Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions

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Abstract
Informal carers make a significant contribution to illness management in communities, but many struggle to access support and remain ‘hidden carers’. We aimed to explore how carers of people with common long-term conditions (LTCs, such as coronary heart disease or kidney disease) conceptualised their caring, and whether they struggled to identify themselves with the term ‘carer’ or access for support. We conducted semi-structured interviews with 19 informal carers of people with LTCs recruited from local support groups. Topic guides were designed to encourage participants to provide their retrospective accounts of identifying as a carer or struggling to do so. Data were analysed using the constant comparative method. The study was designed collaboratively with a patient and public involvement (PPI) partner, and we consulted with a PPI steering group of people with lived experience of caring during the study. Results showed how participants drew on comparisons with those caring for more dependent relatives in explaining their reluctance to define themselves as a carer, and resisted adopting the label due to concerns that it would threaten the identity of the cared-for person. The data were interpreted in terms of types of ‘work’ undertaken to manage LTCs, and revealed that carers of patients with LTCs appear to primarily engage in biographical and emotional support, which may be more difficult to conceptualise as legitimate caring ‘work’. Participants indicated that health professionals may be in a unique position to validate their role as carers and encourage support seeking. The study suggests how the greater focus on self-management of LTCs in the community must be complemented by recognition of this group as potentially ‘hidden carers’, who support the patient to minimise the impact the illness has on their lives and consequently may minimise their own caring role, with negative implications for support seeking.

Keywords: carers, carers’ services, chronic illness, long-term care, public and patient involvement, qualitative research

Introduction
There are 6 million informal carers in the United Kingdom (UK) who, it has been estimated, save the UK economy approximately £119 billion per year (Buckner & Yeandle 2011). Internationally, a similar picture emerges, with 2.7 million unpaid carers in Australia with an estimated replacement cost of...
$40.9 billion (Elderton 2013), and an economic value of $196 billion of caregivers in the United States (Arno et al. 1999). The importance of informal carers to healthcare systems and the need to better support those in caring roles is therefore crucial. An informal carer is defined as:

Someone who, unpaid, provides help and support to a partner, child, relative, friend or neighbour, who could not manage without their help due to age, physical or mental health problems, addiction or disability. (Keeley & Clarke 2003)

While caring can be rewarding, there are considerable costs to the carer themselves which can manifest in physical and mental health problems (Hirst 2004). In the UK, there has been greater acknowledgement of the role and needs of carers since the Carers (Recognition and Services) Act 1995 and Carers and Disabled Children Act 2000 (Thomas et al. 2002), but it is recognised that carers may still struggle to access support in practice (Arksey et al. 2003, Rand & Malley 2013) and that some subgroups of carers remain particularly under-recognised.

‘Hidden carers’ refers to informal carers who may not recognise themselves as a carer and consequently be less likely to access support (The Princess Royal Trust 2003). Specific demographic groups of carers are known to be less likely to receive support (Phillipson et al. 2014), such as those from Black and Minority Ethnic (BME) populations (Milne & Chrysanthopoulou 2005), and resistance to adopting the label of ‘carer’ in the context of specific familial relationships is also well established (O’Connor 2007). Less attention, however, has been paid to whether differences in the types of caring ‘work’ undertaken may impact identification and support seeking. The majority of the current literature on carers’ experiences has studied groups with explicit and/or extensive functional care needs associated with significant impairment, such as the very elderly people and patients with cancer or dementia (Parker et al. 2010). It is possible that identification as a carer and subsequent help seeking may vary across the spectrum of caring work, with implications for understanding which groups of carers are at risk of remaining ‘hidden’ and why.

