



Problematising carer identification: A narrative study with older partner's providing end-of-life care



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ABSTRACT

Internationally health and social care policies have increasingly promoted carer selfidentification as the best way to target and support people in caring roles. There has been remarkably little research concerning how people adopt the identity. This paper explores the carer identification practices of older partners providing end-of-life care. A narrative interview study comprising 41 interviews with 20 participants from 17 couples were conducted between in August 2018–August 2019 in the United Kingdom. This paper coins the term carering to denote the co-constructive practices of policy makers, researchers and broader cultural narratives calling forth the carer identity and the unfolding practices of people interacting with the carer identity in relation to their sense of self. Through three narrative case studies, this paper captures the diversity of older partners carering with three categories defined as engaged, ambivalent and disengaged carering. The carer identity was only taken-up when participants felt that the qualities assigned to being a carer, such as experiencing social isolation and providing 24/7 care, reflected their own personal experience. Given that not every older partner wants to, or will, self-identify as a carer, this paper suggests that carer selfidentification should not be the only strategy to identify and support people involved in caring. Qualitative health researchers also need to be reflexive in their use of the carer identity when studying caring-related topics.

1. Background

The search for carers is on. Internationally health and social care policies have increasingly promoted carer self-identification as the best way to target and support people in caring roles (Ministry of Social Development., 2019; NHS England., 2019; Victoria State Government., 2018). Carers in the United Kingdom (UK) are widely defined in policy as “lay people in a close and supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management” (NICE., 2004). The carer identity was originally popularised by grassroots UK-based feminist activists and scholars in the 1960–70s to petition for the financial support of mid-life women caring for their older parents (Barnes, 2011; Yeandle, 2016). As a collective identity, it was also designed to foster solidarity amongst those in caring roles irrespective of care recipient's age, disease or disability status (Barnes, 2011). The carers' rights movement has tied into wider contemporary discussions about shifting care for older people from

institutions into the community (Heaton, 1999). Since the mid-1990s carers' rights have been increasingly legislated for in the UK (HM Government., 1995, 2004, 2014) and have become a prominent pillar of UK palliative care policy (National Palliative and End of Life Care Partnership., 2015; NICE., 2019). In the UK, the declaration of a carer identity is the necessary first step to claim particular entitlements such as the carers allowance; to access many formal support services; and is also the basis of membership for many voluntary carer support groups (Carers Trust., 2018).

Despite the widespread promotion of the carer identity by policy-makers, health and social care professionals and grass-roots organisations, there has been remarkably little research concerning how individuals come to adopt this identity (Eifert, Adams, Dudley, & Perko, 2015; Funk, 2019). A recent review of caregiver identity among adults with chronic disease identified 23 articles presenting a range of explanations for adopting the identity (Eifert et al., 2015). One explanation is that due to “role engulfment” individuals no longer have capacity to

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sustain other identities outside of caring and therefore become a carer (Skaff, 1992). Another explanation suggests that the carer identity emerges with the loss of a shared identity, lifestyle and reciprocity within the relationship, typically due to the effects of cognitive impairment (Coeling, Biordi, & Theis, 2004; Hayes, Boylstein, & Zimmerman, 2009; Lennaerts-Kats et al., 2020). A third explanation suggests that culturally normative expectations placed on families, particularly women, to provide care naturalises the adoption of the identity (Hughes, Locock, & Ziebland, 2013). Other studies indicate that familial expectations to provide care may impact individual's rejection of the identity. Instead, they may prefer their familial identity as a wife or daughter (Molyneaux, Simpson, & Murray, 2011; Turner et al., 2016) or seek to maintain the dignity of their family member and therefore avoid introducing new hierarchies, denoted by carer/cared-for (Henderson, 2001). To this end, Knowles and colleagues suggest that family and friends supporting people with long term conditions (LTC) did not identify as carers to avoid undermining the independence of the "care recipient", who was attempting to "self-manage" their conditions in line with policy directives (Knowles et al., 2016).

Amidst the range of reasons for adopting or rejecting the carer identity, some consistent qualities have become apparent about the carer identity. First, the carer identity always emerges and is shaped by a range of pre-existing social identities such as relational status, situational identities (worker or retiree) and structural identities such as gender, ethnicity and class (Eifert et al., 2015). Second, the carer identity does not map directly onto levels or types of caring activities. Studies have highlighted how bereaved people may continue to refer to themselves as carers even after the cessation of caring activities (Larkin, 2009). As highlighted above, some people may be involved in physical and/or emotional care tasks yet refuse the identity. Strengthening this point, a recent study with 18 family and friends of people with Mild Cognitive Impairment found that only 3/18 participants identified as carers (Beatie et al., 2021). Participants instead overwhelmingly occupied a "liminal" category where they were unsure about the norms associated with the carer identity whilst also feeling that the current needs of their family member/friend were not severe enough yet to warrant seeing themselves as carers (Beatie et al., 2021). This study among others contributes to the growing scholarly calls to re-consider the prevailing logic that encouraging people to develop the carer identity is the best way to facilitate their support (Funk, 2019). This concern is also supported by evidence that people who identify as carers tend to subordinate their own needs, indicating that identifying with the identity does not necessitate positive outcomes (Broady, 2015; Carduff et al., 2014).

