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Informal carers' experiences of caring for a person with heart failure in a community setting.

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Abstract

Heart failure (HF) is a life limiting condition with a poor prognosis and unpredictable disease trajectory. HF brings physical and emotional challenges for patients and their carers. Predominantly the informal carer population consists of older females, however, caring is evolving as longevity increases and complex conditions are become more commonplace. Consequently, more men and younger people are contributing to daily care. The aim of this study was to explore the positive as well as negative dimensions of caring in HF across a range of carer characteristics. Fourteen semi-structured interviews were conducted with informal carers of people with HF in the UK (median age 71; female 10). Interviews were transcribed verbatim and analysed with the assistance of NVivo10 using Interpretative Phenomenological Analysis. Findings from the study demonstrated that most participants considered caring as integral to their relationships. Dimensions facilitating positivity in caring included compassion, thoughtfulness and understanding. An ability to cope was influenced by a range of attributes including quality of relationships in the carer/patient dyad and with formal social care providers who offered access to tailored and timely information and support. The unpredictable HF disease trajectory influenced the carer experience and enhanced the challenges encountered. The information needs of carers were not always adequately met and younger adult carers expressed particular difficulties with appropriate information and support. Expectations of our informal carer population are increasing and evolving. Health and social care policy requires innovative proposals for the funding and delivery of health and social care that has the contribution made by informal carers at its core.

Keywords

Carers, heart failure, social care, unpredictability, coping

What is known about the topic?

- Financial constraints on health and social care budgets increases the demand on informal carers.
- Evidence suggests the HF carer population are predominantly female, older carers often with their own health issues.
- Carers of people with HF report that the physical requirements of the role impact on their own health.

What this paper adds

- **Insights into the positive dimensions to caring for people with HF.**
- **New understanding of the differing needs of younger and older adult carers**
- **Support for existing evidence about the challenges of caring from the perspectives of informal carers of people with HF.**

Background

Heart failure (HF) is a life-limiting condition associated with debilitating symptoms resulting in poor quality of life. The prevalence of HF increases with age; the estimate in an adult population is approximately 2%, which increases to between 5 and 9% for people aged over 65 years (van Riet et al., 2016). In the UK, HF is the most common cause of medical admission to hospital and readmission rates are high when post-discharge health and social care in the community is limited (Cowie, 2010). HF has a poor prognosis; following the initial diagnosis, survival rates are 50% at five years and 10% at ten years (Roger, 2013).

Whilst carers of people with HF report similar issues to those caring for people with other chronic conditions, HF presents the additional challenge of coping with frequent changes in symptoms. This is alongside the responsibility of managing and administering medication, emergency admissions to hospital and difficulties associated with an unpredictable disease trajectory. Evidence indicates these challenges can impact on carers' physical and psychosocial wellbeing (Doherty et al, 2016.,McIlfatrick et al, 2018). Carers of people with HF report that the physical requirements of the role impact on their own health, which they can neglect due to focusing on meeting the needs of the patient (Petruzzo et al, 2017). A sense of helplessness when the person being cared for is symptomatic, particularly when they are struggling to breathe, can cause carer distress. Carers may become isolated as a reduction in social activities or change in working patterns, can lead to diminished contact with friends, family or work colleagues, enhancing feelings of loneliness (Petruzzo et al ,2017).

Carer burden can increase if the person has recently been discharged home from hospital and the level of social care support available is limited (May et al, 2016). Bidwell et al (2015) demonstrated that carers of people with HF have greater levels of burden and anxiety when there is less social care support available. Based on changing demographics and increasing numbers of people with complex needs, alongside policy changes as to how health and social care is delivered in the UK, this situation is likely to persist, if not worsen, over the coming years.

The aim of this study was to explore the positive as well as negative dimensions of caring for people with HF across a range of carer characteristics. A carer, in the context of this study is defined as 'an unpaid person that provides practical and/or emotional care to a relative or friend' (Candy et al, 2011).

Methods

Study design

This qualitative study formed part of a mixed method study of carers' experiences of HF (Whittingham et al, 2016). The study was conducted in a region of the Midlands in the UK. **The larger study used a qualitative-dominant, mixed methods design following two phases. Phase 1 was a self-completion Family Quality of Life (FAMQOL) survey of 57 carers of people with HF recruited by 8 community-based heart failure nurses (HFNs) in the geographical study area.**

Phase 2, comprised semi-structured interviews with 14 carers recruited from Phase 1. Data were analysed using Interpretative Phenomenological Analysis (IPA).