In particular, the experience of carers of people with common long-term conditions (LTCs), such as heart disease and diabetes, has received less attention compared with those caring for people with more intensive support needs or trajectories of decline. In particular, while the role of significant others has been studied in relation to managing severe or acute illness, it is less well understood in the context of everyday LTC management (Vassilev et al. 2013). For example, there is a recognised dearth of literature on the needs of carers of people with chronic obstructive pulmonary disease (Caress et al. 2009). Increasing numbers of people now live with LTCs, leading to a shift in models of healthcare to focus on ‘self-management’. Self-management support is vital to ensure the sustainability of services for LTCs (Kennedy et al. 2013) and refers to the longer term, everyday management of conditions outside the boundaries of professional care interactions (Barlow et al. 2002). This suggests that support provided informally by family and friends is likely to be integral to these new ways of managing illness. Indeed, it has been recognised that developments in the management of LTCs are extending the role of family caregivers in North America (Yaffe & Jacobs 2008).

Recent research has also shown how this everyday management comprises different domains of ‘work’ (Corbin & Strauss 1985, Vassilev et al. 2013). Vassilev et al. (2013) utilised and adapted the ‘lines of work’ framework developed by Corbin and Strauss to investigate three different domains of work comprising illness (specific) work (referring to work related to treatment regimes, managing symptoms and engaging with formal healthcare); everyday work (household tasks, care of the wider family, aspects of managing general health including diet and exercise, and personal care); and emotional work (diffusing worry and anxiety, and managing biographical aspects, such as personal identity, plans for the future, expectations and relationships). The framework used by Vassilev et al. extended the third category from the ‘lines of work’ framework by Corbin and Strauss which was originally entitled and restricted to ‘biographical work’. Vassilev et al. redefined the third category as ‘emotional work’ to include strategies to manage worry and anxiety in addition to ‘biographical aspects’. [The first two categories (illness work and everyday work) are identical to the original framework by Corbin and Strauss.] Dividing chronic illness work into these distinct domains helps to consider the various roles of multiple members of personal communities in supporting self-management, providing the opportunity to explore how different kinds of ‘work’ may also be undertaken by informal carers and whether this impacts on support seeking.

As part of a broader programme of research investigating the importance of social networks in LTC management (Vassilev et al. 2011), we aimed to explore experiences of informal carers for people with LTCs. There are recognised barriers to individuals accepting the label of ‘carer’, such as resisting the
perceived ‘bureaucratisation’ of their personal relationship with the cared-for person (Hughes et al. 2013), but the extent to which such barriers impact on carers of people with LTCs is unknown. Professional lack of awareness of carers’ needs and under-identification of carers are also recognised problems in health services (Arksey et al. 2003), but to date no study, to our knowledge, has explored this in relation to LTC self-management. To improve efforts to identify hidden carers, it is necessary to explore with carers themselves what factors contributed to, or were barriers to, their own recognition of their role and consequently any support needs they may have.

This research was also inspired by collaboration with a patient and public involvement (PPI) partner (MG). PPI is increasingly prioritised within health services, as PPI partners are uniquely placed to identify new avenues for research or provide novel perspectives on existing research areas (Caress et al. 2012). Through collaboration with MG, we identified the potential tension of supporting people with LTCs in the community if those in a supporting role were not adequately supported themselves. Specifically, the PPI partner’s experience as a ‘hidden carer’, who had only explicitly realised her role as a carer after her husband had passed away, prompted us to consider the potential impact of LTC management on significant others and whether they perceived themselves as carers, as social and family context is an aspect of everyday LTC management although this has been neglected in research to date (Hinder & Greenhalgh 2012). In particular, we wanted to explore with carers of this group of patients whether there were particular barriers to identifying themselves explicitly as ‘carers’, and whether this impacted currently or in the past on their access to help and support.

In summary, to realise the potential of UK policy directives aimed at increasing support for carers and ensuring equity of access to support, it is necessary to explore barriers to identification and support for specific caring groups. The aim of the following study was therefore to explore whether informal carers of people with LTCs defined themselves as carers, and to examine the consequences of this on their access to support.