This paradigm shift has important methodological implications for researchers given that for the most part researchers continue to assign the carer identity to their participants unreflexively. For example, in a recent systematic review of studies about oldest-old spouses providing end-of-life care, 15/19 categorised their participants as carers on the basis of the care-recipient's condition (Morgan, Bharmal, Duschinsky, R., & Beatie et al., 2021). The remaining four studies required participants to self-identify as carers to participate in the research (Morgan, Bharmal, Duschinsky, & Barclay, 2020). Utilising the homogeneity offered by the carer identity, researchers have successfully brought to light the adverse psychological and physical impacts of providing care over the last 40 years (Dassel & Carr, 2016; Pinquart & Sörensen, 2003; Schulz & Beach, 1999). This research has helped to sustain carers' rights as a political issue (Barnes, 2011; Larkin, Henwood, & Milne & Hatzidimitriadou, 2003). Nevertheless, Trevor Adams has aptly acknowledged that much of the scholarship on informal care has become overly reliant on the "analyst's accounts" of the carer identity and a focus on "describing carers' inner mental states" (Adams, 2002) (p. 251).

The two prevailing theories underpinning carer identity development in the current literature are ripe for such critiques. Caregiver Identity Theory, for example, posits that the carer identity a dynamic process that intensifies over time in relation to the demands of their role, as well as being shaped by familial norms (Montgomery & Kosloski, 2009). This

theory has been critiqued for presenting the carer identity in an overly deterministic manner, which as acknowledged above, does not fit with empirical findings that present a more inconsistent picture (Beatie et al., 2021; Knowles et al., 2016).

Positioning Theory, on the other hand, has become increasingly popular in this field of study as it presents a more fluid, situational view of the carer identity by emphasizing how individuals have a repertoire of positions that become more or less salient in particular contexts (Harre, Moghaddan, Cairnie, Rothbart, & Sabat, 2009; Knowles et al., 2016; O'Connor, 2007). Based in the intellectual tradition of Speech Act Theory, Positioning Theory hinges on the account of the "knowing subject" whose actions are shaped by discernible intentions (Austin, 1975). Studies using Positioning Theory often reinscribe an individualistic, cognitive model of carer identification. This is epitomized in the current scholarly definition of carer identity as a "cognitive construction" that serves as an "interpretive frame and sets of standards used by individuals to make sense of personal experiences, actions, and emotions" (Funk, 2019) (p. 14). This theory also contributes to the persistent gap in the literature around the impact of external interactions in shaping the carer identity (Funk, 2019; O'Connor, 2007). Viewing the carer identity as a primarily cognitive process also runs counter to current sociological thinking about identity as no longer a "theory of the knowing subject, but rather a theory of discursive practice" (Foucault, 1977; Hall, 2000) (p. 6).

This paper aims to further the conceptualisation of the carer identity by deepening the account of carer identification as a discursive practice. This paper coins the term *carering* to denote the co-constructive practices of policy-makers, researchers and broader cultural narratives involved in calling forth the carer identity *and* the unfolding practices of people interacting with the carer identity on a psychic level as they square it with their sense of self. For conceptual clarity *caring* is understood in this paper as "persistent tinkering in a world full of complex ambivalence and shifting tensions" (Mol, Moser, & Pols, 2010) (p. 14). To understand carering as a discursive practice, this paper focuses on the process of carer identification, rather than the identity itself. This paper understands identification as a dual process of subjectification (Greco & Savransky, 2018). First, identification is based on a process of interpellation whereby discourses and practices always attempt to hail us into place as social subjects of particular discourses (think about the purpose of the carer self-identification discourse) (Hall, 2000). Identification also always involves what Stuart Hall has termed "psychic surturing" whereby individuals themselves must invest to some degree in the subjective self-constitution (Butler, 1992; Hall, 2000). In other words, there must be something that appeals to individuals in an identity for them to use it; although people need not be entirely cognizant of such reasons. Judith Butler contends that identification is always constructed in relation to the "other" (Butler, 1995). Identification remains an incomplete process and any identities produced never reflect a "true" proper fit as they are always on some level strategic or positional (Hall, 2000).

