micro-instance of identity constitution. The DLA claim form requires caregivers and care-receivers to articulate their relationship through the discourse of the form, and this entails positioning them vis-à-vis each other. For example, each claim of care provision potentially positions the care-receiver as a burden, and each claim of autonomy potentially positions the caregiver as unnecessary. The issue here is not the translation problem of adequately describing the care relationship within the form, but rather, the effects for participants of conceptualizing themselves and their relationship in the terms provided by the form. Our second research question further examines these transformative effects:

> **Research Question 2:** How does filling in the DLA application form transform the positioning of the caregiver and care-receiver?

Method

Previous methodological approaches to studying form-filling can be separated into sociological and psychological approaches (Mallinson, 2002). First, the early sociological research tended to focus on the forms themselves, such as the structure of the forms, how they travel between contexts, and what they enable different actors to do (e.g., Bowker & Star, 2000; Garfinkel, 1984). More recently, there has been a focus on the interactional process of form-filling itself (i.e., Campbell, 2001; Mallinson, 2002). Exemplary is the study by Swinglehurst, Roberts, and Greenhalgh (2010) who observed health professionals using electronic templates to guide consultations with the explicit aim of opening "the black box" of form-filling (p. 3). These sociological approaches have strong ecological validity, but, they have focused on form-filling as it is done by healthcare professionals with the client as a secondary actor.

Psychological research on form-filling has also been attempting to open a black box, but theirs is the black box of cognition. Accordingly, most of this research has used talk-aloud protocols (Ericsson & Simon, 1993) that entail individuals filling in forms while speaking out loud all accessible cognitions (e.g., French, Cooke, McLean, Williams, & Sutton, 2007; van Oort et al., 2011; Wagoner & Valsiner, 2005). Despite providing a valuable window on psychological processes, talk-aloud protocols have been criticized (Hayes, 1986). First, the connections between what is verbalized and the underlying cognitions are unclear. Second, the activity of talking aloud during a solitary task lacks ecological validity. Third, these studies assume that form-filling is an individual activity, thus overlooking the way in which form-fillers often enlist support. Thus, although being commendable for including a psychological level of analysis, these approaches have tended to lack ecological validity.

Our methodological approach combines the strengths of both sociological and psychological approaches. Building on the sociological literature, we will focus on the social interactions that naturally occur during form-filling; specifically, we will focus on the hitherto neglected interaction between caregivers and care-receivers. Building on the psychological literature, we will analyze the discussion between caregiver and care-receiver as if it were a talk-aloud protocol, for example, analyzing how participants interpreted specific questions.

Materials

The research used the U.K. Department of Work and Pensions DLA claim form (version DLA1A Adult November 2009). PwABI and their main informal caregivers worked together to complete part of the section titled "help with your care needs during the day" (pp. 16–28, Questions 35 to 48). We removed four questions due to ethical concerns, because they asked about sensitive issues, namely, toileting (Q36), showering (Q37), dressing (Q38), and eating (Q41). Remaining were nine questions: seven questions asking about getting

into and out of bed, moving around indoors, falling and stumbling, taking medicines, communicating, taking part in hobbies or interests, and cooking, and two questions asking about how often help is needed and whether someone is needed "to keep an eye on you." Eight of these nine questions had follow-up sub-questions.

Participants

Twenty-two dyads (*n* = 44) were recruited from U.K. Brain Injury Rehabilitation Facilities within the National Health Service (NHS; 15 dyads) and Headway (a charity helping people with brain injury) groups (7 dyads). For recruitment from the NHS, brain injury rehabilitation centers acted as gatekeepers, and supported us in identifying potential participants from records and sending them an information pack. For recruitment from Headway, information packs were distributed to groups in the United Kingdom.

Defining inclusion/exclusion criteria for people with a disability is complex (Ahmad, 2000). Rather than impose a definition on our participants, we allowed the DLA form to do the classification for us. We recruited 22 PwABI (and their main caregivers) who were two or more years post ABI, aged 16 to 70, without psychiatric co-morbidity and no known history of alcohol or substance abuse. The mean age of participants with ABI was 47.18 years (*SD* = 12.17 years, range = 19–68 years) and the mean number of years living with ABI was 7.37 years (*SD* = 10.73 years, range = 2–45 years).