PPI methodology

Consistent with calls for more standardised reporting of PPI activities in research (Staniszewska 2009), we follow the recommendations of the GRIPP (Guidance for Reporting Involvement of Patients and Public) checklist for reporting PPI throughout the manuscript (Staniszewska et al. 2011). We did not draw on a theoretical model to inform PPI in the study, but were guided by the INVOLVE definition of PPI as ‘research being carried out with or by members of the public, rather than to, about or for them’ (Caress et al. 2012). Our aim was to involve members of the public with experience of caring as collaborators and ‘critical friends’. The study was co-designed with a PPI co-applicant (MG), who herself had lived experience of caring and presented the original idea for the study. We also recruited a PPI Advisory Group of carers and other key stakeholders (including organisers of local carer support groups), recruited through advertisements to local carer organisations and through snowballing contacts of the PPI co-applicant. Eight members of the public with experience as informal carers volunteered to take part. The group met three times during the course of the study (prior to recruitment beginning, midway through and after data collection). Advice on design was sought specifically on materials, recruitment strategies and interview questions. The final meeting focused on reflection on the study findings.

Sampling and recruitment

Purposive sampling and snowballing were used to identify potential study participants. Information about the study was circulated to 10 carers support groups in North West England. We hoped to retrospectively explore with these participants how they had come to identify themselves as a carer, and whether any particular barriers or facilitators had helped or hindered them in this journey. So, although this group could not be classified as ‘hidden’ carers themselves, their experiences and perspectives could illuminate difficulties they faced in acknowledging their caring role and journeys to access personal support. Nevertheless, we did attempt to widen our recruitment strategies to attempt to reach people who may not explicitly define themselves as carers. This was done in two ways:

1 Based on recommendations from the PPI Advisory Group, we avoided using the term ‘carer’ in these materials, referring instead to ‘helping’ or ‘assisting’ someone with diabetes, kidney or heart disease, as the advisory group highlighted how using the term ‘carer’ may impact on recruitment (with relevant participants self-selecting out of the study due to the very concerns about adopting the label of carer that we wished to explore).

2 To broaden recruitment beyond carers support groups, and attempt to reach people who may not have engaged with any explicit carer-oriented services, we also attempted to recruit through patient
groups. We distributed materials to 17 local LTC disease support groups to ask their members to pass the materials on to their friends and family, and advertised the study in charity shops, university message boards and web pages, and used snowballing. We also contacted two local South Asian support groups to attempt to recruit South Asian participants (given that this population are known to face particular barriers in accessing support (Wilson et al. 2012).

This study was approved by NRES Research Ethics Committee, Reference number 10/H1008/1.

Data collection

Semi-structured interviews were conducted with people who identified themselves as providing regular help to relatives/friends with LTCs including heart disease, kidney disease or diabetes. Interviews were conducted by two research associates (one male, one female), both trained in qualitative methods. Topic guides were designed and discussed in collaboration with the PPI steering group, and structured to elicit a retrospective narrative of the interviewee’s experiences with care-giving, paying particular attention to how they conceptualised their identity as a ‘carer’ and whether they had now or in the past accessed support for their caring role. Interviews were conducted in the participants’ home. Each interview lasted between approximately 40 minutes and 1 hour 15 minutes. Participants provided written consent, and interviews were digitally recorded and transcribed verbatim. An interpreter was present for three interviews with non-English-speaking South Asian participants to translate questions from the interviewer and report responses. Recruitment was ended when data saturation was agreed to have been achieved.

Data analysis

Analysis was guided by the principles and procedures of the constant comparative method (Glaser 1965, Hallberg 2006). The analysis involved an interplay between inductive and deductive approaches, guided in part by our aims to explore the impact of identity on support seeking and the potential role of dimensions of illness work, but remaining open to new and unexpected findings in the data. All transcripts were initially read by a single author (RC), with subsets read by co-authors to allow discussion and exploration in consensus meetings.

The analytical procedure was as follows. First, transcripts were read in full to allow immersion in the data, followed by initial descriptive coding of text segments. These preliminary descriptions and brief codes were then discussed and compared in the consensus meetings to generate conceptual themes. Finally, data were organised into thematic categories and extracts compared to consolidate the over-arching patterns in the data set (specifically, examining the reoccurring theme of biographical and emotional work conducted by the participants and its relationship with their perceptions of being a carer). We also presented the final themes, with extracts, to the PPI steering group to explore with them whether they felt the themes adequately captured the data and whether the themes we identified were consistent with their own perceptions and experience.

