

Institute of Public Care

A Carer's Life: Implications and Considerations for Commissioning

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1 Why are carers important to commissioning?

People who provide unpaid care for a disabled, seriously-ill or older loved one in the UK save the state £132 billion a year – close to the cost of a second NHS (Buckner and Yeandle, 2015). In a time of austerity, smart commissioners will pay close attention to carers and how to sustain caring roles by providing access to support that minimises the burden and maximises the resilience and wellbeing of this often 'hidden' population.

2 Carers

In 2016 only a third of carers who responded to the Carers UK survey, and had a carer's assessment in the last year, felt that the support they need to look after their own mental and physical health was properly considered. One in five who had a carer's assessment said they received little or no helpful information or advice and did not know where to go for support with caring. Half of carers expect their quality of life to get worse in the next year (Carers UK, 2016).



Coming to terms with the caring role can be a long and painful process that requires a huge emotional adjustment (Gray et al, 2009). The reality for carers in terms of the tasks and roles they perform, the emotions they go through and the quality of life outcomes that family carers experience are either undocumented or researched and reported in silos that relate to carer groups e.g. parent carers, carers of people with dementia, carers of people who have suffered a stroke etc.

3 What did we do?

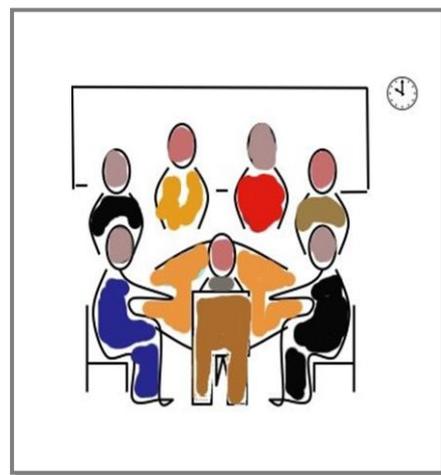
We conducted a study to explore the reality for carers, their quality of life outcomes and the emotional dimensions of their lives across all carer groups to see if there are common themes that are relevant to all carers. Three focus groups were conducted. The only criterion for participation was that participants were both adults and family carers and that they were living in the same house as the person they cared for. This paper discusses the implications for commissioning of that study.

A total of 18 participants, including 15 women and 3 men participated in the three focus groups. All participants were White British. They ranged in age from 38 to 81 years old and had an average age of 55 years. Participants were either caring for their son or daughter, their parent or their spouse. Each focus group contained a mix of carers from across carer groups with carers caring for people with disabilities, mental health conditions, dementia, multiple sclerosis, physical disabilities, autism, Parkinson's and cancer. Focus groups were conducted in three different geographical locations in England: the south-west, west-midlands and the east-midlands.

The following questions were asked at each focus group:

- What tasks do you do as part of your caring role?
- What roles do you play as part of your caring role?
- How does your caring role leave you feeling?
- What is the impact of your caring role on your life?
- What does or would help you?

Focus groups were recorded, transcribed and analysed using Grounded Theory¹.



4 What did we find?

Three common themes were identified:

4.1 The scale of the caring role

The first theme that emerged from analysing the data was 'The scale of the caring role'. It was clear from the vast range of tasks each carer was engaging in that the things they did with or for the person they cared for covered every aspect of daily living. It was also clear that for many of the carers there wasn't much they didn't do either with or for the family member they cared for:

'Perhaps it's easier to say what we don't do.'

The range of tasks and their complexity meant that all the carers performed multiple roles for the cared for person. For some carers there was an element of being forced to take on roles they didn't want and that fundamentally changed the nature of their relationship with the person they cared for:



'.....if you've got somebody that becomes unwell particularly in the mental health context, it kind of immediately forces you into a parent role whether you want to be one or not and if that's your partner then....'

The shift in roles and the impact it had on people's relationships meant that 'being a carer' affected every aspect of their lives. The scale of the caring role isn't just the number of tasks carers are doing or the number of hours they care for. The scale of the caring role is related to the range of roles a carer ends up playing for the cared for person and the impact this has on the relationship.

¹ Grounded Theory is a qualitative research method that offers a practical and flexible approach to collecting "unobtainable views", interpreting complex social concepts and generating theory (Charmaz, 2006).

The enormity of the caring role, the complexity of the tasks involved and the emotional toll of wearing so many hats is seemingly made harder by the onslaught of crisis after crisis, a system that is at breaking point and doesn't successfully involve carers:

'You're sort of then picking up the pieces all the time...'