Caregivers were operationalized as the main persons providing informal care to the participant with ABI. Eighteen caregivers were female, and four were male (82% female, 18% male). This imbalance in our sample is in line with national (Health & Social Care Information Centre, 2010) and international (Pinquart & Sörensen, 2006) trends, which document that women are more likely to be primary caregivers. Ten caregivers were spouses (45%), 9 were parents (41%), 2 were siblings (9%), and 1 was a co-habiting friend (5%). Of the caregivers, 45% had some employment. Caregivers' mean age was 57.05 years (*SD* = 11.75 years, range = 32–87 years).

Ethical Considerations

Ethical approval was obtained from the U.K. National Research Ethics Service (09/S0501/26). Potential ethical concerns were addressed in five ways. First, we removed four questions from the DLA claim form because they were too intrusive (see "Materials" section above). Second, we used the following procedure to inform participants about the study and obtain consent: Potential participants received information packs that provided information about the research and invited dyads to discuss participating in the research; if both parties were interested in participating, they contacted the research team using a tear-out slip from the information pack; we then did a home visit to explain the research and consent procedure to both parties, consent forms were then given to the participants, and the research began on a second visit. Third, during the form-filling task, participants were reminded that they could stop at any time or skip certain questions. Fourth, after the form-filling task, participants were debriefed with a discussion of the complexities of form-filling, their experience of the task, and their experiences of completing the DLA form outside the research setting, as well as answering any questions participants had about the task. Finally, some details in the excerpts presented have been altered so as to preserve the anonymity of the participants.

Procedure

The data were collected by H.M. in participants' homes. An initial home visit was used to explain the research and introduce the informed consent forms. Participants filled out the DLA form on a second home visit. One copy of the DLA form and two pens were placed in front of the participants and they were asked to fill in the form. The dyads were video-recorded completing the task. While dyads completed the form, the researcher remained in the room reading. The average time to complete the task was just more than 15 minutes.

Data and Analysis

The procedure resulted in two datasets: first, the responses recorded on the DLA form and, second, the video recordings of the interactions that produced those responses. The video data were transcribed and analyzed alongside the written responses to the DLA form.

To examine how the DLA form translated and transformed care, we decided to focus upon items in the form that produced discussion and especially disagreements. We reasoned that discussion and disagreements indicate that the form is active, either that it is misaligned with participants' experience (a translation problem) or that the form is intervening in the care relationship (a transformation problem). Accordingly, we pursued a two-step analysis.

The first step was descriptive, namely, to identify DLA items that produced discussion and especially disagreement. Accordingly, operating at the level of dyads, we examined each question in turn and systematically coded: the answer (each question begins with a yes / no component), whether there was discussion (defined as three or more conversational turns engaging with the question

topic), and whether there was explicit disagreement (indicated by words such as "no" and "but"). When there was explicit disagreement, we also coded what the disagreement was about and the standpoints of the caregiver and care-receiver.

The second step was interpretative. We aimed to use the points of tension identified in the descriptive analysis to open up the black box of form-filling by analyzing the interaction sequences in which participants were struggling with the form. Our process of interpretation entailed moving back and forth between a problematic, our conceptualization of the literature, and the video data (Weston et al., 2001). The problematic that required interpretation was the widespread disagreement observed in the form-filling exercise (26% of questions led to disagreement). Our conceptual framework, informed by the literature, was the distinction between translations (i.e., ambiguous questions, shifting frames of reference, and contextual factors) and transformations (i.e., positioning). This iterative interpretive process led us to identify three translation effects and two transformation effects in the video data, and reporting these findings is at the heart of our empirical contribution.

Analysis

Caregivers were slightly more inclined to pick up the form (54.54% vs. 40.9%) and thus take control of writing the answers. As the task proceeded, caregivers increasingly took over the task. The caregivers tended to decide what information was required, that a response was sufficient, and when to move on to the next question.

Table 1 reports the questions asked (excluding sub-questions), the responses ("yes" indicates a functional disability), whether the dyad discussed the question (three or more conversational turns), and whether there was any explicit disagreement (statements such as "no" or "I disagree"). All dyads reported some difficulty in daily function. Fifty-four percent (*n* = 107) of the 198 questions (9 main questions multiplied by 22 dyads) provoked discussion, and 26.26% (*n* = 52) of the questions produced explicit disagreements. The disagreements were usually between the caregiver and care-receiver, but, this was often also in the context of one party disagreeing with the form (i.e., the question being asked). Eighty-eight percent of the questions with explicit disagreement entailed the person with ABI reporting a lower level of disability than the caregiver. The mean number of disagreements was 2.36. Nineteen of the 22 dyads disagreed on at least one question, and 1 dyad disagreed on eight of the nine questions.