Findings

Sample

Nineteen participants were interviewed and their characteristics are presented in Table 1. Fourteen participants were recruited from carer support groups and five from public adverts, snowballing or word of mouth.

Three themes emerged from the analysis: ‘legitimate domains of work’, ‘resisting a carer identity’ and ‘identity resistance and accessing support’. Participants’ accounts revealed that they did not define their caring role as being legitimate caring work, but instead constructed it as a ‘normal’ family responsibility. While resisting a carer identity enabled them to protect their own and the care recipient’s identity, it created barriers to them accessing support and led to their own needs being unrecognised.

Legitimate domains of caring work

Participants compared themselves to other carers who were seen as having greater responsibilities than themselves, engaging in social comparison [referring to the way people perceive their own health and illness experience according to what they observe of others (Rogers et al. 2009)] with what they saw as stereotypical carers:

I sat there and I listened to some of these poor women that had the most horrendous lifestyles because of caring with children with dreadful disabilities . . . I kept thinking to myself they’re the people who really are the carers . . . I felt I didn’t really qualify like they all did. (Carer 4)

When you watch Children in Need and you see these kind of hero teenagers who care for parents with MS, that to me is a carer; someone whose own life is put on hold as they care for someone else 24 hours a day. (Carer 14)
It was apparent that the roles participants performed, such as giving insulin, attending appointments and providing emotional support, were not associated with ‘caring work’ and instead were described in terms of familial responsibilities:

I do it no matter what because they’re my family. Even I suppose if they were healthy I’d always be keeping my eye on them. It’s just keeping more of an eye on them, being more aware of what they’re doing and how they are. (Carer 8)

One participant, however, differentiated between being a ‘family member’ and a ‘carer’ when the distribution of family responsibilities became unequal:

In husband and wife or a partnership, you share your duties, right? But when one person is incapable of doing their duties and the other person then takes those on as well as their own... that’s when they start becoming a carer. (Carer 8)

This suggests that meeting more explicit caring needs, such as practical tasks of managing the household and family (a feature of everyday work; see Vassilev et al. 2013) made it easier to conceptualise responsibilities shifted to the carer as ‘caring work’. However, this was often not the case for carers in this sample, as they were engaged in more subtle caring activities that could be defined as ‘emotional work’ (Vassilev et al. 2013) to support the self-management for people they cared for. As one participant stated, her husband was able to care for himself, so long as she was available in the background, commenting that ‘I’m like a security blanket’ (Carer 4). The data suggest the emphasis was on supporting with emotional work, or helping with illness-specific work in a subtle (even disguised) way, to avoid threatening the independence of the cared-for person:

I had to be exceptionally sneaky there and go and have a word with our GP, and say, look, the next time he comes in, can you have a word with him please, because I feel he is suffering from depression. (Carer 4)

Participants also referred to concealing the impact of the illness from friends and family to protect the care recipient’s own identity. Again, this focus on protecting identity has been presented as a feature of emotional work, but providing such support in this context could isolate carers from potential sources of support for themselves.

You don’t want to let them know that there’s been a problem... so you’re trying to cover up for that, so you try and

