SHORE-C
Sussex Health Outcomes Research & Education in Cancer

Consultations with informal cancer caregivers: informing future research on support needs

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brighton and sussex medical school

Contents:

Key findings

1. Informal caregivers are time poor and may not have the mental energy to think about seeking support for themselves

2. Knowledge about what support services are available is patchy, signposting to appropriate services is needed to reduce the burden

Someone to navigate and signpost to appropriate services was the most requested support need

3. Preference for type of support will vary by individual caregiver. Some will need deeper, professional guidance others will take more comfort in the shared experience of peer support

4. A key barrier to accessing support is not knowing what is available, but many caregivers also say they feel guilty about seeking support for themselves

5. Participants were supportive of the proposed project around inequalities in support service provision

The priority topic most frequently suggested by them was research to inform workplace policy

6. Research design should:
Minimise burden, maximise flexibility
Use methods that are emotionally and practically accessible
Clearly communicate purpose and impact to encourage participation

Next Steps

1. Participants identified a number of priority areas for research
2. We will review the existing evidence around these areas to see if there is a research gap which could be developed into an application for funding
3. We will identify potential funders
4. We will consult further with caregivers on topic and funder selection
5. Caregivers will be invited to be co-applicant on any funding application development

Background

The impact of a cancer diagnosis extends beyond the patient, significantly affecting family and friends.

Informal caregivers to people who have received a cancer diagnosis provide significant amounts of care and support, often alongside many other responsibilities such as going to work or looking after children.

This support is important to the wellbeing of the person with cancer, but research shows that there can be a cost to the caregiver, and they may have considerable unmet support needs of their own.

The need for informal caregiving is likely to increase with the rise in the number of people living with and beyond cancer, in an environment where resources may not be increasing at the same rate.

Research on caregiver wellbeing and support is needed and timely.

To better understand **what research is needed**, we spoke with a range of informal cancer caregivers. These discussions were intended to help us design research projects about caregiver support and wellbeing that:

1. Address the questions most important to caregivers
2. Are designed using methods and approaches that are acceptable to caregivers and that are realistic for people to take part in

What did we do?

We held in person and online consultation events with informal caregivers to people who have received a cancer diagnosis.

Consultation events were promoted through a number of charities (in alphabetical order): Care for the Carers, Carers Support West Sussex, Future Dreams, Macmillan Horizon Centre, Shine Cancer Support, Sussex Cancer Fund and the Wolo Foundation.

In total we ran one in person and three online discussion groups and one in person and four online one to one discussions. We also received written contributions from two people.

We spoke with **21 people**. Participants were from a range of ethnic backgrounds and ages. Seven were male. Their relationship to the person with cancer was most commonly spouse/partner (eight people) but also included caring for a parent, a sibling, aunts and uncles, and friends.

During the events, **we asked people to share their thoughts on key topics**:

- What types of support for caregivers they are aware of and what they have accessed
- What types of support for caregivers is needed
- What the barriers and enablers to people seeking and accessing support might be
- What are important areas for research and why these are priorities

In the groups and some one-to-one discussions, we also presented a project we already have in mind and asked for feedback on the idea for the research and the methods we were planning to use.

Services people were aware of and used

Knowledge of available services

- Participants were aware of some support but overall felt they were not really aware of what was available to them and that signposting is poor (see barriers to accessing support)
- The most frequently known sources of support were charities (Maggie's, Macmillan and other cancer specific charities)
- Some were aware of more formal support such as financial assistance and local council carer's assessment or the Carers Health Team
- Many, but not all, were aware that online and in-person support groups for caregivers existed, though these are not always easy to find
- Others were aware that counselling could be accessed via local council services or charities
- Local hospices and community and religious organisations were also recognised as sources of support

Services they had used

Professional counselling and therapeutic support

- Counselling, talking therapies, mindfulness and listening services were accessed through organisations such as Macmillan, local councils, hospices, and carers services
- Experiences varied. Many valued having someone who would listen and understand. Others found counselling intense or less suited to their needs

Peer support groups

- Many participants accessed peer support through local hospices, charities, Macmillan-organised groups, and online communities.
- Shared experiences and understanding from others in similar situations were often seen as particularly beneficial, although some found hearing others' stories difficult or emotionally triggering

Support from healthcare, local authority and cancer support services

- Some caregivers received support from Clinical Nurse Specialists (CNSs), Macmillan nursing teams, family support services, hospices, cancer charities, and the Macmillan helpline
- Other caregivers accessed local council services, including carers' assessments and dedicated counselling or support provision for carers

Need for a range of support options

- Preferences varied considerably between individuals. Some valued professional, one-to-one support, while others found the greatest benefit in informal peer support from people with lived experience
- Participants highlighted the importance of offering multiple formats, including in-person, online, group-based, and individual support, as needs and preferences change over time

Services that are needed

The most requested support was for someone whose role was to signpost to appropriate support services so that the caregiver doesn't have to do the research themselves:

- A significant barrier to accessing support is simply not knowing it is there
- There is so much work involved in trying to find information and understanding eligibility
- There is a lot of information out there and caregivers don't know what is good and what is not

The navigator role could be a paid employee or volunteers. Though it would be essential that they were well informed and trained to avoid any misinformation

Support services that the caregiver could access on demand when the patient has a hospital appointment

It was appreciated however that this would be a costly intervention

More time and support for caregivers in the workplace

More support during the treatment phase, particularly preparation around what to expect to enable planning and organisation which would reduce stress

