Evaluation of a palliative and hospice telephone hotline for severely affected Multiple Sclerosis patients and their caregivers

Scientific management: Prof. Dr. Raymond Voltz, PD Dr. Heidrun Golla
Contact: Dr. Dr. Julia Strupp, Gabriele Grede
Duration: 01.01.2019 - 31.12.2019
Funding institution: Gemeinnützige Hertie-Stiftung (mitMiSsion)

Project Description

Patients severely affected by multiple sclerosis (MS) - as well as their informal caregivers - have multiple supportive and palliative care needs. Already established care systems alone do not necessarily address all of the patients' needs, and there are first indications that palliative and hospice care (PHC) can be a valuable complementary asset for patients severely affected by MS. In order to bring patients severely affected by MS in contact with PHC, we established a counselling PHC hotline specific for MS. A hotline allows for consultation that does not require patients to leave their home. The preliminary evaluation of the hotline came to the conclusion that it was well accepted by patients and their formal and informal caregivers and seems to be a valuable service in order to gain information about and access to PHC.

Since September 2014 this hotline has been extended nationwide to:

1. provide information about PHC
2. assess the caller’s eligibility for PHC
3. recommend appropriate local available PHC services according to the individual's needs

The aim of this study is to 1) evaluate the hotline including its relevance, its callers, their characteristics and queries, and 2) analyse challenges and possible barriers to integrating PHC services into the treatment of severely affected MS patients by conducting follow-up calls. The nationwide hotline was designed and introduced to the MS community in cooperation with the German Multiple Sclerosis Society (DMSG). Calls were documented using a documentation form supplemented by personal notes capturing socio-demographic and disease-related information as well as concerns regarding death and dying. Data was analysed descriptively.
Dr. paed. Dr. rer. medic. Julia Strupp

Research Coordinator

“Last Year of Life Study Cologne”, „MS-Hotline“, „APVEL - Evaluation of specialized outpatient palliative care“, „iLive - Living well, dying well“

Telefon
+49 221 478-87125
E-Mail
julia.strupp@uk-koeln.de

Zur Person

Qualifications and professional experience

<table>
<thead>
<tr>
<th>Since</th>
<th>Research Coordinator at the Department of Palliative Medicine, University of Cologne</th>
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<tr>
<td>2015</td>
<td>Doctoral Thesis (Dr. rer. medic.) - Validation of the German Version of the Schedule of Attitudes towards Hastened Death (SAHD-D) (Prof. Dr. Raymond Voltz, Medical Faculty of the University of Cologne)</td>
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<tr>
<td>2011</td>
<td>Doctoral Thesis (Dr. paed.) - Successful aging of people with physical disabilities and the sense of coherence as a resource in the aging process (Prof. Dr. Mathilde Niehaus, Faculty of Human Sciences / University of Cologne)</td>
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<tr>
<td>2009 - 2013</td>
<td>Research Associate at the Department of Palliative Medicine, University of Cologne</td>
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<tr>
<td>2005 - 2009</td>
<td>Research Associate at the Leibniz Institute for the Social Sciences (GESIS) at the Center of Excellence Women and Science (CEWS)</td>
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<td>2004</td>
<td>Magistra Artium (M.A.)</td>
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<td>1999 - 2004</td>
<td>Social and Behavioral Sciences (University of Hagen)</td>
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<tr>
<td>1999 - 2005</td>
<td>Division of Disability Services, Family Supportive Services, Diakonie Bonn</td>
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Research Focus

Health Services Research, the last year of life in Cologne, specialized outpatient palliative care, development of a tool to assess a desire to hasten death, palliative care integration for neurological patients (early integration, unmet needs); patient-centered care, palliative care structures for neurological patients
### Teaching

- "Methods of Empirical Social Research, Text Analysis and Counselling and Intervention" (Master Gender & Queer Studies)
- Medical Sociology (Research Processes in Medical Sociology), Seminar
- Lecture series Research Track

### Memberships

- Member of the Consilium for junior researchers at the University of Cologne (Representative for the Medical Faculty)
- Member of the Research Working Group (AG Forschung) of the German Association of Palliative Medicine (DGP)
- Steering Board Member CoReNet (Cologne Research and Development Network)
Completed projects

• Validation of the German version of the Schedule of Attitudes toward Hastened Death (DKH funded)
• Impact of a case management model on the specialised palliative care multi-professional team (DKH funded)
• Palliative Care for severely affected MS patients: a Delphi survey of healthcare professionals (DMSG)
• Multiple Sclerosis and Palliative Care: Assessing Unmet Needs“ (Gemeinnützige Hertie-Stiftung)
• Views on life of palliative care patients (DKH)
• Advance Directive and Health Care Proxy – Strengthening cancer patient autonomy by improving surrogate decision making (CIO)
Reviewer (i.e.)

- Palliative Medicine
- Journal of Palliative Medicine
- European Journal of Public Health
- Zeitschrift für Palliativmedizin
- PLOS One
- Social Work in Health Care
- Psycho-Oncology