| Relationship with cared-for person | Age | Sex | Ethnicity | Working? | Condition of cared-for person(s) |
|-----------------------------------|-----|-----|-----------|---------|----------------------------------|
| 1 Son                             | 37  | M   | WB        | Incapacity benefit | Heart disease                  |
| 2 Daughter                        | 43  | F   | WB        | FT      | Type 2 diabetes, vascular-related dementia |
| 3 Wife                            | 58  | F   | WB        | FT      | Kidney failure requiring transplant |
| 4 Wife                            | 64  | F   | WB        | Retired, was PT | Angina                          |
| 5 Daughter                        | 37  | F   | WB        | Benefits (FT carer) | Heart attack, diabetes, kidney failure |
| 6 Wife                            | 63  | F   | WB        | Retired, was PT | Heart attack, diabetes, kidney failure |
| 7 Wife                            | 69  | F   | WB        | Retired, was FT | Type 1 diabetes                 |
| 8 Mother                          | 45  | F   | WB        | PT      | Type 1 diabetes                 |
| 9 Wife                            | 63  | F   | WB        | FT then PT | Heart attack, diabetes, sleep apnoea, peripheral neuropathy |
| 10 Son                            | 29  | M   | WB and BB | FT      | Kidney failure, ischaemic heart disease, multiple sclerosis |
| 11 Partner                        | 42  | F   | WB        | FT+     | Alport’s syndrome requiring kidney transplant |
| 12 Mother                         | 32  | F   | P         | FT carer | Kidney failure requiring transplant |
| 13 Mother                         | 48  | F   | WB        | PT      | Type 1 diabetes                 |
| 14 Granddaughter                  | 21  | F   | WB        | FT      | Diabetes, dementia              |
| 15 Partner                        | 32  | F   | WB        | PT      | Behc’ts disease                 |
| 16 Granddaughter                  | 24  | F   | I         | PT work, FT study | Diabetes |
| 17 Wife                           | 50  | F   | P         | PT work | Heart disease, amnesia, paralysis, arthritis |
| 18 Daughter-in-law                | 29  | F   | P         | Housewife and FT carer | Type 2 diabetes, heart disease, arthritis, mobility issues |
| 19 Niece                          | 46  | F   | P         | FT housewife | Type 2 diabetes, heart disease, arthritis, thyroid |

BB, black British; WB, white British/English; P, Pakistani; I, Indian; FT, full time; PT, part time.
avoid seeing them... we didn’t want them to see that things weren’t right, because, I suppose, we were living a happy family life that wasn’t a happy family life anymore... I’ve always had to, sort of, double up, when everyone’s there, everything’s fine... you do end up smiling on your face outside... it leaves you like that. (Carer 6)

Reluctance to adopt an identity of carer was also deliberate to some extent, however, due to the perceived negative impact of assuming the identity, which formed the second theme.

Resisting a carer identity

Participants described the negative consequences of adopting the term ‘carer’ both for themselves and for the cared-for person. Participants were concerned that the carer label might subsume other identities such as that of a partner, parent or child (Arksey 2002), and also that accepting the identity could lead to them being expected to take on more caring responsibilities.

More specifically in terms of caring for people with LTCs, participants described a reluctance to adopt the label ‘carer’ due to the cared-for persons’ struggle to accept their need for support from others. Participants reported the distress caused to the cared-for person from feeling that they needed to be cared for:

The hardest part of my dad was him admitting, in himself, that he was ill... my dad has always cared for everybody else... and he’ll worry about me getting ill, or me getting tired and him being this big burden on me. (Carer 5)

To start with, [he] didn’t want me to turn into a carer and every so often [he] will apologise for me becoming a carer. (Carer 15)

Consistent with the findings that some of the caring work undertaken was deliberately minimised, participants resisted framing their work as ‘caring’ to prevent identity disruption to the cared-for individual and help maintain their perception of independence:

Even though on paper I am his carer, sometimes it’s only when people like yourself now have just mentioned it I kind of think, oh, yes, that’s what I actually am... I think again a lot of it is because he is such a fiercely independent proud man that... he doesn’t want me to feel I have to be his carer. (Carer 4)

This suggests that part of the emotional support provided as a carer for people with LTCs is to help them not feel cared for and collude with them to minimise disruption to relationships and identity by constructing and presenting the work within familial roles:

He’d hate... I mean, he didn’t think he’d be cared for, he looks at me as his wife and his friend and moral support and he thinks, well, if [participant] was in that position, I’d do the same for her... he won’t be thinking that I’m in a caring role, any more than I think I’m in a caring role, I think, I’m his wife and that’s why I’m doing it. (Carer 3)