Data collection took place in 2015 and ethical approval for the study was obtained from the NHS Research Ethics Committee (REC reference: 13/EM/0431)

Sampling and recruitment

The sampling strategy for the study was purposive, based on characteristics of gender, age, relationship and time spent caring, and drawn from the participants in phase 1 of the larger study. It is important to note, however, that whilst the sample was homogenous, as required in IPA methodology (Smith et al., 2011), the aim was not to have a group of individuals which were treated as identical; rather it was to have a sample of individuals who had commonality of the phenomenon being explored but differing experiences (Brocki and Wearden 2006).

An information sheet was provided with the FAMQoL survey about the qualitative study and informal carers were asked to provide their contact details if they would like to participate in a semi-structured interview. The aim was to achieve a sample of up to 15 informal carers.

Consent and Ethical issues

Prior to the interview commencing, the aim of the study was reiterated, and queries were answered. If carers were willing to proceed, they were asked to read and sign a Consent Form. The research team acknowledged the following specific ethical issues: Approaching carers in a sensitive manner in recognition that this was an emotionally vulnerable study population. Due to fluctuating symptoms, carers may not have been willing to be interviewed on a given date if the person with HF had become unwell.

Data collection

Interviews were conducted with informal carers who had identified on the survey that they would be willing to participate. Due to the social context of the study, interviews took place with carers in their own home; reducing inconvenience for participants and assisting in making them feel at ease. This was to facilitate participants to talk openly about their experiences.

Interviews were conducted using a schedule which was informed by relevant literature and ideas emerging from the findings of the FAMQoL survey. The aim was to draw out the participants' perspectives regarding their experiences of being a carer, and feelings regarding the support offered to them. There was also an opportunity to explore how support services address carer needs, issues regarding coordination and communication, and any gaps they felt there may be in support.

Using semi-structured interviews enabled the researcher to steer the interview with prepared questions whilst still allowing a level of spontaneity and opportunity for interviewees to elaborate on their answers. Interviews lasted between 30 and 60 minutes and all interviews were audio recorded.

Analysis

Interviews were transcribed verbatim. The research team independently read and drafted an analytical coding framework from a sample of transcripts. Following critical discussion, the coding framework was refined. The transcripts were read and reread to gain familiarity with commonality, patterns and emerging themes (Smith et al., 2011). Implementing founding theoretical and philosophical principles of IPA, the analysis aimed to deepen understanding of the carers' personal experiences and to interpret the meanings associated with the experience from the perspective of individuals. Whilst it is recognised that the analysis was an iterative process with

researcher reflexivity and the need for a level of fluidity in analysing the transcripts, the following structured steps were taken to derive the themes: reading and rereading; initial noting; development of emergent themes; exploring of connection between themes; looking for patterns across cases.

Superordinate themes were developed to bring together related themes. Themes that represented similar issues in the carer transcripts were highlighted, and codes were reviewed and merged for overlapping codes. Whilst the steps identified were utilised, the core principle of the analysis was to maintain an innovative and iterative stance that evolved when the researcher was fully engaged and immersed within the participant carers' experiences as expressed within the transcripts.

IPA encompasses ideography, a concern with the particular. This is twofold; firstly, there is a commitment to the particular in relation to details and therefore the depth of analysis (Smith et al., 2011). Secondly IPA embodies understanding of how a specific phenomenon is understood from the perspective of particular people in a particular context (Smith et al., 2011). It seeks to understand the uniqueness of individuals' experiences and the meanings associated with a specific phenomenon, and focuses on an individual's personal experience of a certain situation (Clarke, 2009; Watson et al., 2008). IPA recognises the importance of the rich narrative dialogue from which key themes can be analysed (Brocki and Wearden, 2006). It follows the double hermeneutic principle of empathy and questioning.

IPA acknowledges that access to the participants' unique experiences is complex and is influenced by the researcher's own conceptions; thus the process of IPA involves joint reflections from both participant and researcher accounts (Pringle et al., 2011., Brocki and Wearden, 2006). This interconnectivity is dependent on the participants' ability to articulate their experiences and the researcher's capacity to reflect and analyse this dialogue to capture the true essence of the phenomenon.

