

What do unpaid carers find helps or hinders their resilience when providing end of life care at home in the United Kingdom- findings of a scoping review

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INTRODUCTION

The number of people choosing to die at home in the United Kingdom (UK) is increasing [1] and this trend is set to continue [2]. Support from family or friends is fundamental to people being able to die at home [3] and is relied heavily upon by health and social care services [4].

Unpaid carers may need a complex range of support from health and social care services (HSCP) as caring can have both negative and positive effects on carers health and wellbeing [5-8].

Unpaid carers support needs are not assessed as routine practice by HSCP in the UK [4][9].

Understanding what these unpaid carers themselves find impacts their resilience or ability to continue to care despite the potential adversity they are experiencing is essential if services are to adequately support unpaid carers.

METHOD

Scoping review conducted to identify current UK based studies exploring the factors that impact unpaid carer resilience when caring for someone nearing the end of life.

Seven databases were searched for literature published from 2008 onwards.

Literature was limited by geographical area, language, research type and phase of disease progression.

CONCLUSIONS

- Lack of current UK based research which focuses on factors which impact the resilience of unpaid carers.
- Research identified relied mostly on recollections of bereaved carers rather than unpaid carers currently caring for someone who is dying at home.
- Further research is needed to explore what current unpaid carers find helps or hinders their resilience.

Scoping review conducted with guidance from Dr. Erica Borgstrom, Dr. Rebecca Garcia, Professor Bee Wee and Dr. Kay McCallum.

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RESULTS

- 11 articles met inclusion criteria.
- 2 studies focused on resilience, 9 focused on coping strategies.
- Studies were based on data collected between 2009 and 2014.
- Majority of studies were based on experiences and recollections of bereaved carers (n=9).
- No studies were identified that solely explored the experiences of people currently caring for someone nearing the end of life at home.
- Factors were identified in the studies through thematic and narrative analysis of interview data.

- No studies specifically asked unpaid carers what they felt helped their resilience.
- Three categories of factors were identified as helping and hindering an unpaid carers resilience or coping, these were Organisational, Personal and Community Factors.
- Factors were mapped across the identified articles and visually presented to illustrate the frequency factors were identified (see Figure 1 and 2).
- Organisational factors were most frequently identified in the studies with 10 factors identified as helping resilience or coping and 13 hindering it.



Figure 1. A sunburst chart to show the factors that help resilience and coping in unpaid carers.

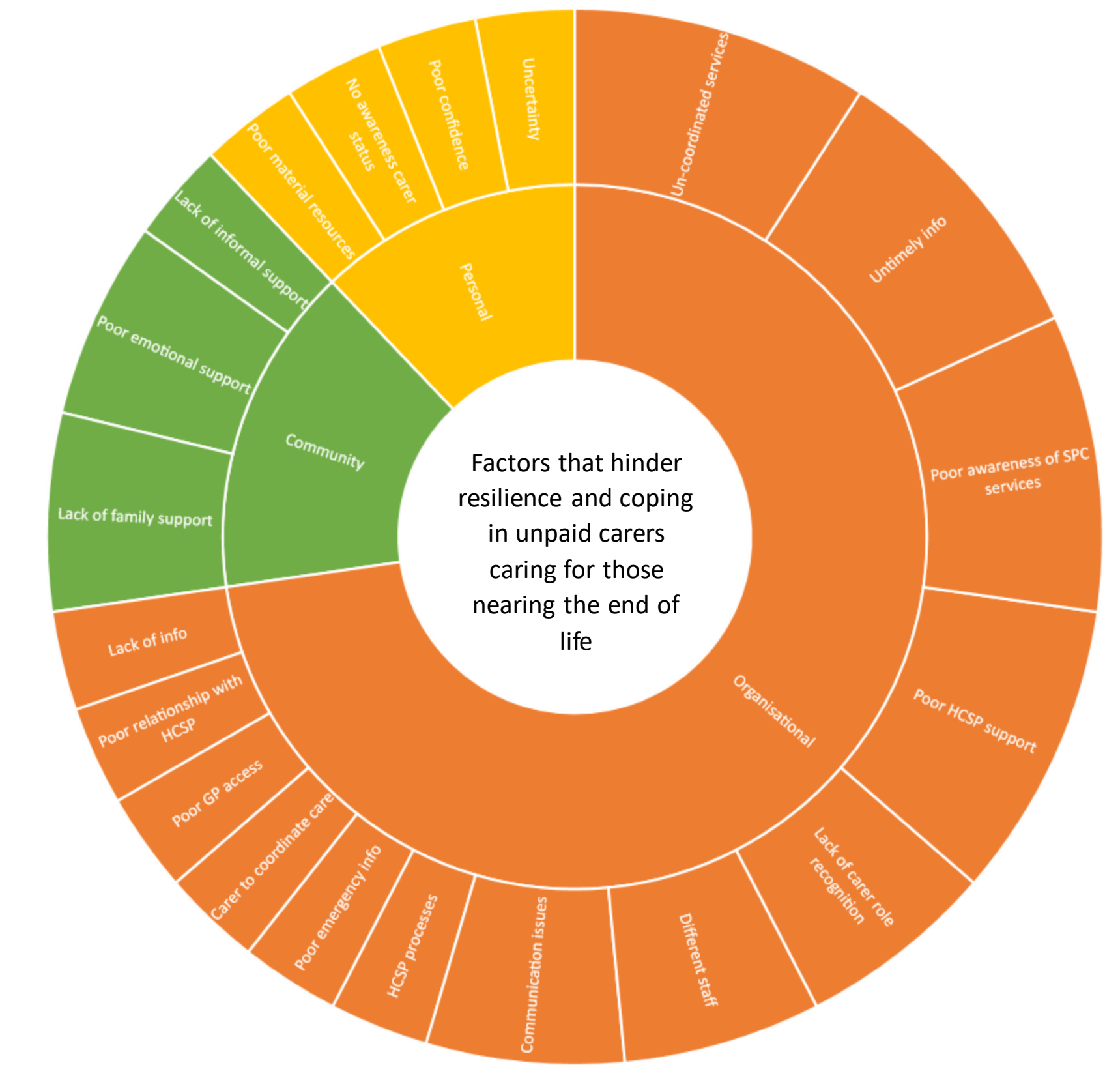


Figure 2. A sunburst chart to show the factors that hinder resilience and coping in unpaid carers.

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