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Lessons learned from the engagement project with older informal caregivers of people with multimorbidity

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PROJECT BRIEFING



AIMS

- To explore the experiences, key support requirements, and unmet support needs of older (aged ≥ 60 years) informal caregivers who live with a chronic condition(s) while looking after someone living with multimorbidity.
- To co-develop potential needs-based support strategies that could improve the quality of life and well-being of informal caregivers in the future.



BACKGROUND

- Rates of multimorbidity (co-existence ≥ 2 long-term conditions within an individual) are increasing rapidly in the UK, especially among older adults (aged ≥ 60 years) and those from disadvantaged backgrounds.¹
- Over 60% of UK older adults live with multimorbidity, with predictions suggesting a doubling of rates of older people with complex multimorbidity (≥ 4 conditions) by 2035.²
- People with multimorbidity often have highly complex healthcare needs and are more likely to rely on informal (unpaid) caregivers (family, friends, neighbours) to assist in the management of their conditions.
- One in five adults in Scotland provides regular informal care to a person with one or more long-term conditions.³
- Nearly two-thirds of older informal caregivers (aged >60) have long-term conditions or a disability themselves.³
- Over 80% of older informal caregivers who participated in a recent survey⁴ reported that their physical and mental health had been affected by their caregiving role.
- One in four older informal caregivers who participated in a recent survey⁴ reported difficulties in finding the support they need and 11% reported that they had not yet found support.



WHAT THE PROJECT INVOLVED

- An online survey with older (aged ≥ 60 years) unpaid caregivers to map the main areas of their unmet needs using the Carer Support Needs Assessment Tool.⁶
- An online workshop to discuss the survey findings and learn more about the experiences and unmet support needs of people who are caring for a person (eg, family member, relative, friend) with multiple long-term conditions. The workshop also aimed to build a group consensus on key support needs to be integrated into an interactive tool to be used during the in-person workshop.
- An in-person workshop to identify and co-develop potential needs-based support strategies that could improve the quality of life and well-being of unpaid carers in the future.



KEY MESSAGES

- **Access to support:** Caregiving was described as a demanding and *'life-changing role'*, especially for caregivers who had no previous experience or awareness of it. Physical health and psychosocial issues such as anxiety or a sense of despair were common among older informal caregivers and some felt trapped in *'the cultural expectations of the ability to provide support irrespective of caregivers' own health problems'*. Caregivers felt they needed tailored support to look after their own health and practical help around the house to *'keep going'*. Timely access to psychological support, peer and family support, and help from paid carers is fundamental to helping caregivers in their role and providing a balanced and varied approach to support for care recipients. Access to care and support from healthcare professionals was felt by caregivers like a *'constant battle'* and needs to be addressed.
- **Access to information:** Caregivers felt overwhelmed with how much information is *'out there in the cloud'*. Caregivers often needed specialised information about care recipients' multiple long-term conditions and how these could progress over time. Knowing what to expect in the future and how to manage symptoms, for instance, *'constant crying because this is the only emotion that now knows'*, was critical, yet hard to access.
- **Access to assistive technology:** Caregivers valued assistive technology if it was effective in improving the care recipients' functioning and independence and reducing caregiver burden. Caregivers question the effectiveness of certain assistive technology when little user guidance was provided. One caregiver mentioned that *'technology often fails'* and anxiety related to responding to alerts often puts both care recipients and caregivers off from using assistive technology again. Complex needs often cannot be addressed with pre-purchased assistive technology available through social care services. This approach reduces allied healthcare professionals' ability to employ assistive technology tailored to individual needs. Caregivers prioritised a need for investment in developing new equipment or assistive technology to better support both informal and paid caregivers in their roles. The problem however lies predominantly in the social care system needing a change in how the

assessment process for assistive technology is made to ensure it meets both care recipients' and caregivers' needs and health goals.