Findings

Twenty one respondents agreed to participate in an interview. Four of these withdrew from the study prior to the interview; reasons for withdrawal included the patient being admitted to an acute care setting or the patient's condition

deteriorating. Three respondents could not be contacted via telephone and did not respond to a further letter. The final number of participants was fourteen.

Participant characteristics are given in the table 1 and pseudonyms were used in the transcripts and report.

Table 1

PSEUDONYM	GENDER	AGE IN YEARS	RELATIONSHIP TO THE PERSON CARED FOR	HOW LONG THEY HAD BEEN CARING FOR THE PERSON
SUE	Female	37	Wife	5 to 10 years
DAVE	Male	75	Husband	Less than a year
JOHN	Male	88	Husband	5 to 10 years
CLARE	Female	72	Neighbour	More than 10 years
KATE	Female	72	Wife	Less than a year
STELLA	Female	71	Wife	2 years
MAUREEN	Female	77	Wife	Less than a year
MARIE	Female	69	Wife	More than 10 years
SARAH	Female	57	Daughter	More than 10 years
BRIAN	Male	67	Husband	Less than a year
SIMON	Male	43	Husband	18 months
PATRICIA	Female	81	Wife	5 to 10 years
BELINDA	Female	47	Daughter	5 to 10 years
HELEN	Female	40	Granddaughter	5 to 10 years

Three themes emerged from the data: Facing the future; Coping with the challenges of caring and; Rewarding aspects of caring. These are discussed in detail below.

Facing the future: “live every day as if it’s your last”

Many participants described dealing with the unpredictability of the patient's condition by living day to day. Whilst they demonstrated insight into the poor prognosis, most participants talked about taking a day at a time without wanting to look too far into the future. Participants avoided trying to predict what would unfold over the next few weeks and months because they had previously encountered the unpredictability of acute exacerbations. Carers described an existence in which they made no plans, which had implications for maintaining social contacts. This lack of ability to plan applied not only at a social level but also to protect themselves from anticipating what they might be facing over the next months or years.

“My wife got diagnosed when she was 32 weeks pregnant. So that came as quite a shock ... and then we’ve realised now that it’s lifelong. It was life changing for us.” Simon aged 43

The findings demonstrated how strength in the social fabric encircling carers positively influenced the caring experience. It was apparent that the majority of participants viewed caring as integral to their relationship with the person they were caring for. A close bond between some of the couples enabled them to discuss the implications of the condition and helped the carer to feel prepared whilst recognising that they are not able to be in control of what comes next. Most participants alluded to valuing the time they had with the person they were caring for, with acknowledgement of the inevitable outcome of HF, albeit difficult to predict when this may occur. Living as a carer became the normality of their daily lives, a new chapter in their relationship.

“... Dot is my life, and I enjoy it. I always say do you want me to do that, Dot. ... And we’ve got one another. If they’re on their own, it must be awful. It just comes natural to me, that’s it.” John aged 88

For those participants with limited social networks they described how they relied on the input of formal service providers to validate their role. Relationships with domiciliary carers and the voluntary sector services were shown to be meaningful. Participants gave examples of domiciliary care workers who had gone ‘above and beyond’; and exceeded what was required of them.

“The carers that they set up and sent were absolutely amazing. I can’t fault them at all. They were there longer than they billed. They cleaned up. She had the same carers ... they were brilliant.” Helen aged 40

However, as a result of living with the unpredictability of HF, carers faced circumstances in which they became increasingly socially isolated. This was because of reduced access to social activities, lack of respite from their caring responsibilities, or limited social networks.

For several of the participants, it had been necessary for them to make adjustments to their work and home situations to meet their changing circumstances. Three had moved house, and several others described adjusting working hours or giving up work as they were unable to cope with the competing demands.

“I have lost lot of friends through it ... I’m letting them down all the time because I’ve planned to go out and then Mark turns sick.” Sue aged 37

One participant spoke at length about the difficulties she experienced when she and her husband had to move away from the area they had been living for 36 years to find a bungalow that was appropriate for their needs. She made it clear that her new home had been chosen based only on its suitability for caring for her husband.