South Asian carers also described how maintaining relationships was an important aspect of caring, and particularly emphasised how this was experienced as an explicit pressure to subsume the caring work into their ‘duty’ within the family:

Religiously and culturally, we are supposed to look after a husband until death do us part... she says, yes she was under a lot of pressure, so she had to do it, there is the duty part of it. (Carer 17 – interpreter)

Influence of identity resistance on access to support

Consistent with previous literature, our data show that care-giving has the potential to have significant psychological and physical consequences. While participants reported feelings of stress and isolation, they described seeing these as less important than the needs of the care recipient:

I was running around here, there, everyone else was more important than myself... I took on the role of taking responsibility all the time... So, then I became depressed and this cycle was going on for quite a few years. (Carer 10)

Despite awareness that support was available, their concerns over whether their caring roles and responsibilities could be defined as legitimate caring work acted as a barrier to accessing such support:

I’m linked up to [a carers support group], but I have to say, I haven’t gone to a lot of their things because I don’t feel it always applies to me... Social Services did an assessment and were willing to give me £100 to do something for myself, but... I didn’t accept it... I felt there are other people that needed that money more. (Carer 15)

I find most of the carers there [at the Carers Centre] are dealing with much harder problems... they’re dealing with things like Alzheimer’s and that type of thing which is completely different... I think that’s set up more for carers with non-independent people. (Carer 7)

Resisting a carer identity could mean that carers avoided explicitly recognising the impact the illness had on them, and consequently were less likely to acknowledge their need for support or ‘respite’. This participant reported only recognising her carer identity retrospectively when her partner moved into...
supported accommodation after being cared for at home for 20 years:
The impact, you never had a day out, you never went for a meal . . . you just don’t realise, because you just go with each day as it comes . . . you don’t see yourself as a carer, you see it as life and you just get on with it, so you don’t recognise it. (Carer 6)

In terms of the type of support required, those carers who did access support found the emotional space and peer support elements to be beneficial:
It’s the one thing I’ve got where it’s away from any kind of caring and to have a moment to offload or even sometimes get advice . . . it’s more the social aspect, just not having to worry, or think about [caring] for them 2 hours. (Carer 5)

We realise that we’re not on our own . . . it’s a sharing thing and that’s what we need to do more of. (Carer 6)

Even participants who did not access support accepted that it might be necessary in future, and that carers may need help in recognising this:
I think the main thing really is trying to get over to carers that they might not think that they need the support, but they do need the support . . . I get physically and emotionally drained and I know at the moment I can cope with it but . . . I’m sure a lot of carers just plod on regardless, and get worse and worse themselves. (Carer 9)

Consistent with the literature on other informal carers, there was little evidence of health professionals proactively recognising the carers’ role. Participants felt, however, that this could be done by health professionals who are well placed to validate their work as being that of a ‘carer’:
That’s where the doctors can break that barrier down, because if they make it easier to speak to us and speak to them, you then have the confidence to go and speak to other people. (Carer 6)

Other participants suggested that healthcare professionals may be best placed to identify carers through their contact with care recipients, and suggested ways in which they could access support:
Say my daughter, so she goes to her yearly diabetic check-up, there should be information there or they should be saying, ‘Well do you get anyone who looks after you? Do you get any care off anyone?’ And then they should say, ‘Oh, well do you know that your mum can get this’ or ‘your mum could go here?’ (Carer 8)

It always starts at the GP, doesn’t it, so that’s one of the earliest places . . . if it was done through the GPs, it’d be caught a lot earlier, and as long as the people then know that there’s support out there a lot earlier, then the opportunity’s there for them to get support and meet other people. (Carer 10)

The South Asian participants particularly emphasised the need for a proactive approach that reached out to carers, given that they had limited opportunities to seek help themselves outside the home or while juggling other family responsibilities:
She says people like us, housewives, we just drop the kids off; we can’t go around looking for organisations for helpers. So, there should be something for people like us. (Carer 18 – Interpreter)