- **Anticipatory care planning:** Caregivers were worried about *'what the future holds for them and their care recipient'*. In this context, little if any consideration was given to the care of *'invisible'* family members including pets. Caregivers shared a sentiment that every caregiver in Scotland should have an anticipatory care plan detailing actions to take in a *'crisis'*. Lack of clarity and uncertainty *on 'where and how to turn for support when the crisis hits'* is an added stressor, needing rapid resolution on the health and social care services part.
- **Breaks from caring:** Caregivers felt there were limited respite care options, with arranging a short stay in a care home being *'practically challenging, if impossible'*. Respite allows caregivers and care recipients to take a break from their daily routines. It gives an opportunity for caregivers to take time out for self-care and to break the feeling that *'life revolves around caregiving'*. Local councils should prioritise addressing barriers to accessing respite care services (many of which shut down during the pandemic but have been slow to open up) to help caregivers and care recipients with multimorbidity sustain their quality of life and wellbeing.
- **Access to financial support:** Although most of the caregivers who took part in our project experienced no acute financial hardship, caregiving is associated with direct out-of-pocket costs and, in the context of a cost-of-living crisis, may affect long-term financial security. One caregiver described accessing a private consultant and paying out-of-pocket £85 per hour for a consultant's time as the waiting time to see an NHS healthcare professional was estimated at 26 weeks. Other caregivers felt that care provision for people with multimorbidity was equivalent to *'a full-time job'* which should be acknowledged by policy-makers and funded appropriately. They felt that gift cards or special schemes need to be put in place to assist older informal caregivers who are lonely, lack wider family support, and especially, those who live in financial vulnerability.



KEY LESSONS LEARNED

- **Recruitment:** Recruiting older caregivers and ensuring ongoing involvement can be a challenge due to numerous reasons. Limitations on caregivers' time mean that they struggle to commit to additional activities, and caregivers discussed that many unpaid carers do not see themselves as caregivers as *'they are simply looking after a loved one'*. Additionally, common recruitment methods, such as through social media, had limited success with reaching the intended audience, and advertising a monetary incentive for completing the online survey and workshop posed additional challenges in terms of the authenticity of potential participants. This was overcome by requiring potential participants to have their cameras turned on during the online workshop.

- **Flexible approach:** To help address some of the above recruitment challenges, it is important to be flexible in how caregivers can be involved in projects. This includes offering sessions at different times of the day so that informal caregivers can fit their involvement around their caring commitments, and offering remote videoconferencing or individual sessions for caregivers who do not wish to travel or join a group session.
- **Third sector collaboration:** Charities offer invaluable support to informal caregivers and build up trusted relationships with their clients. Collaboration with third sector organisations should begin prior to grant submission to maximise the benefits of their networks. Ideally, collaboration would allow time for researchers to speak to clients in person, thereby limiting some of the recruitment challenges mentioned above.
- **Time considerations:** Caregiving is a very emotive and sensitive topic and workshop participants appreciated the opportunity to share their personal experiences with others. Ample time should be provided so that informal caregivers have the space to share their stories and feel listened to.
- **Student involvement:** A number of design postgraduate students volunteered their time to support this project. Including students from a non-healthcare background and from different cultures meant that the designs for the needs-based support solutions were approached from a fresh perspective and allowed for the exploration of topics that may have not been considered by those with previous experience in the field.
- **Reimbursement through vouchers vs a social event:** The traditional approach to thanking patient and public contributors for their time in projects is through a monetary voucher, which is the approach that we took for the first online workshop. Advertising this reward may have contributed to the challenge of unauthentic participants signing-up. In contrast, a social event (ie, an afternoon tea reception) was provided as a thank you to informal caregivers joining the in-person workshop. Caregivers widely praised this opportunity, mentioning that they appreciated the occasion to meet other caregivers and researchers in a relaxed environment and have respite and time away from their caring responsibilities.
- **Clarity on the next steps:** It is important to provide a clear pathway detailing the next steps so that participants are aware of how their input will impact future projects. This was a particular point of discussion during our second workshop.



FINAL REMARKS

- Our ageing society puts enormous strain on health and welfare support systems to meet the needs of older caregivers and care recipients. Promoting informal caregiving is a potential avenue for policymakers to reduce this amounting pressure on services. However, informal caregiving comes at a high cost to older caregivers of people with multimorbidity - a heterogeneous group with diverse and complex support needs.

- Addressing unmet support needs of older informal caregivers and care recipients with multimorbidity requires a multidimensional approach that considers a dynamic interplay between caregiver characteristics and a network of social support available and wider social, economic, cultural, and systems factors. Informal caregivers want the best for care recipients, but promises to address the crisis in social care is not happening. Action should be taken now, otherwise, we might break the very people who keep our *'broken social care system'* going.

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