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Original Study

Care-Related Quality of Life of Informal Caregivers After Geriatric Rehabilitation

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A B S T R A C T

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Objectives: To describe care-related quality of life (CarerQoL) of informal caregivers after geriatric rehabilitation (GR) and identify associated determinants.

Design: A cross-sectional analysis within a prospective longitudinal follow-up study.

Setting: Evaluations at 4 weeks after finishing GR in 16 skilled nursing facilities.

Participants: Included were 350 informal caregivers (66.2% female, age 63 years; standard deviation [SD], 13.3) and their care recipients (63.4% female, age 78 years; interquartile range [IQR], 69–84 years).

Measurements: CarerQoL was measured with the CarerQoL-7D. This instrument describes caregiver burden in seven dimensions (ie, fulfillment, relational, mental, social, financial, perceived support, and physical). Informal caregivers were divided into low and high CarerQoL groups, based on the median CarerQoL-7D summary score (83.9 [IQR, 74.4–91.7]). Potential associated determinants were collected, including demographic variables of informal caregivers and care recipients, self-rated health and burden of informal caregivers, functioning, and cognition and depression of care recipients. Univariate logistic regression was performed for each determinant. For the multivariate regression model, a backward procedure was used, which included age, gender, and variables with $P < .10$.

Results: Multivariate analysis showed that fair or poor health (odds ratio [OR], 1.32; 95% confidence interval [CI], 1.14–1.54), a higher self-rated burden (OR, 2.68 [95% CI, 1.23–5.85]), being happier if one could hand over all care tasks to another self-chosen person (OR, 1.33 [95% CI, 1.15–1.53]), and severely impaired cognitive performance level of the care recipient (OR, 2.52 [95% CI, 1.21–5.25]) were independently associated with having a lower CarerQoL-7D summary score (beneath the median). Happiness (OR, 0.53 [95% CI, 0.40–0.70]) was independently associated with a higher CarerQoL-7D summary score.

Conclusion: CarerQoL after GR in a skilled nursing facility is predominantly and independently associated with caregiver's own health, happiness, self-rated burden, and a severely impaired cognitive performance level of the care recipient at admission to the GR unit.

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The SINGER study took place within the Dutch consortium geriatric rehabilitation: a close collaboration between the academic elderly care networks of the Leiden University Medical Center, VU University Medical Centre and Maastricht University Medical Center.

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Worldwide, the number of people aged ≥ 80 years is expected to escalate from 125 million in 2015 to about 434 million in 2050.¹ This increasing number of older persons implies that more individuals are at risk of developing multimorbidity, causing a rising prevalence of disability, falling, higher rates of health care utilization, and higher related costs.^{2–4} At the same time, in many Western countries, institutionalization is discouraged, and older people are encouraged to live longer in their own homes; this trend implies a demand for a growing number of informal caregivers. Because the care recipient's health condition is often complex due to several health problems in different domains (eg, functional, somatic, mental, and social),⁵ this situation could present a considerable burden on the informal caregiver. Several studies have shown that informal caregiving can cause the caregiver both physical and mental problems.^{6,7}

Each year in the Netherlands, 25,000 to 30,000 older people are admitted to a geriatric rehabilitation (GR) unit of a skilled nursing facility (SNF) after a stroke, elective orthopedic surgery, hip fracture, or other diagnoses that initiate acute loss of function. Of these, 60% return to their own home, where they often still need physical and mental care.⁸ This care will mostly be provided (free of charge) by close family and friends (ie, informal caregivers). The care-related quality of life (CarerQoL) of these caregivers (ie, the QoL related to the informal care the caregiver supplies to the patient) is poorly studied, and most studies focus on the burden faced by informal caregivers, or the patient's QoL, instead of the caregiver's QoL. For example, a Dutch study involving patients shortly after stroke rehabilitation in SNFs, found that neuropsychiatric symptoms and depressive complaints of the care recipient were associated with both the geriatric patient's QoL and their caregiver's burden.⁹ CarerQoL was not examined in this study. Knowledge of which determinants are associated with CarerQoL could be of great importance to health care professionals when planning the patient's discharge from the SNF to home. In response to the existence of specific characteristics of the informal caregiver, they could decide to deploy extra help at home. The present study aims to (1) describe CarerQoL of the informal caregiver 4 weeks after GR of the care recipient and (2) identify associated determinants.

