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Exploration of family carers' experiences of support for rapid discharge arrangements for end-of-life care at home: a qualitative study

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Background and study aim

- Family carers play an integral role in achieving successful hospital discharge especially when people would prefer to die at home (Larsson et al. 2018)
- Strategic Framework for Action – access to palliative and end of life care services (Scottish Government 2015)
- The Carer (Scotland) Act (2016) – individual assessment of carers' needs
- In the North-East of Scotland, there is a lack of information on how prepared family carers were when their loved ones were discharge rapidly from hospital to home
- Aim of this study was to explore family carers' experiences of support for rapid discharge for end-of-life care at home

Methods

Ethics approval: South East Scotland Research Ethics Committee

Eligibility criteria:

- Mix of spouses/friends/parents/siblings
- Bereaved between 3 months to a year post bereavement
- Are aged 16 years and above and have no mental or cognitive disability

Interviews via Zoom Online/MS Teams between December 2020 and April 2022

Topic guide:

- Support received when the patient was discharged from hospital to home
- Concerns and worries and what helped them in caring for the patient
- Preferences for support and what could have been done differently

Interviews were transcribed and analysed thematically (Braun and Clarke 2019)

Recruitment:

- 9 main family carers/friend (Age range 50 – 77)
- 5 other family members (Age range 16 -52)

Findings

	Key themes
1	Challenges around communications
2	Uncertainty arising from planning and inclusion of family carers in the care process
3	Possible psychological impacts and a need for additional support
4	Impacts of the COVID-19 pandemic upon overarching care process

Theme 1: Challenges around communications

- Arrangement and process of discharge is often unclear
- Clarity around the role of family carer
- Inconsistent lines of communication during the climate of COVID-19
- Some participants described being *“left out of the loop”*.

“It was really, because you couldn’t get, and you would phone and the wards, I understand, were really busy but, the phone would ring and ring and ring and eventually, well, we’d phone mum via her mobile, it was the only way we could get any sort of information.” (Daughter)

Theme 2: Uncertainty arising from planning and inclusion of family carers in care process

- Mismatch of expectations of care and the reality of how included they were in the care process
- Support from community staff/GPs helped to clarify uncertainties
- A clear and defined care plan and this should occur prior to discharge of the patient from hospital

“I'm finding that quite traumatic, [...] at the point of discharging people, for somebody to sit down with the family, or with the main carer, and so, you know, your loved one's coming home to die, how involved do you want to be in his medical care? How prepared do you feel? What questions do you have? Is there anything that we can do to make you feel more prepared, oh, you know, all those questions I had that I didn't get answered.” (Wife)

Theme 3: Possible psychological impacts and a need for additional support

- Caring is an emotional and complex experience
- Caring responsibilities may affect the wellbeing of family carers
- Knowledge, reassurance and actions provided by some staff aided in clarifying uncertainties in the home care process
- Psychological support services

Our GP, who is, we're very fortunate, is very experienced in end of life and palliative care, by contrast, was very confident and very reassuring erm, that she, she could help us manage any symptoms of breathlessness in the community that, should the oxygen not be enough. And the other team who were absolutely fantastic, were the home oxygen team." (Wife)

"Being able to talk about it to people other than family. [...] talk about strategies that I can use to deal with big emotions. Erm, just a place to vent if I needed to vent. And, but mostly just really helpful giving me coping strategies and, erm, ideas about memory work as well. if I'm feeling particularly... sad, or particularly anxious or angry. So, we've looked at lots of different things. I started a sort of journal, which has been really helpful." (Daughter)

Theme 4: Impacts of the COVID-19 pandemic upon overarching care process

- Impacts of COVID-19 pandemic were multiple over the experiences of family carers
- Distancing procedures and telephone-based communications as ways of working impacted on care plan/journey
- For example, one of the participants describes the support using digital technology as helpful:

“Neither wife (patient) or I were particularly religious, but she (referring to the Chaplain) was just nice to chat with, you know. And we actually, we had, again, because of the Covid thing, the chaplain wasn't allowed to do house visits afterwards, however, we had a, one of these ‘Near Me’ calls, you know, and, I think wife - found that quite helpful and, it was a worthwhile thing to do...” (Husband)

Conclusion

- Caring is an emotional and complex experience for family carers/members
- Family carers would prefer to be involved directly in the process and arrangements for end of life care at home
- They indicated the need to participate in the construction of the home care plan, clarity of their role, expectations, limitations and reality of caring at home
- Some bespoke training (practicality of caring activities) and psychological support for themselves (respite, mindfulness, befriending) would be beneficial.

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Any questions?

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