Discussion
The study found several barriers that prevent those who care for people with LTCs from identifying as a carer which in turn hindered access to support. Carers held specific perceptions about legitimate caring work and also reported fears about adopting the label of carer, particularly in terms of the negative impact it would have on the identity of the cared-for person. These barriers prevented carers from recognising that support was available for them or from feeling ‘qualified’ to access support, despite the substantial emotional and practical responsibilities undertaken. Those carers who accessed support emphasised the benefits of emotional space to think about their own needs and feeling connected with other carers. It seemed that in taking on a substantial role in performing emotional work to protect and support the people they cared for, they also recognised the need to do some degree of emotional work to protect themselves to enable sustainability of their caring role.

Comparison with the existing research
Consistent with other studies of caring, participants in our study used comparative narratives (McGarry & Arthur 2001) that involve imagined comparisons with a stereotypical ‘other’. Our data go further to suggest that the nature and extent of caring work undertaken are the key attributes compared, with the work of emotionally supporting relatively independent people with LTCs unfavourably compared to the stereotypical ‘hero’ who ‘puts their life on hold’. Helping carers recognise the importance of the everyday support they provide could help them overcome perceptions of themselves as less deserving of support. Importantly, this finding demonstrates that the current focus on self-management in LTCs could have unintended negative consequences for people in the patients’ social network, if those people do not recognise their contribution and access support when needed.

Studies of elderly carers have reported that they often relied on informal networks of support
(McGarry & Arthur 2001), in contrast to the perceptions reported here. This can be understood, however, particularly in the context of the different types of work discussed by Vassilev et al. As discussed earlier, there is a strong component of emotional work performed by carers of people with LTCs. Crucially, this includes biographical work to help preserve the identity of the cared-for person and prevent disruptions to family relationships to preserve their independence. This has implications for support seeking, because part of this emotional work entailed concealing the impact of the illness and disguising other components of work they were doing, including illness-specific work and everyday work. This may, in turn, further isolate carers from their own potential support networks and account for the relative lack of reliance on informal support apparent in this group. This may account for the high-value carers who did access support placed on being able to share experiences with other carers outside the family. Participants emphasised the need for peer support from other carers, to aid learning and to help ease the isolation experienced which has also been reported by carers in Scandinavia (Stoltz et al. 2004), and a lack of social support has been linked to poorer carer mental health in Australia (Butterworth et al. 2010).

The tension of adopting a narrative of oneself as carer, given that it positions the cared-for person as ‘care recipient’, is well established in relation to dementia care (O’Connor 2007) and manic depression (Henderson 2001). The present study, however, elucidates how this tension also exists and is perhaps amplified by the everyday management of LTCs, where the long-term biographical and emotional care provided is explicitly focused on resisting threats to existing relationships and perceived independence. It was apparent from the data that identity as a carer was evaluated, in terms of social comparison, based on the burden of illness work and the level of dependence of the cared-for person in terms of their ability to carry out everyday work. Given that the carers of people with LTCs are first, primarily engaged in emotional work rather than illness work, and second, engaged in biographical work to minimise disruption which involves minimising the extent of the everyday and illness work they do undertake, this may create a perfect storm of barriers to identification and seeking support for carers of people with LTCs.

Finally, participants in the study struggled to acknowledge themselves as carers due to perceptions that a cared-for person should be entirely dependent. Consistent with other studies, carers tended to instead conceptualise their caring work within family roles (Henderson 2001), but the present study demonstrates how carers of people with LTCs may feel particularly obligated to do this as part of the biographical support provided.

Implications for identifying carers and providing support

Consistent with recommendations from the sociological literature to view caring within the context of relationships (Stevenson 2008), efforts to improve uptake of support therefore need to be sensitive to both the carer and cared-for person’s perceptions of their family roles and to the cared-for person’s identity. Concerns about the disempowering effect on the cared-for individual of the label ‘carer’ have been reported in the wider literature on informal caring (Molyneaux et al. 2011), and demonstrate the need to balance a respect for existing relationships with efforts to actively recognise and value care. Recognising the more collaborative and subtle balancing of caring work undertaken between carers and people with LTCs may help overcome perceptions that cared-for persons must be entirely dependent for carers to ‘qualify’ for support.

