Onset, Crises and Emergencies of Swiss Caring Relatives: A Trilingual National Explorative Mixed Methods Study

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Background

Living at home for as long as possible often necessitates the help of relatives. Especially when unexpected events occur, caring relatives reach their limits.

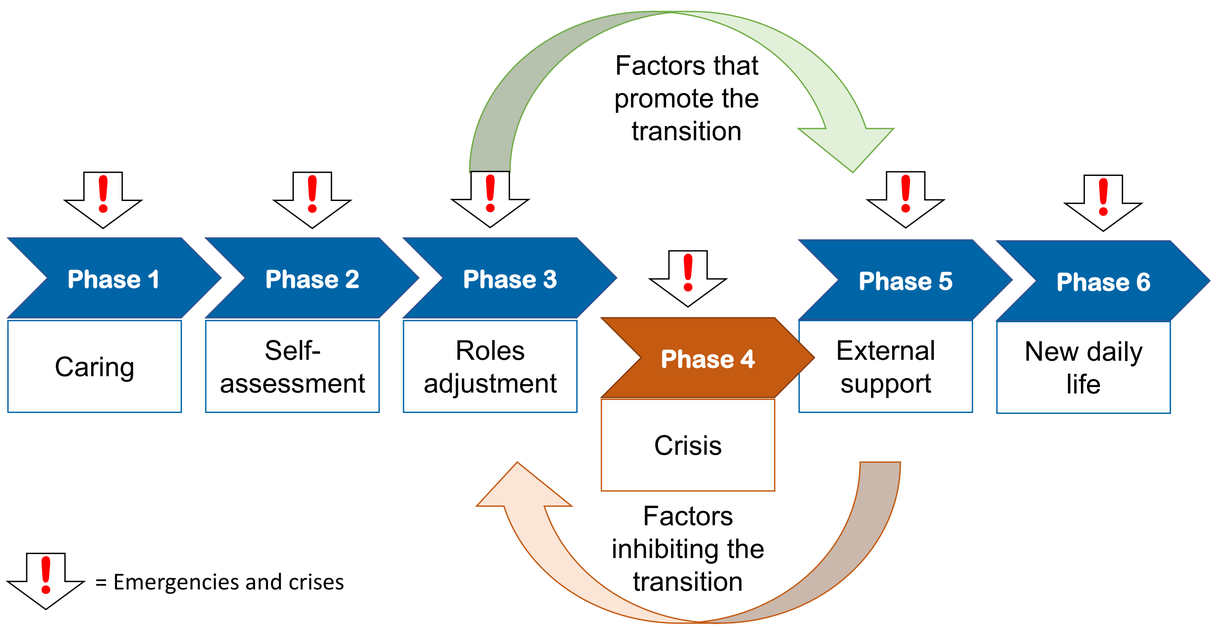
Aims

To identify support services that caring relatives need at the onset of their role as "caring relatives" and in crises and emergencies.

Results

Participating caring relatives (qual: *n*=49; quan: *n*=301) were between 28 and 95 years old and had been providing care for an average of 7 years. Health professionals (qual: *n*=29; quan: *n*=307) were on average 54 years old and had 30 years of professional experience.

Six phases of becoming a caring relative



Source: Modified and extended model of Doherty & McCubbin (1985)[1] with the findings from this study

Onset into the role of caring relative is perceived very differently and is characterized by a total of 6 phases. Not all phases have to be passed through, and the sequence might vary.
Crises and emergency situations can occur at any time and can affect both the person being cared for (progressive illness, fall) and the caring relative (own illness, excessive demands).
In crises and emergency situations, **professional help** becomes necessary in order to provide the best possible support to return back to the new everyday life.

Explorative sequentiell mixed-methods design

- First, explorative interviews were conducted with caring relatives and providers of various health services (e.g. outpatient care, counselling, self-help groups). They were analysed by grounded theory methodology.[2]
- Based on these findings and a literature review, a quantitative national survey of caring relatives and providers of various health services was conducted and descriptively analysed.[3]
- By integrating the qualitative and quantitative data, recommendations could be derived which were validated within a stakeholder workshop.[4]

Onset of the role of the caring relative

While passing through the different phases, stepping into the role of caring relative is extremely time-consuming and memorable. While 11% of caring relatives provide **round-the-clock care** from the onset of first support, 24% do so after an average of 7 years of care.
Entry is strongly influenced by the situation that leads to the need of the person being cared for. Some perceive the entry as **sudden** (e.g. due to an accident), others as **gradual** and recognize in hindsight (e.g. due to slowly progressing age-related infirmities) that they have already assumed the role.
63% of caring relatives said they had received **support** from health professionals at the onset, and one in five lacked these consultations, although they would have liked to have had them. In terms of support, caring relatives wanted employers to be accommodating (11%), although one-third reduced their employment; health professionals (61%) rated this need significantly higher.

2 types of crises and emergency situations

In crises and emergencies of the **supported person**, caring relatives are mostly supported by health professionals (82%), the social environment (68%). The majority however, result in hospitalization (66%). Counselling sessions (47%), home visits (38%) and on-call care (36%) are perceived as especially helpful.
In crises and emergencies of the **caring relatives themselves**, 27% did not request support and managed the situation alone.
A quarter wished for care to be provided on call and wanted to be sure that health professionals would be available around the clock.

Conclusions

It is helpful for health professionals to know what phase caring relatives are in so that they can provide targeted support.
Caring communities that reach out to local caring relatives and raise awareness early on should be encouraged, especially when entry into the role happens gradually.

Health professionals play an important role in accompanying caring relatives and must therefore use their potential and prepare the support well, provide advice, draw attention early on to potential crises and be available as a contact person around the clock.

References

[1]Doherty, W. J., & McCubbin, H. I. (1985). Families and Health Care: An Emerging Arena of Theory, Research, and Clinical Intervention. Family Relations, 34(1). https://doi.org/10.2307/583751
[2]Saldaña, J. (2015). The Coding Manual for Qualitative Researchers (Vol. 3). Sage Publications Ltd.
[3]Colton, D., & Covert, R. W. (2007). Designing and constructing instruments for social research and evaluation (1 ed.). Jossey-Bass.
[4]Creswell, J. W. (2014). A concise introduction to mixed methods research. Sage Publications Ltd.

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