The first step of the analysis showed that the responses that the DLA form collects, rather than being self-evident facts, are often contested and uncertain. The next step in

our analysis was to probe deeper into participants' discussions, to interpret the underlying process of construction. Our iterative, and theoretically informed, analysis identified contestations and uncertainties as stemming from three translation problems and two transformation problems. In the following, we explore these five problems in turn.

Translating Ambiguous Questions Into Definitive Responses

Participants explicitly referred to ambiguity in the questions 28 times, most frequently in relation to Question 40: "Do you fall or stumble as a result of your illness or disability?" As one participant with ABI (age 50–59) said, "I can't answer that 'do I fall or stumble?' because I stumble all the time but I don't fall." Often the dyads did not explicitly mention ambiguities in the question, but nevertheless, their discussion was born out of such ambiguity, as the following excerpt demonstrates:

Caregiver: [Reads out] "When did you last fall or stumble?"
PwABI: Erm about 2 years ago
Caregiver: [Interrupts, sounding exasperated] No it's not, you stumble every, near enough every day! If you go on a wobbly surface or anything
PwABI: Oh yeah but not a fall fall. A fall fall is
Caregiver: No, when did you last fall *or stumble* [emphasis]? . . . So it can be 4 or 5 times in a week
PwABI: I actually wouldn't agree with that, I would probably go for one in a week
Caregiver: No
PwABI: If I'm out of my comfort zone
Caregiver: You can stand through there [points] and you suddenly say "oh I've just had a wobble" [PwABI laughs]
PwABI: Yeah but I don't do it 4 or 5 times a week. I wouldn't agree with that. I would actually say probably, definitely once a week
Caregiver: [puts down pen and picks up water, says in a soft serious voice] Oh no [name of PwABI], its more than that lovey
PwABI: Is it?
Caregiver: Uh-huh
PwABI: I don't really
Caregiver: Remember it's me who's with you sweetheart [picks up pen, writes that the last fall or stumble was "yesterday" and that there are 15/20 such incidents per month]
(Mother, age 60–69, caring for her daughter, age 30–39)

The participant with ABI states that it has been 2 years since her last fall or stumble whereas her mother argues that it happens daily. The mother focuses on the word "stumble" and unusual environments such as "wobbly" floors, whereas the daughter with ABI focuses on the word *fall*, routine activities, and familiar environments.

Table 1. Overview of Questions and Dyads' Responses.

Questions	"Yes"	Discuss	Disagree
Q35. Do you usually have difficulty or do you need help getting out of bed in the morning or getting into bed at night?	3 (14%)	7 (32%)	2 (9%)
Q39. Do you usually have difficulty or do you need help moving around indoors?	8 (36%)	11 (50%)	4 (18%)
Q40. Do you fall or stumble because of your illness or disabilities?	11 (50%)	16 (73%)	7 (32%)
Q42. Do you usually have difficulty or do you need help with taking your medicines or with your medical treatment?	5 (23%)	12 (55%)	7 (32%)
Q43. Do you usually need help from another person to communicate with other people?	14 (64%)	16 (73%)	11 (50%)
Q44. Do you usually need help from another person to actively take part in hobbies, interests, social or religious activities?	12 (55%)	14 (64%)	6 (28%)
Q45. How many days a week do you have difficulty or need help with the care needs you have told us about?	12 (55%)	7 (32%)	3 (14%)
Q46. Do you usually need someone to keep an eye on you?	7 (32%)	11 (50%)	7 (31%)
Q48. Would you have difficulty preparing and cooking a main meal for yourself?	14 (64%)	13 (59%)	5 (23%)
Total	86 (43%)	107 (54%)	52 (26%)

Although the phrase *fall or stumble* is a particularly egregious case of ambiguity, the phenomenon was widespread. For example, the word *stumble*, by itself, had ambiguous meaning. Consider the following excerpts: "it's [the question] a difficult one because he doesn't stumble much but he can be unsteady" (wife, age 50–59, caring for her husband, age 60–69), "well I think it's been a stumble, [to researcher] like more of an accident than just a dizzy spell or something like that" (father, age 70–79, caring for his daughter, age 40–49), and "I don't know what to put here, [to researcher] sometimes his leg goes into a spasm" (wife, age 50–59, caring for her husband, age 50–59). These findings, about ambiguous phrasing, support previous research (Mallinson, 2002; Shweder, 2008). The key issue, we argue, is participants struggling to translate their experience of unsteadiness, dizziness, and spasms into the form's terminology of "stumbles."