“I didn’t want to live here ... by this time I was exhausted. I couldn’t care less what the house looked like ... There was no support. I mean I’m stressed out even now after 18 months.” Marie aged 69

Coping with the challenges of caring: “I don’t know how much more I can take”

Participants commonly reported that the physical demands of the role affected their own health both physically and mentally, which they neglected due to focusing on meeting the needs of the patient. Good care requires the needs of both the caregiver and cared for to be addressed appropriately. Many carers were at the point of exhaustion and at times felt deserted and unsupported by services. One participant perceived that the health professionals had dismissed her husband from their care as nothing more could be done for his condition.

“Angry and upset ... feeling he’s been left on his own, nobody cares ...! We’d been given that statement, well your heart’s knackered, nowt they can do for us ... do they just chuck us on scrapheap and that’s it

then ... I think it was just a dismissive attitude ...” Maureen aged 77

Impact on mental health was also evident amongst some participants. A young male carer who was evidently physically fitter than many of the older participants interviewed, several of whom had their own health issues, recognised that the emotional strain was almost intolerable.

“I thought I knew what I was dealing with, you know, but it has definitely been emotionally straining mentally. Sometimes I just think, god, I don’t know how much more I can take.” Simon aged 43

Incongruence in the patient-carer relationship intensified the difficulties in coping. When asked about the effect of caring for her husband on her social activities, one female participant described the dynamic that had always been present in their marriage.

“... how long you going to be? when you’re going to come back? where are you? Oh really anxious ... I felt like, well I couldn’t do anything unless he said I could ...” Sue aged 37

Furthermore, several female participants felt an expectation to maintain the physical support to the person despite their own chronic health issues.

“ It was a nightmare, because I didn’t feel at all well, and of course when you’re not well, you can’t cope ... But it’s mind over matter and I did it, and I’m just very determined ...” Stella aged 71

Younger spousal carers actively sought out information relevant to them and their family via alternative networks, for example social media. These participants felt that HF was commonly associated with older people, and therefore there was a lack of understanding from friends and family of the nature of HF in younger people, particularly when compared to cancer. Participants were saddened that people did not understand that the diagnosis was life-limiting and lacked understanding of the implications of this for younger people and their families living with the condition. These participants used social media to access peer support and information that was fitting to their particular situation.

As a younger adult carer, Simon was frustrated by a lack of awareness in the wider public about the life-limiting nature of his wife’s condition; he sought acknowledgement that she had a ‘disability’. Additionally he wanted public recognition that people with heart conditions need information and appropriate support.

“...there’s no awareness of it, and they don’t understand these conditions. It’s hard, so hard to explain to people what it is and what you’re going through because no one understands it. ... it’s that sort of support ... you don’t know where to go to get it, and that’s a massive thing.” Simon aged 43

He sought validation for the difficulties he encountered and for understanding and empathy; as HF commonly affects older people, the information and support he was offered did not meet his needs. Sue, also a younger adult carer, was obliged to seek information from her peers via the internet.

“ I used the website, Cardiomyopathy Association, and it was like a forum you go on and you explain that you’re a carer ...” Sue aged 38

What was crucial for Sue was that the people she was communicating with were in the same situation as her, namely they were a similar age and caring for someone with the same condition. Peer support was the essential element to the success of the forum and the carers’ sense of ownership.

Evidently, for the participants there were circumstances in their lives that intensified the difficulties in their resilience to cope; this related to both external and intrinsic factors including poorly timed support, incongruence in relationships, their own health needs, gender expectations and lack of understanding.

Rewarding aspects of caring: “it really is a pleasure”

In spite of the emotional demands placed upon them, participants talked about positive and rewarding aspects they gained from providing care. For these carers there was a sense of reciprocity; namely considering the how the other person is experiencing being cared for and viewing caring as a two way process; giving back to someone who has supported them.

*“... she’s my mum. ... if there’s anything I can do to make her quality of life any better I’d do it, so ... at least I can think, well, we did all we could do. And anything you need I’ll do it for you, it’s a pleasure.”
Sarah aged 57*

These participant carers were offering support to a close member of their family and it could be proposed that they were driven by family expectations; however,

another participant described similar rewards when she spoke about caring for her elderly neighbour.

“It’s just something I do automatically. You know, it’s as though she is a relative, it just makes me feel good and ... It makes me feel positive ... that I can help somebody” Clare aged 72

She gained satisfaction in the care she was giving, enjoying the fact that she was helping somebody, and embraced the new knowledge she had gained. She associated caring as something inherent in her personality and considered it her role in life despite never having worked in the caring profession.