This paper explores carering through narrative interviews with older partners providing end-of-life care. Older people represent the fastest-growing group of "carers" across economically developed nations (Carers, 2015). They have been identified as a particularly vulnerable, as they tend to be caring whilst grappling with their own health issues (NHS England., 2019). Paradoxically, they have also been identified as a group who tend to underutilise existing support services (The Princess Royal Trust., 2003). It is therefore important both from a health service and social theory perspective to clarify the notable ambiguity arising around older people's views and uses of the carer identity in order to design strategies that best support them (Grande & Ewing, 2019; Larkin et al., 2018). Such ambiguity is captured in Corden and Hirst's study based on a sample of 750 couples from the British Household Panel Survey, which found that partners aged 75 or more were twice as likely than those aged less than 50 years to identify as carers when providing end-of-life care. Nevertheless, only half of respondents aged 75+ identified as a carer. The authors suggest that the disinclination to self-identify as a carer may be due to respondents own health issues, meaning that they may sometimes

be the cared-for too (Corden & Hirst, 2011). The authors concede that further qualitative research is required to unpack these issues further (Corden & Hirst, 2011).

To contribute both to the theoretical concerns and practical questions that remain at large about the carer identity this paper seeks:

- To understand the carer identification practices of older partners providing end-of-life care.

2. Methodology

This study is shaped by a narrative approach that posits that storytelling is a fundamental “human impulse” through which people make sense of the world, themselves, and others (Kleinman, 1988; Mishler, 1984). Narratives provide a “referential context” through which people are made, known and interpreted by others (Kelly & Dickinson, 1997; Polkinghorne, 1988). Narrative approaches have received growing interest in the health and social sciences as part of a broader challenge to positivist claims to a fixed reality (Bury, 2001; Greenlaugh, 2011; Riessman, 2008). As a sub-genre of qualitative research, a narrative approach analyses personal narratives, which comprise a “distinct form of communication” that involves the organisation of “events, objects, feelings or thoughts” and the “connecting and seeing the consequences” of these over time (Chase, 2017, p. 928). Narrative approaches focus on the content, form and context of individual cases (Wiles, Rosenberg, & Kearns, 2005). The key aim of narrative analysis is to explore “the contradictions of social interaction and self-presentation” in such accounts (Bury, 2001) (p. 278). Analysts are also able to explore the ways individuals use stories to emplot their lives; as Arthur Frank puts it, to make “particular futures not only plausible but also compelling” (Frank, 2010) (p. 10). Therefore the narrative method is ripe for exploring the dual nature of carer identification as involving the interaction of broader discourses and individual's sense of self.

From a narrative approach, all parties in the interview are “necessarily and ineluctably active” in the production of meaning (Holstein & Gubrium, 2002) (p. 114). This method acknowledges how researchers participate in the constitution and reproduction of carering (Blue, Shove, Carmona, & Kelly, 2014) (p. 46). Recognising this, we used the phrase “looking after” to recruit participants rather than requiring they self-identify as carers to participate. Other empirical studies have used this phrasing to successfully recruit non-identifying carers providing care (Corden & Hirst, 2011; Jarvis & Worth, 2005). Public consultation with 33 “carers” and seven formal care providers, and a care commissioner, during the conceptualisation of this study supported the decision not to use the carer identity on recruitment materials as it was identified as a barrier to participation.

Fieldwork took place between August 2018–August 2019 with participants living at home with their partner in Cambridgeshire or West London, United Kingdom. Participants took part in up to three semi-structured in-person audio-recorded narrative interviews held approximately a month apart. The longitudinal approach enabled the interviewer (TM) to build rapport with participants whilst capturing their unfolding priorities and storylines, which enhanced the detail and depth of the data (Murray et al., 2009). To qualify for the study, participants had to be 70 or over and looking after their partner at home who had a diagnosed palliative condition. A horizontal sampling method was used, utilising strong and weak ties as “bridges” into new social networks (Geddes, Parker, & Scott, 2017), meaning participants were recruited via two General Practitioner (GP) surgeries, two former carers and the dissemination of a recruitment flyer to carers’ organisations. All potential participants were first contacted via the telephone to explain the study, to confirm their willingness to take part and arrange in-person meetings. All participants provided written consent at the beginning of each interview. Two participants agreed to interviews but subsequently withdrew from the study, one because he was himself diagnosed with terminal cancer and another because her husband only had days to live.

In total, 41 interviews were conducted with 20 participants across 17 couples.

As indicated in Table 1, nine participants took part in three interviews, five took part in two interviews and three took part in one interview. Reasons for not taking part in subsequent interviews were high care demands and/or physical and mental decline of one or both partners. In two extreme cases a couple were evicted and in one instance a carer died, thus precluding their study participation.

Participants were offered the choice to be interviewed either together or on their own, rather than predetermining the interview dynamic in line with divided scholarly opinion (Rose & Bruce, 1995; Wadham, Simpson, Rust, & Murray, 2016). Due to the high level of cognitive-impairment amongst end-of-life partners, only two couples both became participants as they were cognitively capable as judged by the health care professional who referred them and were both willing to participate. For one couple a mid-life daughter also took part. Additionally, twelve severely cognitively-impaired partners were present during the interviews. While they were not included formally as participants as they could not legally consent, their presence and talk shaped the direction of the interview discussion. In the cases where both members were active participants there was a general ease of communication between partners and equal turn-taking to answer questions. Similar to Ryan and McKeown's (2020) observations from interviews with couples where one had dementia, we observed subtle forms of participants self-silencing in order to maintain a front of coping and solidarity. This dynamic is explored in further in the third case study offered in this paper.