Questions always entail frames of reference (Linell, 2009; Wagoner & Valsiner, 2005), and ambiguities were also evident in this regard. For example, should participants answer the questions based on the restricted activities that the person with ABI engages in or based on the activities that the person with ABI would like to do? Such ambiguity is evident in the following exchange:

> Caregiver: Right an odd question, [reading aloud] "your care needs during the day continued. How many days a week do you have difficulty or need help with the care needs you have told us about?"
> PwABI: Well the answer is zero because I don't do them [laughs]
> Caregiver: Well yes, but I think you are supposed to [laugh] answer as if you do
> (sister, age 40–49, caring for her brother, age 50–59)

The brother with ABI states that there are "zero" days a week when he needs help because he avoids everything

outside of his ability. As his sister later summarized, "you don't do the things that cause you problems." Should he answer the question "as if" he did everything he wanted to? For example, what does "no" to Question 40 ("fall or stumble") mean? "No" could mean that falling or stumbling is not a problem. Or, it could mean that the caregiver has been exceptionally active preventing falls and stumbles. Or, it might be that falling and stumbling is such a major problem that the person with ABI is in a wheelchair to prevent falling and stumbling. That is to say, uncertainty about the frame of reference makes translating the answer "no" impossible.

Translating Contextual Variability Into Apparent Consistency

The psychological literature on questionnaires has long established that ambiguous questions and uncertain frames of reference can lead to strikingly divergent interpretations and thus responses (Rosenthal, 1976). The assumption has tended to be that further refinement can lead to unambiguous questions (Stone, 1993). However, we suggest that there is a more fundamental translation problem, namely, disability and care can never be shorn of contextual variability (Mallinson, 2002).

The day-to-day experience of disability is rarely clearcut or categorical. Participants with ABI mentioned the disability waxing and waning, having good and bad days. They mentioned being relatively independent at home, but becoming much more dependent when in unfamiliar environments, engaging in unfamiliar activities, or meeting new people. Not only do PwABI adapt to their familiar environments, but home environments, for example, are often adapted to the person with ABI (Chan, Campo, Estève, & Fourniols, 2009). We can illustrate this contextual variability with the first excerpt above, in which the

daughter with ABI argues with her mother about the extent to which she "falls or stumbles." The debate hinges upon the context being discussed: The daughter emphasizes activities that are within her "comfort zone" whereas her mother focuses on more unusual contexts. The daughter is inclined to discount the more unusual contexts because they are optional; she puts herself in these more challenging contexts. Thus, not only does her disability, and thus care needs, vary between contexts but, also, the extent to which it varies is a function of the risks that she *chooses* to take.

To what extent can disability and care be translated into a standardized grid with quantified components? The purpose of the DLA form is to abstract disability and care from specific contexts and relationships, so that comparisons can be made between care relationships, and thus money can be disbursed according to ostensibly simple facts. The problem is that the abundance of human experience, the rich complexity of our relational and contextual being, will always overflow any attempts at final description or fixation (Feyerabend, 2001; Furman, 2006). This impossibility of perfectly categorizing human experience does not mean that the effort should be abandoned; indeed, in the present case, it is being used for the laudable aim of ensuring that a financial resource is distributed equitably. However, the fundamental limitation of the approach must be recognized, namely, forcing contextual complexity into a quantitative grid will tend to conceal complexities (Townley, 1993). Moreover, such an approach tends to affirm itself, precisely because complexities that do not fit the scheme are, by virtue of not being in the scheme, excluded from further consideration.

