



Supporting older people with multimorbidity: Experiences of caregiver burden among paid care workers in Ireland

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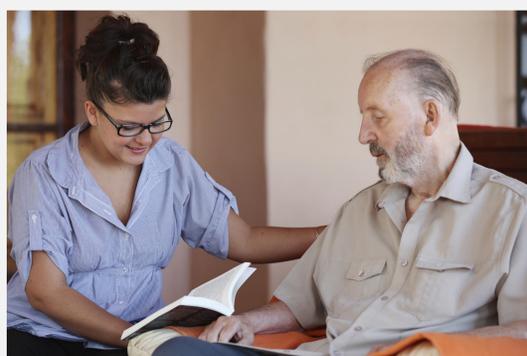
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Background

As the number of older people with multiple chronic health conditions increases, there is a growing recognition of the burden associated with management of these conditions, for both the person with multimorbidity (PwM) and their caregivers. Care support networks for older PwMs increasingly include paid healthcare assistants (HCAs), yet, there has been little examination of the challenges experienced by such care workers in supporting their clients.



The work of HCAs gets little recognition, despite the crucial role they play in supporting the most vulnerable in our communities. The current study aimed to explore the experiences of HCAs in Ireland, who support community-dwelling older people with multiple health conditions. The data presented here were collected as part of a wider requirements gathering study to inform the design of ProACT, a digital health ecosystem that aims to improve integration of care for older PwMs and members of their care network.

Methodology

- Focus groups were conducted in Dublin and Louth with Healthcare Assistants (HCAs) (n=14, f=13) and Quality Assurance Managers (n = 5) from a national home care organisation.
- Focus groups, lasting between 45 and 120 minutes included questions asked as a series of open-ended probes.
- Discussions were recorded and transcribed verbatim for analysis.
- Nvivo (Version 11) data analysis software was used for coding and analysis. Codes were developed iteratively, following a semantic thematic analysis approach.

Key Findings

HCAs experience a range of challenges in caring for older people with multimorbid, chronic health conditions, a responsibility few take lightly. Lack of sufficient time to complete tasks was identified as a significant barrier to providing the best care and a source of job-related stress.

Difficulties in providing medication support, lack of information and poor communication were also highlighted as impacting care provision. Additionally, job-related stress including: emotional stress, role limitations, unreasonable expectations of clients or family members, inadequate training and lack of equipment and resources were identified as ongoing challenges faced by HCAs providing care for older PwMs.

Results

A range of challenges are experienced by HCAs who support older PwMs in a home care context. Verbatim quotes from focus group participants highlight some of the key issues:

A lack of information needed to support clients: 'you get information that some people think is relevant enough but don't give you the overall picture.' (05-0011). 'You get the care plan which basically lists out if they are mobile or immobile, if they are on meds and whatever' (05-0002), 'it's very brief' (05-0006).

Poor communication across the care network: 'if you are coming and going, you don't always have the full picture' (05-0011). 'unless you know the other carer, maybe you have a phone number and you can send her a text or whatever' (05-0005).

Frustration of role limitations: 'you are the man in the middle but you're not really' (05-0011), 'you kind of have to be aware of your place' (05-0006).

Insufficient time to provide care: 'it's a strip bath, you have to strip him, you bath him, everything, you make his bed ...that is a priority, you must do it in the morning, so then you have to make his meal, all ...[in] 30 minutes!' (05-0016).

Dealing with aggressive behaviour: 'believe me, talking of anger, it's hellfire!' (05-0016), 'for the first time in my life I feel like crying... this anger is too much' (05-0015). '.... [he] spat on me...maybe you want to wash and dress him, it's tough' (05-0017). 'Caregivers must have a strategy to make sure they have the ability to handle that' (05-0016).

A sense of responsibility for clients: 'once the carer goes in, the family step way back and it's all yours' (05-0002).

Worry and concern for clients: 'sometimes I don't even want to go home because I don't want to leave him, so it's affecting me at home that way, you know...I'm thinking about him and that' (05-0004). 'I find that difficult sometimes. I find it upsetting' (05-0002).

Discussion

A wide range of challenges have been identified as routine experiences for HCAs working in the community. These data suggest that the concept of a 'burden of care' may be both relevant and underrecognised in paid caregivers.

This critical cohort of care providers are expected to meet the physical and emotional demands of providing care with compassion, dignity and respect.

Additional research is needed to further explore care provision experiences of paid home healthcare assistants and inform strategies and responses to reduce such burden of care for members of this essential workforce.

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