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SHORT REPORT

Changes in social, psychological and physical well-being in the last 5 years of life of older people with cancer: a longitudinal study

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Abstract

Background: older people with cancer are at risk of complex and fluctuating health problems, but little is known about the extent to which their well-being changes in the last years of life.

Objective: to examine changes in physical, psychological and social well-being in the last 5 years of life of older people with cancer.

Design: prospective cohort study.

Setting: Belgium, the Netherlands.

Participants: people with a new primary diagnosis of breast, prostate, lung or gastrointestinal cancer, aged ≥ 70 years, life expectancy > 6 months, were recruited from nine hospitals. We analysed data of deceased patients.

Methods: data were collected from participants around diagnosis, and after 6 months, 1, 3 and 5 years through structured questionnaires administered through interviews or as self-report. Outcomes were physical, emotional, social, role functioning (EORTC QLQ-C30), depressive symptoms (GDS-15), emotional and social loneliness (Loneliness Scale). We conducted linear mixed model analyses.

Results: analysing 225 assessments from 107 deceased participants (assessments took place between 1,813 and 5 days before death), mean age at baseline 77 years (standard deviation: 5.2), we found statistically significant deterioration in physical functioning ($b = 0.016$ [95%confidence interval 0.009–0.023]), depressive symptoms ($b = -0.001$ [–0.002 to 0.000]) and role functioning ($b = 0.014$ [0.004–0.024]). Changes over time in emotional and social functioning and in social and emotional loneliness were smaller and statistically non-significant.

Conclusions: care towards the end of life for older people with cancer needs to put their social and psychological well-being at the centre, alongside physical needs. Future research should focus on understanding inter-individual variation in trajectories.

Keywords: longitudinal study, prospective cohort study, older people with cancer, well-being, end of life

Key points

- Physical functioning, role functioning and depressive symptoms deteriorate over the last 5 years of life of older people with cancer.

- End-of-life care needs to put their social and psychological well-being at the centre, alongside physical needs.
- Future research should focus on understanding inter-individual variation in trajectories.

Introduction

Global annual cancer-related deaths are projected to reach 11.5 million in 2030 [1], with the increase disproportionately affecting older people [2]. As they near the end of life, many older people with cancer experience important fluctuations in their health that can affect their physical, psychological and social well-being. These problems are often caused by the cumulative effects of cancer, cancer treatment and other chronic conditions as well as social problems for which age is a risk factor [3–5]. As there are very few longitudinal studies on the end of life, little is known about changes in the well-being of older people with cancer as they near death. The available longitudinal data mostly concern physical decline [6–8] but largely neglect psychological and social well-being, even though these are key domains of well-being towards the end of life that also interact with physical health [9–11]. Better knowledge of these changes could inform anticipatory care for individual patients [12] as well as support public health policy-making and resource planning for health and social care [6]. We studied to what extent physical, psychological and social well-being change in the last 5 years of life of older people with cancer.

Method

Study design and population

We analysed data of an existing prospective cohort study in Belgium and the Netherlands that was set up to study the well-being of older people with cancer (KLIMOP study) [13]. We selected participants aged 70 years and over at baseline, who had died by October 2019 and whose date of death we were able to ascertain (communicated by the family to the researchers or identified in public obituaries). We included assessments that had taken place within the last 5 years of the patient's life. The KLIMOP study included patients who had a new primary diagnosis of breast, prostate, lung or gastrointestinal cancer (i.e. most frequently occurring types); a life expectancy of >6 months as judged by the attending physician; a thorough command of the Dutch language and if the first interview could take place within 3 months after diagnosis. The KLIMOP study excluded patients with a formal diagnosis of dementia, a previous diagnosis of invasive cancer and people too ill to participate in data collection. Recruitment took place at nine hospitals in Belgium and the Netherlands from June 2010 until October 2014, with the last follow-up completed in 2019. The KLIMOP study protocol has been approved by the Ethics Committee of UZ/KU Leuven and by the Medical Ethics Committee of Maastricht University Medical Centre.

All data were collected anonymously following informed consent, and participation was voluntary.

Data collection and measurements

Data were collected upon inclusion (baseline) and 6-month, 1-, 3- and 5-year follow-up periods through structured questionnaires administered in personal interviews or as self-report. Physical well-being was assessed through the 'physical functioning' subscale of the quality of life questionnaire of the European Organisation for Research and Treatment of Cancer (EORTC QLQ-C30; five items) [14]. Psychological well-being was assessed through three outcomes: emotional functioning, measured using EORTC QLQ-C30 (four items, feeling tense, worrying, feeling irritable, feeling depressed); depressive symptoms, measured using the 15-item Geriatric Depression Scale (GDS-15; higher scores indicating higher symptom burden) [15] and social and emotional loneliness assessed using the Loneliness Scale (11 items, higher scores indicating higher levels of loneliness) [16]. Social well-being was assessed through two outcomes: the social functioning (i.e. physical condition or medical treatment interfering with individual's family life and social activities) and role functioning (i.e. being limited in doing work or other daily activities or in pursuing hobbies or other leisure time activities) subscales of the EORTC QLQ-C30 (two items per subscale). Higher scores on the EORTC QLQ-C30 subscales indicated better functioning [17]. Sociodemographic data and co-morbidities were assessed at baseline, through medical records and patient interviews.