Translating Local Perspectives Into a View From Nowhere

The third and final translation problem stems from the perspectival nature of the social world. Ambiguities in either the questions or the phenomena of living with ABI cannot explain the observed pattern of disagreements. Specifically, why did 88% of the disagreements entail participants with ABI arguing for a lower level of disability than the caregiver? We suspect that the ambiguities discussed above are not only the source of disagreements but also opportunities for participants to voice different understandings of the disability and care provision. Research has shown that caregivers often conceal the burden of care to protect the self-esteem of the care-receiver and encourage feelings of independence (A. Power, 2008) and that this can lead to the care-receivers feeling more independent than their caregivers perceive them to be (Moore & Gillespie, 2014). As an example,

consider the following excerpt discussing a sub-component of Question 43, about using the telephone:

> Caregiver: Do you have difficulty on the phone?
> PwABI: No, no
> Caregiver: Well, you just don't answer it! [laughs and ticks "yes," there is a problem with communicating on the phone]
> (father, age 70–79, caring for his daughter, age 40–49)

The daughter with ABI reports no difficulty using the phone. Her father disagrees, arguing that she "just" ignores the phone, whereas he has to deal with it. This is similar to comment of the caregiver in the first excerpt, who says "Remember it's me who's with you sweetheart," implying that she sees the care needs more clearly than the care-receiver. In both cases, the answers that the participants with ABI give, to questions that the claim form addresses to them, are dismissed. That they may not be concerned about stumbling or missing telephone calls does not find a place in the form-filling. Specifically, the participants with ABI are positioned by the claim form as having a cognitive disability, which, in turn, facilitates the caregivers dismissing their answers on the implicit assumption that they lack insight into the support that they need or want.

While there is research purporting to show that PwABI often lack insight into their own disability (Prigatano, Altman, & O'Brien, 1990; Schmitz et al., 2006), an alternative explanation is that caregivers and care-receivers are exposed to divergent streams of information (Nisbett, Caputo, Legant, & Marecek, 1973). While caregivers have privileged access to information about care provision, care-receivers have privileged access to information about independent activity. Whereas caregivers spoke about working behind the scenes to provide care, care-receivers would often refer to their independence when the caregiver was not present. Such divergent flows of information create divergences of perspective (Farr & Anderson, 1983). Thus, maybe neither caregivers nor care-receivers see the whole of the disability and care needs. Caregivers are not always present, and thus they have an incomplete understanding, but equally, PwABI may lack insight or may not perceive all support and care work, much of which occurs outside of their field of view.

The DLA claim form not only strips away the contextual nature of care but also elides the plurality of interpretations about the care. The claim form forces translation into a single monological perspective. Yet, such a translation is artificial because there is considerable evidence demonstrating that caregivers and care-receivers view the same care activities differently (Gillespie, Murphy, & Place, 2010; Moore & Gillespie, 2014). However, this abundance of the pluralistic social world (Feyerabend,

2001; Furman, 2006) finds no place in a claim form that purports to document social life as if with a view from nowhere.

Transforming: Care-Receivers Positioned as Dependent

Beyond the translation problems of how to document the contextual and perspectival complexity of disability and care, form-filling also produces problems due to transformation effects. The process of form-filling is an intervention in the care relationship, forcing the dyad to confront certain issues and position each other in the terms provided by the form. Specifically, participants with ABI often resisted the way that the DLA form positioned them as dependent, and even a burden. Consider the following, quite typical, excerpt. The participant with ABI is arguing that he does not need much "help from another person to actively take part in hobbies, interests, social or religious activities" (Question 44):

> Caregiver: So taking it right back to basics, like working the TV, working the Zeppelin [iPod music player], working the CD players
> PwABI: If it's a new, erm, like the new telly. I think I've gotta ask what to press. But once that's. I mean that's there and
> Caregiver: I know, I know
> PwABI: If it's a complex piece of equipment.
> Caregiver: Uhum
> PwABI: But I mean I can go from the zeppelin there to that one and then through to the kitchen. That's 3 different things that I'm comfortable with.
> Caregiver: Are you gonna record a program for me tonight?
> PwABI: Listen, even before [caregiver laughs], if you're, the change of equipment is quite. I think not just me, most people find it a bit complex and that. Old people like me. [Caregiver writes "needs help with new electronic equipment" and "most days, few minutes each time"]
> (wife, age 50–59, caring for her husband, age 60–69)

This disagreement focuses on the extent to which the husband with ABI can use the TV and media player. The caregiver points to his inability to record a TV program as indicating disability. He resists, arguing that "most people find it a bit complex." Again, ambiguity in the question facilitates disagreements to emerge, and, again, we see the caregiver challenge the validity of the perspective of the person with ABI. However, our current question is, "Why is the participant with ABI so keen to emphasize his ability?"