On average, interviews lasted one-and-a-half hours but ranged from 30 min to 6 h. The seven participants whose first interview lasted over 2 h tended to be socially isolated women often caring for non-verbal husbands with neuro-degenerative diseases. These participants tended to use the interview as a way of processing their caring situation as well as seeking to connect and spend time in a more relaxed fashion with the interviewer who was much younger woman in her mid-20s, something similarly observed by Jen, Zhou, and Jeong (2020).

The first interview began with the question “What is it like looking after your spouse?” and was subsequently directed around what participants perceived as important and noteworthy (Zieband, 2013). In the cases where both partners were present, this question was posed more broadly as “how do you look after each other?” The interview context triggered a carering moment by explicitly asking participants if they “saw themselves as carers?” typically as one of the last questions in the first interview. After a year in the field, the research team agreed that enough information had been collected for a nuanced analysis (Braun & Clarke, 2019).

2.1. Data analysis

Analysis began during the interview process with TM recording fieldnotes directly after each interview (Green et al., 2007). Each audio file was sent for transcription immediately so that TM could read each transcript and make notes about the key stories ahead of each follow-up interview. TM discussed these observations with participants to support the transparency and trustworthiness of the findings (Lincoln & Guba, 1985). Participants were subsequently categorised in relation to their responses to the explicit question about being a “carer” and to their wider use of the terms “carer” and “care” throughout their interviews. Once each case had been analysed, patterns of meaning were identified across cases (Riessman, 2008). Below we present three narrative case studies which exemplify typical examples of participants in each of the three carering categories. As indicated in Table 1, seven participants (notably all women) consistently engaged with the carer identity; eight were ambivalent about the label and four participants (including the 3 oldest participants in the sample) disengaged from identity completely. As the paper is focused specifically on older partner's identification practices, the mid-life daughter's identification was considered separately from this analysis.

Table 1
Characteristics of participants.

Couple number	Partner providing care	Age	Ethnicity	Care-receiving partner	Age	Ethnicity	Care recipient diagnosis	Number of interviews	Type of carering
1	Wife	78	Scottish	Husband	78	Scottish	Alzheimer's	3	Ambivalent
2	Wife	74	White British	Husband	74	White British	Alzheimer's	1 (Caregiver died)	Engaged
3	Husband	84	White British	Wife *	78	White British	Advanced Frailty	3	Disengaged (both)
4	Wife	70	White British	Husband	85	White British	Vascular Dementia (deceased)	3	Engaged
5	Wife	73	White British	Husband	85	White British	Front temporal Dementia	3	Engaged
6	Wife	77	Welsh	Husband	89	Jamaican	Cancer and Alzheimer's	2 (Couple evicted)	Ambivalent
7	Wife	80	White British	Husband	84	Irish	Cancer, Vascular Dementia, Stroke	3	Engaged
8	Husband	75	White British	Wife *	73	White British	COPD	3	Ambivalent (both)
9	Wife	78	White British	Husband	82	White British	Vascular Dementia, COPD	1	Engaged
10	Wife	71	White British	Husband	72	White British	Alzheimer's and Vascular Dementia	3	Ambivalent
11	Wife	73	White British	Husband	72	White British	Parkinson's	3	Ambivalent
12	Husband	85	White British	Wife	85	White British	Alzhiemers	2	Disengaged
13	Wife	73	White British	Husband	79	White British	Parkinson's/Lewy Bodies Dementia	2	Ambivalent
14	Wife	80	Indian	Husband	84	Indian	Alzheimer's	2	Engaged
15	Wife	77	White British	Husband	82	White British	Vascular Dementia	3	Engaged
16	Wife	89	Italian	Husband	89	Indian	Lewy Bodies Dementia	2	Disengaged
17	Husband	80	White British	Wife	87	White British	Stroke	1	Ambivalent
		M = 77.5		* = care recipient also participated	M = 81.05			41	Engaged = 7 Ambivalent = 8 Disengaged = 4 = 19 (excluding mid-life daughter)

For the record, however, she actively referred to herself as a carer as did her mother. Participants are referred to with researcher-selected pseudonyms and the number of their interview. Quotations are presented at length with the interviewer's questions included in bold to capture the flow and interactions within interviews.

