

Title Improving support to informal caregivers of older persons from minority groups who also work

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We know little about informal caregivers of older persons from minority groups who also work. We need to know more in order to improve support for caregivers and provide patient centered care. Why we need to do this is because initial research shows some minority groups in Stockholm make little use of services, are often not involved in care planning and caregivers and are at risk of health breakdown. This has a high cost in terms of suffering and use of acute services.

Objectives

Q1 What are the needs of caregivers of older family members from non-EU familial cultures who also work in demanding jobs and their rate of health breakdown, compared to others?

Q2 How can support interventions, reported to be effective, best be implemented at the individual and service level?

Data collection Sample S1: Working caregivers of PwAD, including those with familism cultures, living in rural and urban municipalities in the Stockholm region: Survey n=50, Focus group interviews n=25. Sample S2: Practitioners, managers and policy advisors: Survey n=50, Individual interviews n=15.

Results Providing more flexible and individualised services is challenging because standardising service design (that defines the options and procedures that staff have to follow) is necessary to maximise efficiency and optimise for the many requirements that formal providers are required to meet.

Conclusion Help from family and community support networks can be flexible, but the help from formal services has fairly limited flexibility and often does not coordinate well with the caregiver and their support networks.

The new Stockholm strategy for integrated care in the home has plans for implementing these requirements. However, in Sweden only 5% of the municipalities were found to offer any kind of support to family caregivers whose native language was other than Swedish.

Background People caring for an older family member may experience high levels of stress, especially if they also have a demanding job. Support for them is important to implement person-centered and close-care. There is no empirical research into the support needs of carers from minority groups or about implementing effective interventions.

Objectives

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Methods To maximize the validity and cost-effectiveness of data collection and the generalisability of the research, we chose from previous research the dyad theoretical framework (Köhler et al 2021). This focuses on i) "the time course" and "change", which recognizes changes to the illness and its impact and the need for adjustments to the dementia care arrangement through a cyclic process of change and balancing over time ii) the characteristics of the care arrangement, iii) the context, comprising formal and informal social factors and the healthcare system.

Data collection Sample S1: Working caregivers of PwAD, including those with familism cultures, living in rural and urban municipalities in the Stockholm region: Survey n=50, Focus group interviews n=25. Sample S2: Practitioners, managers and policy advisors: Survey n=50, Individual interviews n=15. Data collection is based on three validated measures for caregiver unmet needs, burden & caregiving self-efficacy and perceptions of value of the communication & coordination tool.

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