The data suggest that health professionals are unlikely to be involved in helping carers to self-identify, consistent with previous research which found healthcare professionals tend to adopt reactive (relying on the carer to self-identify) rather than proactive (supporting the carer to identify) approaches both in the UK (Arksey et al. 2003) and North America (Yaffe & Jacobs 2008). Health professional involvement may itself help to validate the work of the carer, consistent with previous research demonstrating that ‘legitimisation’ is a collaborative undertaking between informal carers and health professionals (May et al. 2001). It is recognised, however, that South Asian carers may be particularly neglected by health professionals due to language barriers and cultural assumptions (Katbamna et al. 2002), and so, future research should explore whether South Asian carers also identify primary care as a focus for support, and if so how culturally sensitive services can be developed.

In the UK, the National Strategy for Carers identified the NHS as being the single most important initial point of contact for many carers, with a particular role for identifying carers in the primary care (The Princess Royal Trust 2003, Arksey & Hirst 2005), which was also reported by our sample. Health professionals may be best placed to more rapidly identify carers as identification could be initiated when the person themselves first becomes ill. Recent studies suggest primary care professionals are open to working with local carer organisations to improve their role in signposting carers to services (Jones et al.
2012), but it is possible that different types of carers, such as those of people with LTCs, would be less likely to identify themselves to professionals.

The findings were discussed with the PPI steering group, who recognised the barriers to the term carer and themselves being unsure whether their work ‘qualified’ as caring. In concordance with the findings, the steering group emphasised the need for early identification, for example, at the point of hospital discharge or following diagnosis, and the need to educate professionals to take advantage of such opportunities, in contrast to the ‘You can take them home now’ mentality (Holzhausen & Clark 2001).

Limitations

Although we explicitly attempted to recruit participants who may not have been involved with carer support groups in an attempt to include participants who may not identify with the carer label at all (and may still be fully ‘hidden carers’), all of our participants reported at least occasional contact with carer support organisations, which suggests they all identified as a ‘carer’ on some level. Nevertheless, the retrospective narratives elicited shed some light on experiences prior to accessing support, and we found that even participants engaging with such groups continued to struggle with the term ‘carer’.

Although we specifically approached two BME Carer Support groups and offered translation services for non-English-speaking participants, we were only able to recruit four South Asian carers. Although the findings were largely consistent, the data do suggest some areas where specific cultural factors impact on caring (such as the perception of explicit duty to the family and the relative isolation of South Asian women who predominantly attend to family responsibilities), and specific research with this population should be a priority for future research, as studies in other countries have demonstrated that the needs and support preferences of carers of different ethnic groups can vary (Navaie-Waliser et al. 2001).

There are also some limitations regarding PPI in the study. We did not include any formal impact assessment and we did not include PPI partners directly in data collection or analysis. Future research should explore whether more in-depth involvement of PPI partners would be beneficial, and if so ensure that training and financial resources are adequately provided.

Conclusions

Changes to the way that conditions are managed, with an increase in self-management approaches for people with LTCs, may risk creating a new group of ‘hidden’ carers who are providing substantial support which is less stereotypically recognisable as ‘caring work’. The study demonstrates the value of PPI in identifying priorities for research – the PPI co-applicant, with her personal experience of being a ‘hidden carer’, was uniquely placed to recognise that relatives/friends of people with LTCs may struggle to acknowledge their caring role, enabling us to explore an otherwise neglected aspect of self-management support. The study identified how social comparison to other ‘ideal’ carers and the need to maintain the cared-for person’s perception of themselves as independent combined to prevent carers of people with LTCs acknowledging their caring role and accessing support. Future research should explore whether health professionals recognise the different kinds of work (illness, everyday and emotional) that carers can be involved in, and whether they have a role in countering negative social comparisons.

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