

**Supporting caregivers of persons with life
threatening illnesses: a nationwide survey**

Kjer Møller, Jens-Jakob; Mikkelsen, Tina Broby; Rottmann, Nina; la Cour, Karen; Dieperink, Karin Brochstedt

Publication date:
2021

Document version:
Final published version

Citation for pulished version (APA):
Kjer Møller, J.-J., Mikkelsen, T. B., Rottmann, N., la Cour, K., & Dieperink, K. B. (2021). *Supporting caregivers of persons with life: threatening illnesses: a nationwide survey*. Poster session presented at Rehabilitation World Congress (RIWC), Aarhus, Denmark.

Go to publication entry in University of Southern Denmark's Research Portal

Terms of use

This work is brought to you by the University of Southern Denmark.
Unless otherwise specified it has been shared according to the terms for self-archiving.
If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim.
Please direct all enquiries to puresupport@bib.sdu.dk

Supporting caregivers of persons with life-threatening illnesses: a nationwide survey

Jens-Jakob Kjer Møller, Tina Broby Mikkelsen, Nina Rottmann, Karen la Cour, Karin B. Dieperink

INTRODUCTION

Caregivers are often the most important source of support for patients with life-threatening illnesses. According to recommendations from the Danish Health Authority, caregivers require focus as individuals, since they can become vulnerable because of the patients' illness. Knowledge about existing initiatives for caregivers to patients with life-threatening illnesses in Denmark is sparse.

PURPOSE

The purpose was to map current initiatives for caregivers to patients with life-threatening illnesses across sectors and to identify barriers in providing and receiving initiatives from the health care personnel's perspective in Denmark.

PARTICIPANTS

Health care personnel treating patients with one of five chosen life-threatening illnesses (apoplexy, dementia, cancer, heart illness and chronic obstructive pulmonary disease) in all 98 Danish municipalities (n=490) and hospital departments (n=425).

METHODS

A nationwide survey conducted with electronically distributed questionnaires from November 2018 until closure January 2019.

RESULTS

The response rate was 80% for municipalities, 44% for hospital wards and 53% among outpatient departments. The survey reports a certain focus on caregivers, which, however, is not in all cases sufficiently targeted in relation to the recommendations from the Danish Health Authority. Identification of caregivers is common, whereas identification of the caregivers' needs for support is relatively seldom (municipalities: 28%, hospital wards: 39%, outpatient departments: 42%). According to the healthcare personnel, sometimes the caregivers do not receive offers of involvement because the patient have no wish to involve caregivers (municipalities: 72%, hospital wards: 69%, outpatient departments: 59%). In general, municipalities tend to involve caregivers least in opposition to hospital wards. Further, the survey reveals differences in initiatives for caregivers between hospitals and municipalities as well as between diagnoses.

DISCUSSION & CONCLUSIONS

The focus on caregivers is present but not completely sufficient in accordance to Danish recommendations. The caregivers are usually identified, but the caregivers' preferences and needs are not identified. According to the health care personnel, the patients and caregivers are sometimes barriers to caregiver involvement and caregiver support.

RECOMMENDATIONS

Future studies should investigate the potential change in caregivers' needs during an illness trajectory, and how the caregivers' needs can be identified and met. Finally, guidelines may be required to ensure sufficient support for caregivers

ACKNOWLEDGEMENTS

Assistance provided by Sarah Frausing has been a great help in identifying respondents and compiling the questionnaire.

CONTACT DETAILS

jens-jakob.kjer.moller@rsyd.dk