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ABSTRACT

Title: Living at home with advanced cancer: what people do and how they manage their Activities of Daily Living in the home environment

Background Globally the number of people living with advanced cancer for extended periods of time is growing. Evidence shows that these people spend a significant part of their time in the home environment and up to 30% have problems with daily activities. Yet, little is known about how they manage their everyday activities in the home environment.

Aim: To describe the everyday life of people with advanced cancer in the home environment including the specific activities that occupy their time and their perceived ability to manage and perform daily activities.

Methods: Based on a cross-sectional design a consecutive sample of 164 participants with different cancer diagnosis in advanced stages and a WHO functional performance score of 1-3 were included in the study. Participant reported their daily activities in structured self-completed time-geographic diaries and were interviewed by trained occupational therapists using the ADL-Interview (ADL-I) combined with open-ended qualitative interview questions. Analysis of the data from diaries was conducted by use of descriptive Time Geographical analysis program, Rasch measurement methods were applied to generate linear ADL-I ability measures, and the qualitative data were thematically analyzed.

The results indicate that daily life of people with advanced cancer is dominated by activities in the home environment. They report most problems with physically demanding household activities and express frustrations in not being able to maintain prior activities.

Conclusion The study contributes significant knowledge on the specific daily activity problems and challenges people with advanced cancer experience in regard to managing at home. Researchers and clinicians can draw on this knowledge as a prerequisite for developing and implementing home-based goal-directed interventions.

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