4.2 THE Skilled Helper

The second theme to emerge from the analysis was that of 'THE skilled helper'. Many people become carers due to negative change in their lives e.g. someone they are close to or live with became ill, had an accident or they've had a child with disabilities. Therefore, many carers wish that they were not having to care because they wish the outcome for their loved one had been different i.e. had not become ill, had an accident or been born with a disability. The nature of the relationship between the carer and cared for person, means that the carer naturally becomes THE default carer. When they look around there is no one to hand the caring baton on to because they are the only person who lives with the cared for person or they are the person's husband, wife, parent, or adult child and there is an expectation that they will care for their loved one. Many carers love the person they care for and so want to protect and look after them. Yet, taking on the caring role is still less of a choice and more of a default position they find themselves in.



Not only do family members find themselves as THE default carer, they become THE skilled helper. This is not least because they tend to be the person who knows the cared for person best. As a husband, wife, parent or adult child they know the cared for person's likes, dislikes, what's important to them, how they like to do things, etc. The knowledge they have about the person they care for makes them very skilled carers and so they become THE skilled helper. Quite often in the eyes of the cared for person and professionals THE skilled helper is the preferred care option:

'.....people have an idea that you should be behaving and conducting yourself in a certain role because that's what is expected of you so there's that added pressure of, of what you want for yourself and what people expect of you.'

The role of THE skilled helper takes over from everything else resulting in a loss of identity:

'The thing is though you lose your self-identity, you don't know who you are anymore, you don't know who you've morphed yourself into.'

Being THE default carer, the one skilled enough to help, demands availability at a moment's notice. For many carers becoming THE skilled helper means that they are very restricted in what they can do and when they can do it which results in a further

loss of identity. Many carers report feeling like their life is on hold whilst they tend to the needs of the cared for person:

'You definitely put your life on hold, I mean, you have aspirations and things you want to do and you just never get round to doing them because you haven't the time or the energy.'

In summary becoming THE Skilled Helper is less of a choice and more of a default position that results in the loss of other roles and a loss of identity. Ultimately, it results in huge levels of sacrifice:

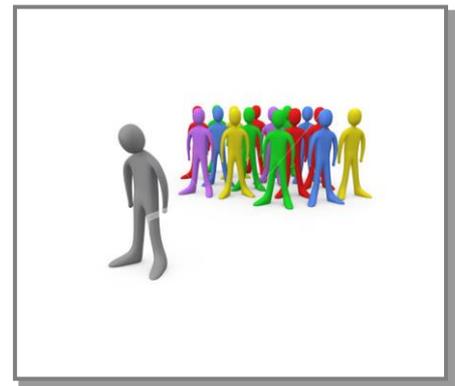
'And this is what as carers we do, we give up a lot, we give up so much.'

4.3 The Hidden world of the carer

The third theme that emerged from the analysis is the concept of the 'hidden world of the carer'. No one really knows what a carer does because most of it occurs behind closed doors, in the family home. From the perspective of service provision and professionals the spot light is on the cared for person. Meanwhile the carer moves around the shadowy edges trying to keep all the plates spinning with little recognition of the expertise they have or the job they do in the background.

'Society does not value what we do.'

This lack of recognition of the role of the carer is compounded by a lack of acknowledgement of the impact the condition of the cared for person has on the carer:



'...they've kind of acknowledged my existence but beyond that it's like nothing, no sort of follow up in terms of the impact it's having on me.'

So not only are the tasks a carer performs invisible because they occur, in the main, behind closed doors but carers are ignored by professionals to the point that they feel invisible and the feelings carers experience remain hidden because no one seems to understand or be able to really listen to them:

'It's just such a dark world, you know, the carer's world is such a dark world because people think they understand but actually until you're put in that position of day in, day out, they have no idea what it's like to, to apply yourself in the same situation over and over again.'

This results in the life of a carer becoming increasingly hidden as they isolate themselves more and more:

'You isolate yourself because other people don't understand.'

Increasingly carers hide their feelings from others:

'And then when you get calls like from your son or you daughter and they go oh how are things? you go fine, fine.'

As the world of the carer becomes smaller and more isolating so their feelings of desperation increase:

'But who cares about whether you live or die, when you're doing that job.'