No single excerpt from our data can capture the feelings that participants with ABI experienced through the cumulative interrogation of their disability. As Table 1 shows, participants answered "yes" to 43% of the questions. Each

"yes" was followed up by several sub-questions. Thus, question by question, sub-question by sub-question, PwABI had to document the minutiae of their dependency. Receiving daily care can undermine identity (Coeling, Biordi, & Theis, 2003), and successful care relationships often entail a degree of identity protection (Moore & Gillespie, 2014). The DLA claim form, however, undermines such efforts, forcing an explicit and consensual documenting of potentially humiliating care needs.

The resistance of the participants with ABI seems to have three layers. First, there is resistance to the stigma of repeatedly being positioned as unable to do basic tasks (Goffman, 1963). Second, there is resistance to the caregivers who are repeatedly dismissing their answers. Third, there might also be resistance to the implication that they require a lot of help from loved ones (Clare & Shakespeare, 2004). Being positioned as dependent upon one's closest companions can undermine the representation of that relationship, potentially transforming the feeling of friendship into the feeling of being a burden.

The DLA form itself is an actor (Swinglehurst, Greenhalgh, & Roberts, 2012); it is repeatedly positioning the care-receiver as dependent upon the caregiver, and thus transforming the care relationship. By translating care into dependency and translating relationship into asymmetry, the DLA claim form transforms the relationship, undermining the status of the care-receiver within what is likely their most important social relationship. Thus, we suggest, PwABI are often resisting not only the way in which the DLA form positions them (i.e., as disabled) but also how it reframes their care relationship as a relationship of dependency and burden.

Transforming: Caregivers Positioned as Agents of the Form

Finally, let us turn to the caregivers. Why did they emphasize the extent of disability in 88% of the disagreements? One possibility is that they were orienting to the Department of Work and Pensions who administer the DLA funding. Consider the following excerpt from a dyad disagreeing about the amount of help required to "actively take part in hobbies, interests, social or religious activities" (Question 44):

> PwABI: That's another activity, is my groups. [Turning to the researcher] Mum and I also teach horse riding on a Tuesday. They pick me up to take me there
> Caregiver: Aye but that's not, that's
> PwABI: It is an activity, teaching, cos it's what I used to do before
> Caregiver: Aye, I know, but you can't put that down on your DLA form. [Caregiver looks at researcher and laughs]
> PwABI: This isn't a DLA form, it's

Caregiver: It is your DLA form
PwABI: This is a, getting recorded for the University
Caregiver: Yes, I know but it's [starts reading what has been written, mumbling], 2 hours at a time
PwABI: I don't get paid for it, I do it because I'm helping somebody. The DLA people don't need to worry about these sorts of things. Going to my blind group is another thing, once a month, and also [event] on a Monday night. [Caregiver writes "attending blind groups"]. What else do I do? Not a whole lot actually. And then if I'm going to ask for other things, like if I'm going to visit somebody
Caregiver: This is enough, the space is running out
(mother, age 60–69, caring for her daughter, age 30–39)

Here again we can see the person with ABI resisting being positioned as dependent. The PwABI defiantly emphasizes her ability and independence to both her mother and the researcher by mentioning that she assists in teaching horse riding. The caregiver, however, is concerned that this might give the appearance that her daughter is sufficiently able to live without a disability benefit. A loss of financial support would create an additional burden for the mother as the primary caregiver. The daughter, however, is correct; they are not submitting a "real" DLA application. That participants, such as this caregiver, approached our task as if it were a real DLA application indicates the validity of the data. Indeed, despite her daughter's insistence, because the mother controlled the pen, horse riding never appeared in the completed form.

Alongside removing information that might weaken the claim, caregivers were also concerned whether they had omitted details that might strengthen the claim. Consider the following dyad discussing Question 46: "Do you usually need someone to keep an eye on you?" The pair have ticked "yes" and they are discussing the open-ended sub-question: "Is there anything else you want to tell us about the supervision you need from another person?"

Caregiver: Do you need any other [supervision], do you wanna expand on that?
PwABI: What do you think?
Caregiver: Is this where the money is? Is this the fundamental one?
(Caregiver, age 50–59, caring for her friend, age 50–59)

The caregiver suggests that some of the questions are "fundamental" to unlocking "the money." Specifically, she suspects that not filling in the extra details for the open-ended questions might indicate a lack of genuine need, and accordingly, she presses the care-receiver for additional information. Arguably, this is an instance of the form-fillers attempting to exert agency over the form (Bonnin, 2014).