3. Results

3.1. Engaged carering

Mary, aged 74 white British, reflected that her husband Paul's diagnosis of early-onset Alzheimer's disease at the age of 64 had left her "in bed crying, crying, crying" (int 1). After the initial shock, she thought: "This isn't doing me any good, I've got to keep well, and I wanted to keep him going. So I toughened up (laughter)" (int 1). Mary's process of "toughening up" involved seeking out her local dementia carers support group which she and Paul, now aged 74, had remained members of for the past eight years. When asked "what it's like looking after your husband?" Mary directly referred to herself as a carer and linked it with the range of dementia-related organisations and activities she and her husband attended:

Hmm, I'm his carer, yeah. And he's fine, he's really good to lots of people. Yeah, but he gets well you can see. [pause] But he is, yeah, we do lots of things, uh huh, we play table tennis, we play short tennis, we go Memory Notes which is a singing group, we go to choir, we got to the [name of Carer's Organisation] with some friends, we go out for meals, go on holiday, we see our children and our grandchildren. (int 1)

By forming friendships and a social life through dementia-related connections, Mary hints at the way she has been "hailed" into the carer identity. Through frequent discussions at the carer group, which she refers to as the "best thing", Mary learnt that being a carer is to experience social isolation, chiming with her experience of caring as "so isolating", leaving her "in the same boat". By discussing the issue of isolation in the encompassing second person (you) and first-person plural (we), Mary underlines how the carer identity has been "surtured" into her sense of self:

They think it's the best thing ever because you feel so isolated, it's just you and the world and this poor person who we love and it's so isolating and it's such a shell shock to hear but erm, hmm, it's wonderful cos everybody's, oh, we're they're in the same boat and you have a good old chat about the problems that you have and a lot of them are very similar, obviously, with a lot of Alzheimer's are similar and, you know, the different types but there are similarities in them. (int 1)

While her isolation was directly related to her husband's inability to hold a conversation due to his declining cognition, it was intensified by her decision as a parent not to burden her children who had "busy lives". She quipped that "the last thing" her daughter who was a doctor needed "is a problem from me". Normative expectations of not burdening other family members responsible for their own nuclear families shaped the conditions of Mary's carering. This was also evident in her subsequent definition of what it was to be a carer in terms of its temporal intensity. This aligned with her perception, gleaned from the carer's group, that for the most part as carers you are "on your own" facing a high level of care responsibilities:

What do you think to being carer means?

Being available 24 hours a day to do all the things that need to be done (laughter).

Have you had any problem like adopting that term, or?

No, like I'm his wife and that's what wives would do, isn't it? So, it's not, you know, it's not a title, it's just something a wife erm, would help a husband do because, you

know, take them on for better, for worse and hopefully he will do the same for me

(laughter)(int 1).

Mary's definition also incorporated her view that the carer identity was an inevitable extension of her wifely duties reasoning: "that's what wives would do isn't it?". Such wifely tasks had changed throughout the course of her husband's advancing dementia. While Mary spoke at length about Paul's generosity as a husband, father and boss, referring to him as "Mr King-fix-it", she also recognised that he now did "nothing" around the house or for himself. Mary and Paul had a traditionally gendered heterosexual relationship where she had been a housewife and he the breadwinner, meaning she had always been responsible for daily household activities. Being in charge of her "directing" her husband in all matters of his personal care was a discomfiting new experience that changed the relationship hierarchy. It also translated into more daily care. Laughing ironically, she exclaimed it "t [ook] a lot of effort" to ensure her husband looked so dapperly dressed; something he was known for at the carer group. It was at this point she returned to the narrative she begun with about how to keep caring she had to: "stay well (laughter)". The discursive limits of her "will to health" were laid bare a month after this interview when Mary's daughter informed us that Mary had had a brain haemorrhage from an aneurysm whilst out at dinner with Paul and two friends. She had died shortly after. Her daughter in a telephone conversation put her death down to "the stress of caring". Mary's carer identification as a process of "toughening up" had unforeseen consequences, serving as a shell shock for all involved.

3.2. Ambivalent carering

Charles, white British 80, had been caring for his wife Dolores, 87, for the last eight years since her severe stroke that left Dolores wheelchair-bound, incontinent and able to communicate only through her facial expressions. Charles, who was one year into his remission from prostate cancer, was supported by a team of three privately-paid for health care assistants and two involved step-daughters. While formally registered and recognised as a carer - with the card to prove it - he nevertheless felt that it was an "awkward" fit that did not square with his internal view of self:

I have to say because of the circumstances I'm a full time carer I feel quite awkward actually. I am who I am and I'm looking after my wife and the title is not relevant

although it's true it's what I am. And I'm registered as a carer I'm with an organisation in [West London]. And I carry a red card (int 1).

Underpinning his continued use of the carer identity appeared his hope for improved access to health care for himself and Dolores. Nevertheless, the luke-warm response to his using the term at the G.P. surgery intensified his ambivalent identification:

I'm officially a carer. Don't think of myself as that really unless it crops up in conversation and we're very lucky with our medical practice up the road never have to wait too long for an appointment. And I say to them, "am I registered as a carer because I gather if you are you get precedence if necessary", and they said "well I don't know whether

you are and anyway you don't get precedence" and I thought you did but again I don't go around thinking I'm a carer (int 1).