And there is a loss of hope for the future:

'...you can't necessarily see an end point, it's not like, oh well I've only got this for a couple of months and then it will all be okay.'

5 What do we think our findings mean?

Further analysis of the three themes identified above brings into focus key aspects of the life of carers that have not been explored in literature because previous research has often looked at carers in their silos rather than bringing them together as one group. The following discussion attempts to explore this deeper analysis against the backdrop of previous research thus revealing further commonalities across carer groups and a more profound understanding of a carer's life regardless of who they care for.

5.1 Expectations

The findings suggest that across carer groups many carers do not proactively 'choose' to care but rather are in a position where they can't say no to the caring role either because of the practicalities, finances or expectations placed upon them.

These expectations can come from a range of places. Expectations of themselves to be a good parent, or partner/spouse; or expectations of the person in need of care that their parent, partner/spouse, sibling or adult child will automatically, without question, be there to care for them. The expectations of other family and friends and the expectations of health and/or social care professionals who make assumptions about the caring role a person will play without ever asking if they want to or feel they can do. In fact there is some evidence to suggest that some professionals (unconsciously perhaps) are very skilled at 'persuading' people to take on caring roles when discharging the person in need of care from hospital (Westlake et al, 2016).



5.2 Identity

Many of the carers talked about how taking on the role of carer meant losing other roles either because it became impossible to continue with other activities such as work (and hence losing the role of employee); or because becoming a carer for their spouse

meant they felt like they had stopped being their wife or husband because the two roles were in conflict.

Some carers do not identify with the label 'carer' (Knowles et al, 2016). Knowles et al (2016) identified that the majority of research has focused on barriers to accessing support for carers of very dependent people and that little research has explored whether 'hidden' caring may occur in the context of people living with those who self-manage their long-term conditions at home. Knowles et al state that supporting self-management of long-term conditions involves considerable biographical and emotional support and that the barriers to identifying as a carer include self-comparison to stereotypical caring duties and a desire to protect the cared-for person's identity as independent. This requires us to consider whether 'carer' is the most useful term for identifying people in need of support (Hughes et al, 2013).



Throughout a lifetime our roles might multiply, change or diminish. Likewise our identities are not fixed but shift according to the roles we play at any one time. Similarly, the obligations and social status attached to these roles also change (Goffman, 1959). Society tends to appraise an individual by the way we talk, look and behave. Labelling of behaviour can lead to diminished social and personal identities and roles (Goffman, 1962). When stereotypes, labels and stigma begin, social identities are lost.

5.3 Oppression

Unanimously carers talked about how they were often not listened to and left out of decision making processes. Carers also reported that their caring role exposed them to stigma and judgemental attitudes, and restricted their ability to engage in other activities. Marin (2014) maintains that 'the need to be flexible' is fundamental to the care-giving role and that it is this aspect of care-giving that makes it difficult for carers to engage in activities that are important to them. This is because of the constraints 'being flexible' places on opportunities. These constraints are not limited to the simple logistics of ensuring someone else is present to care for their loved one. Carers spend time meeting the needs of someone else which means that they have less time and energy for developing their own interests and skills. Carers have to be ready for and anticipate new or unpredictable care needs which, makes planning difficult and puts further obstacles in the way of their own self-development. Marin (2014) links these constraints to self-development to Young's (2004) definition of oppression.

Young (2004) states that powerlessness is the strongest form of oppression and she describes constrained opportunity for self-development, lack of decision making power and exposure to disrespectful treatment as being central to the experiences of inequality suffered by oppressed groups. The concept that oppression always involves a dictator employing cruelty as a means of controlling groups of people is inaccurate. In many cases, oppression is the result of well-meaning decision makers developing policies that create 'a normal way of doing things'. These norms are rarely questioned and can become the barriers which prevent a group of people from accessing the same opportunities or attaining the same quality of life outcomes. Oppression can be defined

as systematic and widespread social inequity occurring through the use of power (Case et al, 2012; Deutsch, 2006; Watts et al, 1999). Young (2004) goes on to explain that powerlessness is the strongest form of oppression because 'it allows people to oppress themselves and others'.

To suggest that all carers are oppressed is inaccurate and overstated. Environmental and individual factors are likely to affect one's experience of oppression (Perez and Soto, 2011). For example, the degree to which carers are unable to engage in activities for their own interest and self-development depends, in part, on the flexibility of the support they receive from their social network and the help they get from services. But many carers report incidents of not receiving the help they need and as a result experience negative emotions and poor quality of life outcomes (Langridge, 2002; Bruce and Paterson, 2000; Thompson and Briggs, 2000).

