

The caregiver's journey: who cares for the carer?

A holistic approach to cancer care through integration of informal caregivers (HIPPOCRATIC)

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Background: Currently more than 76 million unpaid caregivers in Europe provide care for a relative or friend, which represents 12.7% of the European population and has an estimated economic value of about 3.63% of Europe's gross domestic product (GDP) ¹. Informal caregiving is a valuable but invisible resource in the field of healthcare worldwide. Caregivers experience often a double burden: providing clinical care at home, on one side, and managing personal emotional distress, on the other side ². Beside the information needs, many cancer caregivers report feeling of losing one's identity and setting aside their own work ³. Despite all unmet needs who cancer caregivers experience, there is no existing standardized screening tool for caregivers' needs in Germany ⁴. We aim to address this gap developing a pilot check-list-guided intervention, which aims to identify cancer caregivers at high risk of caregiver burden, assess their individual needs, refer them to appropriate services and empower them through education to an active, visible partner during the cancer journey.

Methods: The intervention on the structured involvement of caregivers in cancer treatment, which is currently being tested as a pilot project, consists of two parts: 1) A survey, capturing the individual needs and problems of patients and caregivers as a dyad pair completed by the study participants prior to their consultation session with the physician; 2) A checklist for clinicians that includes guidance on how to integrate cancer caregivers in a structured way and that relates to aspects of the pre-completed survey. Semi-structured qualitative interviews and focus group discussions will be then conducted with patients, caregivers and health care professionals to evaluate the intervention. The evaluation will be used to derive some practical insights for future improvement and possible implementation into clinical care routine.

Discussion (expected outcomes): The role of Informal cancer caregivers remains invisible in healthcare delivery and particular attention should be paid to their empowerment and burden reduction, strengthening the patient-caregiver-physician triad. In order to achieve that, caregivers should be included in all-important aspects of the clinical care routine shifting the focus from the patient to a dyadic centered care. Since there is no existing standard assessment of caregivers' needs and risk of burden in Germany yet, this pilot project would fill this gap with an innovative approach including an innovative checklist-guided approach. A structured assessment and integration of informal caregivers within the clinical cancer care routine with the help of a guiding checklist for the physician would enable a better quality of care experience for all participants of the cancer journey, reducing caregiver burden and potentially improving mental health outcomes, for both patients and their caregivers. This would help physicians 1) to consider the patient's and caregiver's health-related quality of life on a regular basis (similar to tumor markers and other blood values), 2) to assess the patient-caregiver-dyadic-relationship in terms of cancer care and 3) to recognize and address the individual caregivers' needs which usually remain hidden and forgotten beyond the hospitals' walls.

References

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