Charles acknowledged that much of his feelings about his carer identity were unintentionally formed, summarised in his statement that "I don't go around thinking I'm a carer". On reflection, prompted by the interviewing context, Charles felt that his ambivalence related to his dislike for the way the carer identity redefined his relationship. It hurt Charles to undermine Dolores's position as the care-provider in her household by rendering her the "caree". At seven years her junior, he had always been her "toy boy" and had been "just assumed as an extra plate to fill" when they married later in life. So to avoid affronting her womanhood and her identity as an "intelligent lady", he did not identify as a carer in her presence:

And if you're the carer does that make her the cared-for in terms of the terminology?

Is she the caree I don't know I hate to think of her having to accept, it makes me very, very sad because as I said before, for a really intelligent lady who now can't communicate properly, ...you know she used to get really very angry when I used to wipe her mouth after food she now accepts it. And that hurts me for her because she shouldn't have to accept that she should be able to do it herself and it makes me cry ... And having somebody to, particularly your husband, to do things which you used to be able to do yourself (int 1).

Being a carer also presented challenges to his masculinity, as he was involved in the intimate dirty work of toileting etc. That men do not typically do. Charles shrugged off this cultural baggage describing caring for Dolores as a habitual practice which he had grown competent at due to necessity. He explained that he was frequently met with intrigue or confusion by others, particularly women carers, which he found "strange":

I don't know it just happened as I said earlier on I didn't think twice about it, I was going to have to do it, don't enjoy it but it's part of life now the more you do things that are part of life the more you get used to them but as I said before a lot of people seem to think that it's not the man's job "aren't you good for doing it"[mimicking a woman's voice]. I think strange (int 1).

Charles felt that caring had made him more emotional making him "cry at anything". However, he felt that his enhanced emotional sensitivity made his care superior to the female formal paid carers:

What would being a carer involve?

I think what we've been talking about it's physical and emotional both sides of it. But the emotional side is because we're married and the love element comes into it, respect friendship all these elements, but if I was employed as a carer like [HCA's name] ... I would probably take a long time to get the emotion, because there's how many patients, clients whatever they're called, service users, are they seeing every day fourteen easily (int 1).

This differential in physical and emotional support perhaps links to why he continued to claim the mantle as her "primary carer" so as to indicate that Dolores's care always included the "love element", despite the carer identity never thoroughly permeating his sense of self. Ultimately, Charles was content with bending his identity situationally if it meant that he could achieve his goal of "being carried out of the house in a double coffin" with his "intelligent lady" when their time came.

3.3. Disengaged carering

At their first interview John, white British 85, was referred to the study by a G.P. as being the carer for his wife Betty, 79, whose limited mobility and abscessed leg had led to her G.P. diagnosis of advanced

frailty. John's mobility was not much better, however, so much of their daily life involved pottering around their small council bungalow. Betty and John embarked on slightly different responses concerning their carer identity, though both showed awareness of it and reluctance to apply it to themselves:

What do you think about the label carer?

Betty: Uh huh, yeah some people –

John: Well, yes, there is.

Betty: to look after each other, so they are both carers. Yeah. They can work it.

John: There is a girl up the road, isn't there, Betty?

Betty: Yeah.

John: [Betty]'s got bad legs and a little girl who lives, that's the advantage of being in this set up, erm, she, her friend drives her now because Betty can't drive, so, you know, she helps that way and you find, I suppose when you live in a town, if, erm, you know, you get to know people, I think that's the main, for us anyway, it's getting to know people – [pause]- and helping one another, you know - if you need it, if you need help but the, erm, and the clubs as well, like the over-60s, but erm, you know, meeting people but while you, while you keep your health, being able to go out and meet people -

Betty: and talk to people and yeah (int 1).

Fundamental to their discussions of care was the importance of taking personal responsibilities for one's own health and building up social networks to “work it” so they could remain independently home with the occasional instrumental support of neighbours. Notably, John conceded that much of the community groups relied on being able to “go out and meet people” which neither were able to do currently. Nevertheless, both remained remarkably optimistic, describing how they were attempting to “make do and mend” (int 1). This phrasing, redolent of the British war logic, fit into the couple's detailed reflections of having to ration as children during World War II. Their notions of self-sufficiency similarly inflected their understandings of care, with the only task Betty conceded that John helped her with was breakfast:

How did he look after you?

Betty: He did the cooking didn't you made lovely scrambled egg better than I could make.

John: Well you always burn the saucepan.

Were there any other ways you had to help?

John: No. Because you sat in the chair most of for about a year didn't you?

Betty: I hobbled about I need I'm not one for sitting for hours in a chair but I like to potter on (int 3).