There is also evidence to suggest that repeated individual or group experiences of oppression result in low self-esteem and a sense of not being valued or heard by society. The Carers UK survey in 2014 found that half of carers (49%) said they feel society does not think about them at all.

6 What are the implications for commissioning?

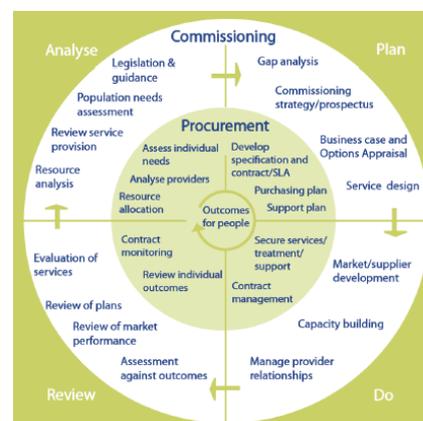
The range of implications for commissioning are considered below against the Institute of Public Care commissioning cycle².

6.1 Analyse

Analysis involves undertaking needs analysis to identify the current and likely future needs of the population; mapping and reviewing services across agencies to understand provider strengths and weaknesses and identifying the resources available and agreeing future resources across agencies.

Understanding the carer population and identifying more hidden carers will require commissioners to:

- Stop using the traditional stereotypes of carers and caring tasks to define and identify carers.
- Raise the awareness of frontline health and social care staff so that they recognise carers even when carers don't identify with the label 'carer'.
- Develop processes so that anyone living with a family member who has a disability, or long-term condition is automatically referred by frontline health or social care staff to the local carer's centre. This will provide opportunity for carer's centres to have an initial conversation with carers thus enabling carer's centres to proactively identify and offer support to carers even when they don't identify with the label. This is important for ensuring that carers get information and advice earlier, rather than waiting until they are in crisis.



² For further information on commissioning visit www.ipc.brookes.ac.uk

6.2 Plan

Planning services and support involves shaping the market and co-designing services and support. To plan services well commissioners need to:

- Support and facilitate carer organisations to raise awareness of carer issues across the community and the various organisations that provide services and support.
- Put the carer voice (along with the voices of those in receipt of care and support) at the centre of strategic planning. The voices of those giving and receiving care should be loud and clear in commissioning strategies and market position statements.
- Ensure carers are involved in co-designing support solutions both for themselves and their family member.
- Work with community organisations to ensure carers have equal access to activities (e.g. work, leisure, exercise, etc) and services (e.g. health, education, community) that help to maintain or develop their sense of well-being.

6.3 Do

Doing involves ensuring that the services needed are delivered as planned. Delivering good support services for carers means that commissioners need to:

- Embed training of health and social care staff into specifications and/or development strategies. Staff should not make assumptions about the degree to which a family member will take on a caring role. We need to help people find ways of engaging in conversations that are more empowering for the potential carer.
- Increase the use of direct payments for carers as a way of increasing the flexibility of services and support. This will enable carers to balance their caring role with other interests and responsibilities so that they maintain their roles and identities past that of being a carer.

6.4 Review

Reviewing involves monitoring the impact of services and support. Reviewing services and support is the best place for commissioners to start when considering whether they support carers to achieve well-being outcomes and what, if anything, needs to be done differently. In reviewing services commissioners should:

- Actively seek out and listen to the voice of carers. Work with carers to design both the review questions and the methods for collecting the data.
- Measure carer outcomes using quality of life measures such as the Carers Outcomes Star.³

³ Carers Outcome Star: Triangle Consulting Social Enterprise Ltd *Carers Star* Online: <http://www.outcomesstar.org.uk/carers-star/>

7 Conclusion

During the focus groups many carers recounted stories of 'reaching the end of their tether' but being forced to continue their caring role because there was no alternative, no services, little support and no one else to do the job. But is that really all carers can hope for – to survive? Is that really what society wants – an army of carers just trying to survive another day? Surely, first and foremost carers are people who have rights and dreams. People who, to be resilient, must be recognised and valued for the experts they are and supported to do the job no one else can do. In a time of austerity can smart commissioners afford to do anything else?

For more information contact the Institute of Public Care on ipc@brookes.ac.uk or call Sarah Broadhurst for an informal chat on (01865) 790312.

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