Keeping implementation in mind: development of an e-mental health intervention for caregivers of people living with kidney disease

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The Problem

- E-mental health interventions can provide caregivers with mental health support which can be easier to access compared to in-person interventions
- Some evidence has shown e-mental health interventions are effective for caregivers
- However, few interventions for caregivers are implemented into practice

Study I: Caregiver support context and needs

Aim: Explore caregiver experiences accessing or receiving support

Methods: Interviews with 13 caregivers analysed using reflexive thematic analysis

Findings:
- Caregivers had to navigate complex health and social care systems while seeking support which was challenging

  “Because sometimes I think, we have a wonderful NHS in this country. But it felt like so many of the emotional problems were caused by the systemic issues.”

  Olivia – carer for her husband

- Caregivers had to independently find the information and support they needed using their own skills. However, having to rely on themselves for support left some support barriers unaddressed

  “We went to the first appointment and the doctor said, ‘right yes, you’ve got PKD [polycystic kidney disease], […] It was me who went home and did all the research and joined all the groups, did all the reading.”

  Freya – carer for her husband

- Support systems had the potential to help caregivers cope with the caregiving role if they were empathetic and reliable

  “I feel that if something really desperately terrible happened or whatever I would have the support here, definitely”

  Emily – carer for her husband

Study II: Caregiver’s caring situation and intervention preferences

Aim: Examine the caring situation, mental health, and intervention preferences among caregivers

Methods: Online survey with 65 caregivers

Findings:
- 58% of caregivers were experiencing at least mild depressive symptoms
- 51% of caregivers were likely to use a self-help intervention
- Preferred an internet-based or workbook intervention
- Wanted a wide range of topics including information about living with kidney disease, support services, physical health
- 62% wanted extra support as part of the intervention provided in-person or via email from a trained professional at a community organisation

Interventions need to be flexible as needs and preferences can change

Read the full paper here:

Next steps

Apply an equity lens to intervention development to ensure interventions are accessible and acceptable to people with different backgrounds and resources

Deeper exploration of social networks to guide implementation planning

Think about how to build care pathways and policies to better integrate caregiver support into healthcare systems

References


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