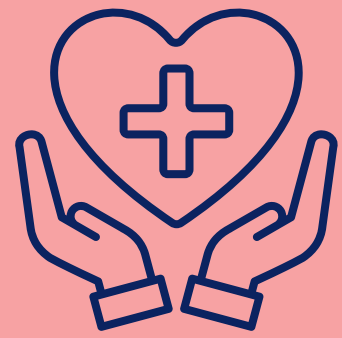


Online Guidance to Support Unpaid Carers After Hospital Discharge: A Participatory Co-design Approach to Understand What Works, for Whom, and in What Context.

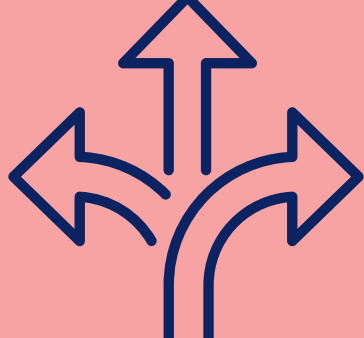
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BACKGROUND



Unpaid carers often support coordination during hospital discharge for older adults (aged ≥65 years) with dementia and long-term conditions.



However, they frequently encounter unclear guidance, inconsistent information, and difficulties navigating health and care services, which can increase stress.



In an attempt to bridge the gap, many seek support via online information, yet the usefulness and accessibility of this information remains unclear.



This study aimed to identify the contexts and mechanisms enabling carers to successfully find, access, and use online information during hospital-to-home transitions.

METHODS

- Carers searched online for information to support their needs following discharge home after an acute hospital stay for a person with dementia.
- Information was extracted into a reference framework based on UK statutory discharge guidance for content analysis.



- Carers completed detailed narrative accounts to reflect on their lived experiences during the task, and semi-structured interviews were conducted afterwards.
- Data were analysed inductively and deductively following a realist approach.

This work formed part of a realist evaluation

Which explains how complex processes work

By identifying context, mechanisms and outcome patterns

RESULTS



- Seven carers took part. All were female, aged between 22 -76 years.



- Four carers provided support to more than one person.



- Most reported caring for someone with Alzheimer’s Disease (n = 6) and an average of 2.7 long-term conditions.



- Participants extracted data from 18 webpages, across 10 websites including national & local charities and the NHS.

- Findings from the content analysis highlighted differences in the information covered across the websites, with only one source (Alzheimer’s Society) including information in all of the framerowrk criteria.
- Multiple participants visited the same information sources, but reported differences in the information they contained, highlighting limitations with website accessibility and navigation.
- Data frequently described a mismatch between website content (e.g., references to case managers or information provision) and lived experiences.
- Carers felt the guidance did not adequately support their needs. Many were unaware of carers’ rights or available community support.

Finding 1) Carer Identity

Sudden, unsupported transitions into caregiving were overwhelming, resulting in carers minimising their own needs through ongoing, patient-focused interactions.

Viewing caregiving as a normal family role reduced engagement with supportive information.

Finding 2) Relationship with Healthcare Professionals (HCP)

Credible, centralised information, aligned with lived experience and signposted by HCPs enabled engagement by acknowledging the carer’s role in patient care.

HCPs were a credible source to signpost carers to relevant information, reducing navigation overwhelm.

Finding 3) Information Resources

Accessible, structured and empathetic information supports understanding and agency, whereas fragmented, impersonal or vague content reduces engagement and reinforces carer burden and feelings of invisibility.

Step-by-step information about discharge planning reduced uncertainty by giving carers more control.

CONCLUSION

1

Carers need proactive, early signposting to information during hospital discharge as reliance on them finding and navigating this information alone is insufficient.

2

There was a need for clear, segmented information explaining hospital admission and discharge processes, improved website navigation, and content more empathetic to carers’ needs.

3

Interactions with HCPs can serve as a point to legitimise carers’ needs during transitions, while acknowledging the carer role in patient care.

4

Findings informed recommendations to improve accessibility and relevance of online information for carers, with context-specific mechanisms to support their engagement.