It is unsurprising that caregivers are particularly concerned with obtaining the disability benefit, as they are usually responsible for financial issues and frequently have financial worries (Ponsford et al., 1995). Moreover, caregivers benefit from their partner with ABI receiving benefits because the resultant financial support lightens the responsibilities of the main caregiver.

It would be, however, overly simplistic to portray PwABI as locked in a clash of perspectives with the caregivers, focusing on identity and money, respectively. Not only are PwABI aware of the importance of obtaining financial support (e.g., in the previous excerpt) but also the caregivers are often painfully aware of the negative positioning of their partner with ABI. The boundaries of self and other are not so rigid; in such a close relationship, the identity of the caregiver is often entangled with the identity of the care-receiver (Goffman, 1963).

As poorly as the DLA form positions PwABI, arguably, it creates an even more difficult position for caregivers. Although the form-filling may undermine care-receivers' feelings of independence, and even make care-receivers feel like a burden, caregivers are in the unenviable position of acting as agents of the claim form; reading the questions, seeking the answers, and translating the minutiae of care needs into the discourse provided by the claim form. The caregivers enact the governmentality of a petty bureaucrat, diligently documenting the intimate details of care. There is a "rerouting of ruling power" (Campbell, 2001, p. 249), which now runs through the care relationship and especially the caregiver. However, the caregivers carry out their task with knowledge of the potentially undermining effects of these actions. Thus, the claim form traps caregivers: If they resist the way it positions their partner or their relationship, by not documenting the full extent of care needs, then they reduce the chances of obtaining the benefit, which, in turn, will increase the dependency of the care-receiver. Equally, attempts at agency vis-à-vis the claim form (i.e., the form-fillers in the previous excerpt wondering "where the money is") come at the expense of potentially undermining the care-receivers' self-perception as independent.

The extent of the dilemma created for caregivers was evident in their responses to the DLA claim form. For example, one caregiver (age 50–59) exclaimed "Oh God" when she saw the claim form, during the task she exclaimed how "depressing" it was, asking "how much of this have we got to do?" and, on completion of the task, she erupted "Yes!" Another caregiver (age 40–49) upon seeing the form crystallized the prevalent emotional response, stating, "I hate DLA forms." These sentiments, we suspect, arise out of the fact that it is almost impossible for caregivers to come away from the form-filling with both a positive conception of the care relationship

and financial support. Or, put the other way around, caregivers' striving to obtain financial support entails transforming and undermining the care relationship.

Discussion

The reported research has found that the DLA application form does not document self-evident facts, but rather it is a form that "gives form" to disability and care in two ways. First, it translates experiences of care, stripping away complexities such as ambiguity, contextual variability, and divergences of perspective. Second, it transforms the phenomena, positioning the care-receiver as dependent and positioning the caregiver as an agent of the form, encouraging claimants to characterize their relationship as a burden. These translations and transformations were evident in the discomfort, disagreement, and open resistance that both caregivers and care-receivers had toward questions in the DLA form. The following sections discuss the practical and theoretical implications of these findings.

Practical Contributions and the Future of the DLA Form

Our findings support the established importance of avoiding questions that contain multiple elements (Oppenheim, 2000), such as "fall" and "stumble," and clarifying the frame of reference (Mallinson, 2002; McLean & Hoskin, 1998). For example, questions should ask about what happens *with* current informal care provision and what would happen *without* any informal care provision. Using examples and maybe even images would also reduce the ambiguity and increase the accessibility of the form. These issues are particularly important for a form, such as the DLA form, that people with cognitive impairments will use (Headway, 2012).

However, clear questions and fixed frames of reference will be insufficient to dispel the translation problems. Social reality is pluralistic (James, 1907). Neither caregiver nor care-receiver has access to the complete social phenomenon of care (Moore & Gillespie, 2014). We found that caregivers emphasize care provision whereas care-receivers emphasize independence. Moreover, it might be that neither side is right, and that forcing a translation into a single account is fundamentally misleading. This finding has huge implications for the proposed changes to the DLA benefit.