The participants felt valued when they were listened to and were viewed as an expert in the person’s care. It was important to them that they were able to be involved with discussions about the patient’s care

“... I think you’ve got to be involved. That’s what it’s all about, isn’t it? I think you’ve got to involve the carer.” Stella aged 71

Fundamental to participants acknowledging rewarding aspects of the role was the relationship they had with the person they were caring for. For those carers with strong emotional bonds with their partner, they did not see what they were doing on a daily basis as an additional expectation, rather a deep-rooted reciprocal part of their relationship.

“Still loving him the same way that I did when I met him, because he’ll say to me sometimes how can you live with me when I’m like this? Because he’s still the same person”. Sue aged 37

An elderly male participant talked about how he considered what he did for his wife as an expression of his love for her. They had a close, loving relationship and had been married for 63 years.

“Well, I wouldn’t want to be caring for anybody that I wasn’t close to, you know, although I have a bit of a caring instinct. But no, Dot is my life, and I enjoy it.” John aged 88

Younger people receiving the diagnosis of HF face living with the implication of the condition being ‘lifelong’. For participants, this impacted on their physical and emotional health with social and financial implications. Yet despite these difficulties

younger adult carers viewed their role as fundamental to their relationship, something they would do without question and unconditionally. Their situation had become 'normal' for their family and they re-established the focus within their relationship; their old life was left behind.

"...I try and turn it into a joke and say yeah, for better or worse, I think I've got the worse, and I try and make it a joke ... I just think as long as we talk to each other." Simon aged 43

This acceptance of the transition and moving into a new phase in the relationship was also evident in Sue's dialogue.

"... we've always been close anyway ... but we've been through that many testing things it's just, like I said I've left my old life behind." Sue aged 38

What appears to be key for couples, young and old, was the depth of the emotional love and respect they had for one another, and this was integral in enabling them to appreciate the rewards caring offered them.

Discussion

The findings from this study demonstrate that carers of people with HF have specific needs which differ from carers of other chronic conditions such as cancer and frailty. These findings show how the unpredictable disease trajectory influenced the carer experience and enhanced the challenges encountered. Despite capacity to encompass this unpredictability into their everyday lives, the subsequent lack of control lead to negative consequences for carer quality of life. Findings also indicated that the information needs of carers were not always adequately met and younger adult carers expressed particular difficulties with appropriate information and support. **However, the findings show essential dimensions to facilitate positivity in caring including compassion, thoughtfulness and understanding. The ability to cope was influenced by a range of attributes including quality of relationships between carers and patients, and with formal care providers, as well as access to tailored and timely information.**

The unpredictable disease trajectory influenced the carer experience and enhanced the difficulties they encountered. Whilst they demonstrated insight into the poor prognosis, many participants described feeling out of control and coped with the unpredictability of the patient's' condition by taking a day at time without wanting to look too far into the future.

Whilst participants in the study showed empathy, compassion and consideration to the person being cared for, several female participants described maintaining their caring duties despite chronic health issues of their own. This finding is similar to that of Williams et al (2017) who conducted focus groups with 36 women and 3 men to explore understanding of Advanced Care Planning. Their findings showed that older female carers framed their responses in the context of gender, believing that caring was normal for women and they were experienced to fulfil the role. Additionally, they spoke of putting their caring duties before their own health needs. However, male participants alluded to a lack of recognition of their own needs and how the enduring demands of the caring role were impacting on their own wellbeing. This highlights the need to move beyond boundaries of gender and consider caring as a normal aspect of human existence with recognition of the associated challenges that should be addressed from an individualised rather than gendered perspective (Barnes, 2012).

HF is typically associated with the older population, and commonly older spousal carers provide support (van Riet et al., 2016). Some participants in the study felt there was a lack of understanding from friends and family of the nature of HF in younger adults. Frustrations were associated with information and support services and how they did not consider the needs of younger adult carers. Doherty et al. (2016) proposed that research evidence indicates a need for information to be fitting for the patient and the stage of the HF. In the absence of such provision, younger adult carers in this study actively sought out information relevant to them and their family via alternative networks, for example social media. Social media has been shown to be a useful means of conveying information and support in other chronic conditions affecting younger people and their carers. For example, Muhammed et al. (2014) described an initiative in which patients and carers developed an online support group for people living with chronic kidney disease, and Craig and Strivens (2016) explored the support available from the Young Onset Dementia Support Group community page. Whilst the latter research focused on patients, they faced similar challenges to the younger carers in the present study. They described lack of access to age-appropriate support, higher levels of unmet need and financial constraints.