Support about how to talk to children and manage the family and family communication

Support services specifically designed for young carers

Psychological support/counselling and clearer information on how to access it

Peer support – some participants were unaware that support groups for caregivers exist

A regularly updated handbook with local support available, eligibility criteria and how to access

A diagram to help caregivers understand the different pathways to organise care – this would reduce stress

Barriers and enablers to seeking and accessing support

Lack of awareness and difficulty navigating support

- Caregivers often do not know what support is available, where to find it, or what they need until they reach a point of crisis
- Information about services can be difficult to access, and language barriers can further limit awareness and uptake
- It may be more effective to proactively offer and signpost support rather than expecting caregivers to identify and articulate their needs

Caregiving priorities, guilt, and reluctance to seek help

- Caregivers frequently prioritise the patient's needs above their own and may feel guilty seeking support when they are not the person with cancer
- There can be a tension between recognising the need for self-care and feeling that time spent on themselves takes away from caring

Practical barriers to accessing support

- Lack of time, exhaustion, work commitments, and caring responsibilities can make it difficult to engage with support services
- In-person support groups may be inaccessible due to timing, location, transport issues, or an inability to leave the person they care for.

Need for flexible and personalised support options

- Support needs vary considerably between individuals and can change over time; what works for one caregiver may not work for another
- Online options can improve accessibility and flexibility, particularly for those balancing work and caring responsibilities, although they do not suit everyone
- Some caregivers prefer face-to-face interaction, highlighting the need for a range of support formats

Challenges with support group and counselling models

- Not all caregivers are comfortable discussing their experiences with others, particularly when hearing stories from people at different stages of their journey
- Comparing themselves with other caregivers can create additional stress or feelings of inadequacy
- Some may find one-to-one support or counselling emotionally difficult and may be reluctant to express their feelings openly.

Need for recognition and proactive support for caregivers

- Caregivers often feel that healthcare services focus primarily on the patient, leaving their own needs overlooked
- Support offered during treatment may not always be taken up because caregivers are focused on coping and may not yet recognise their need for help
- Sign-posting to support services by a health care professional can validate caregivers' experiences and give "permission" to acknowledge and address their own wellbeing needs

Priority areas for research

Views on the proposed project

- We proposed a project to look at inequalities in support service provision, using a national survey and interviews with a smaller group
- Participants supported the methodology, appreciating that the survey gives you a wider range of viewpoints through large scale data collection whilst the interviews give greater depth and opportunity to better understand people's experiences
- Participants noted several points including:
    - flexibility will be key when scheduling interviews and neither the survey nor the interviews should take too long to complete
    - not everyone has access to or is able to use the internet, which might cause some bias in who responds to an online survey

Priority areas for research identified by participants

- Participant suggested 28 topics for research. Some are listed below
- Most frequently suggested topic was research to inform workplace policy. The personal and societal impact is large if caregivers have to stop working
- How can caregivers be supported to look after their own physical and mental health?
- The impact of stress on caregiver physical health
- How can caregivers be supported to return to everyday life and activities after a period of caring?
- 'Prehabilitation' – how can the information and support be put in place to prevent crisis, rather than fixing it after it has happened?
- Could caregivers benefit from emotional and informational support delivered via AI chatbot?
- How to capitalise on positive experiences of caring, where events can carry more quality and richness because of the situation
- Recognising and reducing the loneliness, loss of identity and loss of confidence that can be part of being a caregiver
- inclusion of carers in the clinical decision making and the inclusion of caregiving role in those discussions and decisions - i.e. the practicalities of supporting that person and the impact on the caregiver are considered as part of the overall planning
- Developing and evaluating series of postcards (concrete or digital) which can be shared with friends and family to identify tasks the caregiver would like support with. Further sets could be for carers to give to their employers and for young carers to give to teachers or other adults in their life to highlight support needs.
- We will review the existing evidence around these and participants' other suggestions to see if there is a research gap that we could develop into an application for funding

Considerations when designing research for caregivers

Minimise burden and maximise flexibility

- Participation should be brief and easy to fit around caregiving responsibilities
- Flexible, self-paced, in your own time options may be preferred over fixed appointments, as caring demands can change unexpectedly

Carefully consider timing and setting

- Hospital appointments may be appropriate for introducing or promoting the study, but often not for completing research activities
- Research should be accessible across multiple settings and formats to reach caregivers at different stages of their journey

Choose methods that are emotionally and practically accessible

- Interviews can feel more personal and meaningful than surveys, but some caregivers may not be in the right emotional state for these conversations
- One-to-one interviews may be preferable to focus groups, which can feel overwhelming, triggering, or difficult to attend
- Any method should be sensitive to caregivers' limited time and emotional capacity

Clearly communicate purpose and impact

- Caregivers are more likely to participate when they understand how the research will benefit future caregivers, improve services, or address gaps in current support
- Providing a clear rationale and anticipated outcomes helps justify the time commitment and can make participants feel their experiences are valued and recognised

Support recruitment through trusted, appropriate channels

- If recruiting through the NHS or hospitals, strong local champions and advocates can help raise awareness and encourage participation
- Care should be taken to ensure caregivers do not feel pressured to take part simply because the invitation comes through healthcare services
- Relying solely on hospital-based recruitment risks excluding caregivers who are no longer in active treatment settings
- Piloting recruitment and research methods with a small group would help assess feasibility and acceptability before wider rollout

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Contact Us

If you would like to know more about our work, if you have any questions about the consultation events or if you would like to share your views on this topic, please get in touch

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