Analysis

To determine changes in physical, psychological and social well-being, we conducted one linear mixed model analysis per dependent variable, with number of days before death as independent variable. All models were estimated with random intercepts and, if model convergence allowed, also with random slopes for days before death. Linear mixed models handle missing data through maximum likelihood estimation. Plots were created in R; linear mixed model analyses were conducted in SPSS v26.

Results

Sample

We identified 110 deceased people with cancer whose date of death we could establish. We excluded three patients whose five assessments all occurred >5 years before death. The remaining 107 participants provided a total of 225

Table 1. Changes per day before death in physical, psychological and social well-being in older people with cancer ($N = 107$; 225 assessments)^a

Well-being constructs	Coefficient b (95% CI) for change per day before death ^b	P -value
Physical well-being		
Physical functioning (scale 0–100)	0.016 (0.009–0.023)	<0.001
Psychological well-being		
Emotional functioning (scale 0–100)	–0.002 (–0.007 to 0.004)	0.523
Depressive symptoms (scale 0–15)	–0.001 (–0.002 to 0.000)	0.017
Social loneliness ^c (scale 0–11)	0.00 (0.00–0.00)	0.261
Emotional loneliness ^c (scale–11)	0.00 (0.00–0.00)	0.233
Social well-being		
Role functioning (scale 0–100)	0.014 (0.004–0.024)	0.009
Social functioning (scale 0–100)	0.005 (–0.003 to 0.013)	0.210

^aLinear mixed models with days before death as independent variable and random effects for individual. Full model estimates, including intercepts and random variance, are presented in [Supplementary Table S1](#). ^bPositive b coefficients indicate lower values in the well-being construct as death approaches (fewer days); negative values indicate higher values as death approaches (fewer days). ^c b coefficient is very small because the Loneliness Scales have a relatively small range, from 0 to 11, and the coefficient captures the change per day.

assessments, ranging from 1,813 to 5 days before death ([Supplementary Figure S1](#)).

Mean age at baseline was 77 (standard deviation 5.2), and half (49.5%) of participants were female. Of the 107 patients, 68.2% lived with family, 25.2% lived alone, 5.6% in a nursing/care home and 0.9% in another location. Fifty-nine percent lived together with the person who provided most care to them. In total, 11 and 14% had co-morbid heart failure and chronic lung disease, respectively. Missing data did not exceed 6.5% on any variable.

Changes in physical, psychological and social well-being towards the end of life

Among older people with cancer, physical functioning (regression coefficient b for change per day: 0.016 [95% confidence interval, CI, 0.009–0.023]; $P < 0.001$) and role functioning ($b = 0.014$ [95%CI 0.004–0.024]; $P = 0.009$) significantly declined towards death and depressive symptoms increased ($b = -0.001$ [95%CI –0.002 to 0.000]; $P = 0.017$) ([Table 1](#)). There were small and statistically non-significant changes over time in emotional and social functioning and in social and emotional loneliness. [Figure 1](#) visualises the trajectories of physical and role functioning and depressive symptoms. Statistically significant random effects in the linear mixed model analysis for social functioning indicated inter-individual variation in the extent to which social functioning changed towards the end of life (slope variance: $b = 0.000$ [95%CI 0.000–0.001], $P = 0.01$; intercept–slope covariance: $b = -0.53$ [95%CI –0.89 to –0.16]; $P = 0.004$) ([Supplementary Table S1](#)). The slope variance indicates variation in trajectories between individuals; the negative intercept–slope covariance indicates that a higher initial score is associated with a more rapid decrease.

Discussion

This longitudinal study of the last 5 years of life of older people with cancer found statistically significant deterioration

in the physical, psychological and social domains. Specifically, physical functioning and role functioning decreased and depressive symptoms increased. While there were no statistically significant changes in social functioning towards the end of life, we found that social functioning trajectories varied significantly between individuals.