This passage also indicates Betty and John's attempt to communicate the egalitarian nature of their household management. This dynamic was also evident in their equal turn taking during the interview where they added to each other's reminiscences of their long marriage and life working together running youth hostels. Their mutual attempts to highlight how they were attempting to self-manage their own health in order to take the strain off the other may also reflect subtle forms of self-silencing and minimising need to promote solidarity. Notably this is something they held-fast to across all three interviews.

John's diagnosis of terminal bowel cancer, with six months to live, between the first and second interview could have been a significant turning point in the couple's carering story. Their narrative remained one of in John's words of “muddl [ing] through” (int 2) though John quipped when Betty was out of the room that they were now “babysitting each other”. For the most part, Betty successfully steered the conversation away from John's despondency toward a radically hopeful outcome which meant their identity as a couple remained intact:

And you can like if you shower all by yourself? And stuff in terms of it doesn't ...

John: They don't let you go from the hospital 'til you've got to show 'em you can work with the bag on. Do that.

Do you find you have to help out?

Betty: No I mean he's done it, I mean I would do if I had to but he

seems to cope alright don't you?

John: Mm. Don't know. Done the first bit couldn't do all of it cos I was too old and too frail.

Betty: But there's a lady on the television and she had breast cancer and she had radiotherapy. I suppose they try that don't they first if they think they can do it with it.

John: Need to just get some more fire radio.

Betty: [pause] just keep going John. did I tell you I fell out of bed? (int 3).

Betty crafted an account where illness was something to be overcome rather than a formidable obstacle by appealing to cultural imperatives to stay optimistic gleaned from the mainstream media. Ironically, Betty's narrative pivot deployed to express their control over the situation in fact underscored their vulnerability. Betty continued the above passage by explaining she had to wait 2 h for the ambulance to arrive at their remote village. When asked, “what did you do when she was on the ground?”, John responded:

John: I don't know suppose I got down and had my normal cup of tea.

Betty: Did you? Left me. [pause] No but you kept saying “do you want a cup of tea” I said “no thanks” but he just couldn't do anything (int 3).

That John “couldn't do anything” in Betty's time of need showed how the process of carer identification was bound up with the changing abilities of each to care for their own and each other's bodies. Precisely because of these changes, it became even more important for Betty and John to preserve their identity as a self-sufficient couple. For them this necessitated with the disengagement from the carer identity. They perferred radical hope, summarised aptly by Betty's sign-off of their third interview where she turned to John and said: “we're fine the sun's shining isn't it here? You're alright love” (int 3).

4. Discussion

So while the hunt for carers is on, is it appropriate? Exploring the narrative accounts of older partners providing end-of-life care, we suggest that while the carer identity might be used by some, or atleast sometimes; it is not appropriate for all. Indeed, requiring people to identify as such might conflict with important coping strategies partners have put in place to sustain caring as well as being a barrier to accessing available support services. This analysis raises important questions about the centrality of carer identification at the heart of health and social care policies internationally. In doing so we support growing calls to identify alternative strategies to support people involved in caring (Funk, 2019).

4.1. What this paper adds

The first key contribution of this paper makes is to introduce carer identification as a discursive practice we term “carering”. Through interacting with carer organisations and health care professionals, participants encountered broader carers discourses and their imperatives to self-identify. However, these discourses were only embodied when participants felt that the qualities assigned to being a carer, such as experiencing social isolation and providing 24/7 care, reflected their own personal experience (Hall, 2000). To this end, being a spouse need not necessarily conflict with being a carer as has been previously mooted (Molyneaux et al., 2011; Turner et al., 2016). Participants embraced a fluid understanding of identity which transformed over time in relation to their own understanding of their context and material changes to their own and partner's physical health. Interestingly, we identified a case where someone identified as a carer but was attempting to back away from it: challenging the deterministic trajectory offered by Caregiving Identity Theory (Montgomery & Kosloski, 2009).

In line with previous studies, normative expectations around familial care were fundamental in influencing carering. Novelty, we observed that older husband's fear of compromising their wife's femininity and

position in the domestic setting shaped whether and when older men engaged as “carers”. This adds to previous findings that older men engage in caring as a way to reciprocate care received by their wife across their life-course (Milne & Hatzidimitriadou, 2003). We add that older men’s minimisation of their caring identity, at least in front of their wife, was part of this reciprocity. We also observed that carering frequently occurred on an unconscious, or at least unintentional, level (as gender and heterosexuality also tend to) with their logic of identification only brought forth and explicitly reflected on when they were requested to in the research context (Butler, 1995). This is another reason why it is preferable to view “carer” as a discursive practice rather than a quality of a cognisant “knowing subject” as in much of the current literature (Eifert et al., 2015; Funk, 2019). As researchers we must reflexively consider our role in this carering process, and resist making claims about participant’s identities ipso facto. To do so, researchers could use more inclusive practice-orientated language about caring not “carer” in our recruitment, analysis and presentation of findings.