Younger adult participants described dealing with an interrupted life course as difficult but considered their circumstances as fundamental to their relationship. The study findings reflect the work of Barnes et al (2006) who demonstrated that caring was accepted as part of ordinary life; despite the difficulties encountered.

Carers' lives were interwoven with an awareness of, and concerns about, family members. There is limited research literature relating to younger adult carers in the context of HF, but the study undertaken by Kimbell et al. (2015) with patients and carers living with advanced liver failure included younger adult carers. They reported similar findings as regards employment, the inability of the patient to work and the subsequent financial pressures this caused.

Over the next few years, people will be working longer due to increasing retirement age, and commonly families do not live in close proximity to each other due to changes in the societal framework. It is timely therefore to reflect on how this will impact on the expectations of younger adult carers in the context of HF. Changes to health and social care provision require increasing emphasis to be placed on informal carers providing support in the community. Whilst research with carers of HF patients indicates the difficulties and complexities associated with this, overwhelmingly these studies have focused on carers aged 60 and above (Doherty et al., 2016).

Secure social networks encircling the participants positively influenced their caring experience. It was apparent that the majority of the participants viewed caring as integral to their relationship with the person they were caring for. Rooted in supportive caring relationships is trust and respect as well as congruence which is considered as a partnership in which there is a mutual understanding of the patient's and carer's needs as regards the implications of the condition (Retrum et al., 2013). A systematic review by Li and Loke (2014) examining the mutual impact of spousal carer and cancer patient dyads, found effective communication within the relationship related to reduced distress and improved adjustment to living with the disease. To cope, couples searched for shared meanings and understanding and tried to retain a positive outlook. These strategies support findings from the present study, in particular in the dialogue of the younger spousal carers who felt they could cope because they were still 'strong' as a couple despite the consequences of the condition.

In being part of a family there is the expectation that older members will be cared for within the family with adult children caring for elderly parents and spouses caring for each other. Engster (2007) extends this responsibility beyond family boundaries to people with whom there is a special kinship and those in a shared close proximity or a social relationship. This is supported by findings from this study with participants comprising spouses, adult children, friends and neighbours who spoke about caring being natural to them and something from which they gained satisfaction. Despite the increased demands this placed on their lives, they enjoyed helping.

Study limitations

This study has provided valuable insight into the day to day experiences of carers of people with HF, however, certain limitations need to be acknowledged. Firstly, only a small number of participants were recruited into the study, representing a convenience, rather than a purposive sample. Nevertheless, the sample did demonstrate variability in the intended purposive characteristics. Additionally, only a small number of male participants were recruited, with the investigation of male carers of people with life-limiting conditions remaining an under-researched area.

Conclusion

Almost one and a half million people provide 50 hours or more care a week for a partner, friend or family member and consequently these unpaid carers make a substantial contribution to society and the NHS (Carers UK, 2019). The recent NHS England Long Term Plan (NHS, 2019) aims to recognise the contribution of carers and sets targets for better recognition, identification, and tailored support for them. Whilst these aims are welcomed, this study has shown the complexity of meeting carers' needs. Health and social care policy requires innovative proposals for funding and delivery of health and social care that has the contribution made by informal carers at its core.

Expectations of our informal carer population are increasing and evolving, with caring considered as integral to the social fabric. The findings from this study show the essential dimensions to facilitate positivity in caring including compassion, thoughtfulness and understanding. However, future health and social care policies should consider how to bridge the gap of unmet needs for carers such as those who have their own health concerns, are socially isolated and may experience incongruence in their relationships, to mitigate against negative aspects of caring.

In advance of the publication of the Social Care green paper at the end of 2019, Carers UK calls for 'concrete measures to support carers to juggle work and care and ensure they receive the financial and practical support to care without putting their own lives on hold' (Carers UK,2019 p6). Future research should explore how services can meet the increasing demands on existing social care provision with an exploration of new and innovative ways of working with the carer population to provide personalised, proactive supportive initiatives that recognise their role in society.

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