Concluding from these data, care towards the end of life for older people with cancer needs to put social and psychological well-being at the centre, alongside physical needs. Importantly, within the social domain, attention should be paid to deteriorations in role functioning and differing social functioning trajectories between individuals. This finding is an important addition to existing research on the social domain towards the end of life, which has focused mainly on social support, including structural and functional indicators thereof, such as marital status and hours of family care received [18, 19] and on caregiver burden [20, 21], but has largely neglected people’s perceptions of their social connections and activities. Yet such ‘qualitative’ aspects of social connection were found to be important determinants of health outcomes [9, 22]. Several outcomes, all in the psychological well-being domain (i.e. emotional functioning, social and emotional loneliness), did not show large changes over time. This partly corresponds to findings from other populations showing that loneliness, on average, does not change to a great extent over time [23, 24]. However, it is also possible that individual patients experience fluctuations in these outcomes that are not visible in assessments that are 2 years apart. This highlights the need for longitudinal studies on the end of life with larger samples and shorter assessment intervals that balance a higher temporal resolution with limited patient burden and that can examine variation in trajectories between individuals. So far, such work has been limited to the physical domain [6].

This study has several limitations, related to the KLIMOP study having a different primary aim [13]. It excluded patients with a life expectancy below 6 months at diagnosis (baseline) and those with a formal dementia diagnosis. Our findings may therefore not be generalisable to patients whose health deteriorates very quickly and may not capture the

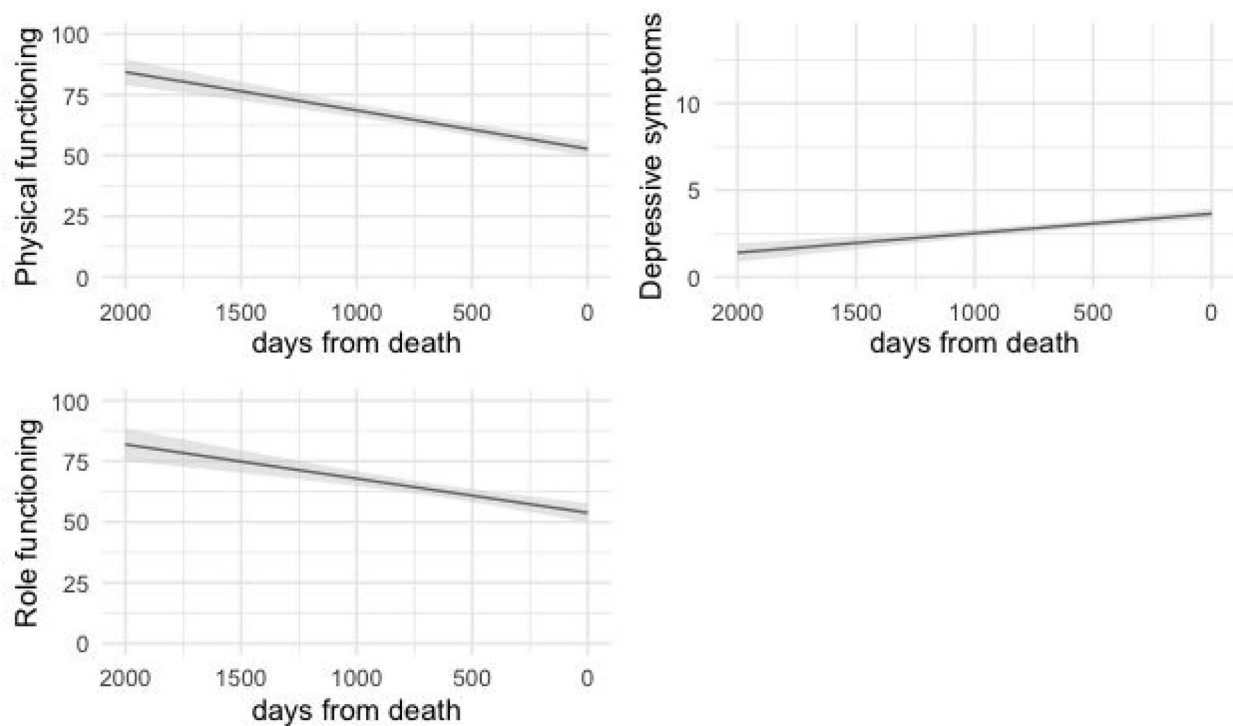


Figure 1. Changes over the last 5 years of life in physical functioning, role functioning and depressive symptoms among older people with cancer ($N = 107$; 225 assessments), based on predictions of unconditional linear mixed model analyses with number of days before death as independent variable and random intercept for individual.

possibly unique changes in psychological and social well-being of older people with cancer who additionally face deterioration in cognitive abilities due to dementia. The prevalence of co-morbid cancer and dementia is not clear, which makes it difficult to estimate the impact of this exclusion on our findings [25]. Future longitudinal studies should seek to develop data collection methods that allow involving people with dementia for as long as possible. Our sample size was not very large as we included the subset of KLIMOP participants who had died. Nevertheless, we obtained a good distribution of measurements over the last 5 years of life (Supplementary Figure S1) and captured important changes in well-being. As is common in longitudinal ageing studies, there were losses to follow-up, most likely due to participants' poor health [26, 27]. While we still included assessments of participants who died after dropping out of the study, measurements close to death from those who were in very poor health may be underrepresented.

Supplementary data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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Declaration of Conflicts of Interest: None.

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