Methods

Design

Data for this cross-sectional study were obtained from the Synergy and INnovation in the GERiatric Rehabilitation (SINGER) study. The SINGER study was a prospective longitudinal follow-up study, aimed to describe changes in the innovations and supply of GR care in 16 Dutch SNFs, as experienced by professionals, patients, and their informal caregivers during the implementation of a national program.¹⁰ In 2011, the Dutch Ministry of Health, Welfare, and Sports initiated this national program to improve the quality of care delivery for GR in the Netherlands. They stimulated participating GR service organizations to develop integrated GR health service delivery.¹⁰ Detailed information on the SINGER study design and outcomes are described elsewhere.¹⁰ The study population was recruited in three consecutive cohorts starting in March 2011, September 2011, and March 2012 (spanning a 4-month period for each cohort) in 16 SNFs in the Netherlands.

Briefly, measurements were performed on care recipients at admission to the SNF and at discharge. Informal caregivers were asked to fill in a questionnaire 4 weeks after discharge of their care recipient.

The Medical Ethics Committee of the Leiden University Medical Center approved the study.

Participants

Informal caregivers were recruited by their care recipients when they were seen as a primary informal caregiver (ie, the person who was expected to provide the most informal care to the care recipient after discharge from the GR unit of the SNF). Care recipients were included once they were admitted to a GR unit of one of the participating SNFs after hospitalization because of planned surgery (elective orthopedic) or an unplanned medical emergency (trauma, stroke, and other). Care recipients were excluded by the treating elderly care physician if they had pre-existent dementia.

Data Collection

Informal caregivers

Data of informal caregivers were collected via a written questionnaire 4 weeks after discharge of the care recipient from the SNF. The questionnaire was based on The Older Persons and Informal Caregivers Survey Minimum Data Set (TOPICS-MDS), developed as part of The National Care for the Elderly Programme (NPO) in the Netherlands. The TOPICS-MDS is a uniform, national database on the health and well-being of older persons and informal caregivers and consists of standardized, validated questionnaires.^{11,12} Measures selected from the TOPICS-MDS were demographic characteristics, CarerQoL, happiness, valuation of life, health, and self-rated burden.

Demographic characteristics. The informal caregiver provided information on the following: date of birth, gender, relationship with the care recipient, and their personal living situation (eg, living with the care recipient or not).

Care-related Quality of Life. The impact of caregiving on the QoL of informal caregivers was measured by the CarerQoL instrument.¹³ The construct validity of this instrument was maintained in different studies,^{14–16} and it appeared applicable in different settings (ie, general population, hospitals, long-term care facilities, and primary care centers).^{13,16} The instrument comprises two parts: the CarerQoL-7D and the CarerQoL-Visual Analogue Scale (CarerQoL-VAS). The CarerQoL-7D describes caregiver burden in two positive dimensions (care-related fulfilment, social support) and five negative dimensions (relational problems with the care recipient, mental health problems, financial security, problems completing daily activities, and physical health problems), each with three response categories (no, some, or a lot of problems). To be able to provide standard utility scores, a relative utility weight called a "tariff" was assigned to each of the seven dimensions by Lutowski et al, based on the preferences of a sample of the Dutch general public.¹⁷ In this way, the CarerQoL-7D provides standard utility scores, which facilitates the inclusion of informal care in economic evaluations.¹⁷ This weighted total summary score ranges from 0 (worst informal care situation) to 100 (best informal care situation). The CarerQoL-VAS is an additional valuation component to evaluate general happiness, using a visual analogue scale ranging from 0 (completely unhappy) to 10 (completely happy). The CarerQoL-VAS is seen as a measurement of general well-being in terms of happiness.^{13,16} Informal caregivers were then asked to report their happiness on the CarerQoL-VAS "transfer," that is, in the hypothetical case that the informal caregiver could hand over (transfer) all care tasks to another self-chosen informal caregiver, ranging from 0 (completely unhappy with transferring caregiving tasks) to 10 (completely happy with transferring caregiving tasks).¹⁸

Health and self-rated burden. Health was self-reported based on two questions from the RAND 36-item Health Survey¹⁹ ie, (1) In general, would you say your health is: excellent/very good/good/fair/poor and (2) Compared to before GR of the care recipient, how would you rate your health in general now: much better/somewhat better/about the same/somewhat worse/much worse.¹⁹ The RAND-36 is the short version of the RAND Health Insurance Study Questionnaire²⁰ and assesses eight health concepts, including functional status, well-being, general health, and the assessment of change in perceived health during the last 12 months.^{19,21,22}

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