The DLA benefit scheme is scheduled to be gradually replaced from 2015 by a new benefit, titled a Personal Independence Payment. This new scheme proposes a "more objective assessment" (Department for Work and Pensions, 2013a, p. 4). Claimants will still complete a self-report questionnaire, but there will be greater use of face-to-face interviews. Claimants will be allowed to bring companions to the interview, but, the focus will be "predominantly" on the claimant and their circumstances "and not the companion's views on these" (p. 37). However, the basis on which this approach is "more objective" is not clear. The present research leads us to project that the new scheme will lead to significantly less evidence of disability, and thus provide an evidence-based rationale to reducing welfare payments (Campbell, 2001). First, the socially charged interview, which will cover topics that we felt were too intrusive to be included in our research, might exacerbate the tendency of care-receivers to self-present as independent. Second, the presence of the interviewer will likely inhibit caregivers from arguing up the care needs to avoid stigmatizing their partner and/or appearing to be domineering. Third, because the procedure privileges the care-receivers' accounts, it will tend to produce a much more optimistic assessment of care needs, one which silences the voice of the one who actually provides the informal care. Arguably, if care-receivers are to obtain the benefits to which they are entitled through the new Personal Independence Payment scheme, they will need to fully subordinate their identity to their disability.

Theoretical Contributions

Our contribution has been to use the distinction between translating effects and transforming effects to conceptualize the problems that participants encounter when form-filling. The data show how form-filling both translates and transforms the phenomena that are purportedly being documented. We conceptualized forms as boundary objects, that is, objects that operate in more than one social world (Star & Griesemer, 1989). The DLA claim form creates and moves information from the social world of informal caregiving to the social world of administration. It requires claimants to translate their local experiences of care into a format that is digestible by the administrative procedures. Moreover, the form-filling also transforms the local relationship by making claimants author themselves and their relationship through the generic, disability-centric, and resource-focused frame of the claim form.

The translation process is instigated and guided by the DLA claim form; yet, the form itself operates in the background, enlisting claimants to carry out the actual work of translation. The interaction is similar to an interrogation; the form asks the questions and answers must be on the terms provided by the form (McLean & Hoskin, 1998). The claim form does not allow for the everyday conversational processes of calibration and repair (Schegloff, 1992). It puts the onus on claimants to fit their own experiences into the terminology of the form, and claimants

become complicit because they try to fill in the form according to what they think the administration is looking for.

The outcome of the translation process is the stripping away of local context, such as, environmental and social supports, secondary conditions, avoidance of difficult tasks, and the waxing and waning of the disability itself. In this sense, the claim form has selective hearing, tending only to hear what it expects. It easily assimilates what is expected, but has limited means for accommodating unexpected information, new frames of reference, or new concerns. This selective hearing, one could argue, is a deliberate ignorance (McGoey, 2007). Indeed, the aim of the DLA claim form process is to make comparisons between idiosyncratic care relationships on common generic criteria, that is, to strip away contextual factors.

The transformative effects of the claim form, observed in the present research, enrich previous descriptions of forms as social actors (Cooren, 2004) and vehicles of power (Campbell, 2001). Previous research has shown how forms can structure interviews and consultations, select information, and focus attention on certain issues (Komter, 2006; Swinglehurst et al., 2012). The present findings show that the social action of forms also extends into social relationships. The DLA claim form creates an impossible choice: Either claimants can bolster the care-receiver's identity as independent and be unlikely to receive financial support, or, they can undermine the care-receiver's identity by emphasizing the disability and thus increase the chances of receiving financial support. Moreover, in subjugating themselves to the claim form, form-fillers learn to characterize themselves and their relationship in terms of dependency. Arguably, the power-laden effects of the claim form are visible in the extent of the claimants' vehement resistance to the way in which the claim form questions positioned them and their relationship.

Qualitative research is particularly suited to examining the translation and transformation effects of forms. Qualitative research should engage with the institutional and material world (Sandelowski, 2002), and, we suggest, it should examine the processes of quantification that are spreading throughout our institutions. The key to observing these processes of quantification, we have shown, is not only to examine the responses contained within the forms but also to extend the analysis to a qualitative examination of the interaction surrounding the form-filling. Filling in a disability claim form lends itself to such an analysis because it is usually done by dyads. The relevant data are not in the form itself, because the form is blind to its own translation and transformation effects. The crucial data are, so to speak, in the offcuts from this Procrustean bed, offcuts that reveal the limitations of the bed itself.

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