The second key contribution of this study is the exploration of older partners who partially or consistently disengaged from carering. This finding fits recent studies questioning the orthodoxy that carer identification as an inherently emerging identity (Beatie et al., 2021; Henderson, 2001). Contrary to previous theories (Montgomery & Kosloski, 2009), neither lack of awareness about the carer term and/or newness to caregiving could sufficiently account for their lack of use of the identity (O’Connor, 2007). We posit that such disengagement with the carer identity was related to a wider protective strategy of self-and-partner preservation. This process has analogies to the concept of disidentification in queer scholarship (Munoz, 1999). This tactic has been identified as a way family members manage threats to their older care-recipients health (Knowles et al., 2016). Previous research has found that frail older adults use this strategy to manage the challenges of daily life (Nicholson, Meyer, Flatley, Holman, & Lowton, 2012; Wiles, Miskelly, et al., 2019), and consultations about advanced care planning with health care professionals (Etkind, Lovell, & Nicholson, 2019). By focusing on frail older people providing care, we marry these insights of these studies and contribute much-needed insight into the way carer identity shaped coping strategies (Corden & Hirst, 2011). By emphasizing their marital identity and stressing the things they could do for themselves, and underplaying situations of dependency, participants fashioned a positive “persistent present” which strove to normalise and downplay changes (Greenwood, Pound, Brearley, & Smith, 2019; Nicholson et al., 2012). We suggest that such therapeutic plotlines (Frank, 2010; Mattingly, 2014) that reject the carer identity are particularly important for those experiencing poor health and managing threats to their own independence: in other words, precisely the “vulnerable” oldest-old people whom policy-makers and health care professionals want to reach through the carer identification drive.

4.2. Contribution for practice

By clarifying the nature of carer identification practices, this paper provides theoretical justification for alternative identification strategies to help locate and support people involved in caring. We suggest a two-tiered approach is advisable to capture the diversity of caring experiences. For those who identify as carers, health and social care professionals need to ensure that the resourcing and infrastructures are sufficient so that when older partners seek help, they receive it. Evidence presented here indicates that formal care is not currently meeting the preferences of older partners as in the second example above, where the lack of awareness of carers’ entitlements by his G.P. actually deepened his ambivalence around whether he ought to pursue the carer identity. This finding aligns with conclusions of a recent scoping review that interest in carer awareness in policy has not necessarily resulted in tangible improvements in support for older carers (Henwood, Larkin, & Milne, 2017). A starting point for improving the context of care should be thinking about what systems are needed to improve older partners

material needs and physical and emotional competencies to sustain them in their caring roles. Addressing social isolation must be an important first step as this analysis and previous research (Greenwood et al., 2019) has identified it as a major concern of self-identifying carers. We add that it has become part of the informal definition of what it means to be a carer. Befriending services for those looking after a partner might be a fruitful first step (Wiles, Morgan, et al., 2019) and would particularly be helpful for individuals who can not attend conventional carer groups due to caregiving demands or their own physical ill health. Such regular social check-ins particularly over the telephone are perhaps even more pressing in the COVID-19 context whereby social distancing measures and safe-guarding requirements have made caring acutely socially isolating and lonely (Jones, Jopling, & Kharicha, 2021).

For partners who either actively or implicitly reject the carer identity, we recommend focusing on couples as the joint unit of care rather than viewing their needs individually. This aligns with the shift to thinking about relationship-based care which is receiving increasing attention in chronic care and palliative care models (Ateş et al., 2018; McCarthy, Lyons, Schellinger, Stapleton, & Bakas, 2020; Wadham et al., 2016). This could be practically achieved in primary and secondary care by ensuring that every time either partner comes into the system, they are asked about their own and their partners needs (Ewing, Austin, Jones, & Grande, 2018). Health care professionals could then follow-up with couples at regular intervals by proactively offering G.P. and/or nurse appointments (Ewing et al., 2018). Linking of older couple’s health and social care clinical files, with their consent, might also help ensure couple’s support and health needs are met irrespective of whether one, both, or neither identify as “carers”. This would help promote couple’s self-preservation strategies whilst ensuring that they do not slip through the cracks.

5. Conclusion

This paper raises important questions about the centrality of carer identification at the heart of health and social care policies internationally. This paper introduces the concept “carering” to highlight how carer identification is a discursive practice involving a range of external and internal motivating factors. This paper presents in-depth narrative case studies which illustrate how the carer identity is unevenly taken up by older partners involved in care, with some disengaging with the identity completely. In order to best support people providing care, particularly those in precarious situations, we need to identify alternative strategies of engagement that do not require people to first identify as a “carer” in order to qualify for support and care.

Ethical approval

Ethics approval was attained from the University of Cambridge Psychology Ethics Board: PRE. 2018.057 and NHS research ethics committee: 18/NW/0858.

Declaration of competing interest

N/A.

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