

Quality of life assessments in nursing homes revealed a tendency of proxies to moderate patients' self-reports

Ruslan Leontjevas^{a,b,c,*}, Steven Teerenstra^d, Martin Smalbrugge^e,
Raymond T.C.M. Koopmans^{a,c,f}, Debby L. Gerritsen^{a,c}

^aDepartment of Primary and Community Care, Center for Family Medicine, Geriatric Care and Public Health, Radboud University Nijmegen Medical Centre, P.O. Box 9101, 6500 HB, Nijmegen, The Netherlands

^bFaculty of Psychology and Educational Sciences, Open University of the Netherlands, P.O. Box 2960, 6401 DL Heerlen, The Netherlands

^cRadboud Alzheimer Centre, Nijmegen, P.O. Box 9101, 6500 HB, Nijmegen, The Netherlands

^dSection Biostatistics, Radboud Institute for Health Sciences, Radboud University Nijmegen Medical Centre, P.O. Box 9101, 6500 HB, Nijmegen, The Netherlands

^eDepartment of General Practice and Elderly Care Medicine and the EMGO+ Institute for Health and Care Research, VU University Medical Center, Van der Boechorststraat 7, 1081 BT, Amsterdam, The Netherlands

^fJoachim en Anna, Centre for Specialized Geriatric Care, Postbus 31071, 6503 CB, Nijmegen, The Netherlands

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Abstract

Objective: Research into different patient populations suggests that, on average, proxies report poorer health-related quality of life (HRQoL) compared to self-reports. We aimed to investigate whether the difference between proxy reports and self-reports (interrater gap) varies across the whole range of self-reports from low to high HRQoL scores.

Study Design and Setting: A cross-sectional study in 16 Dutch nursing home (NH) dementia special care (DSC) units ($n = 256$) and 17 somatic units ($n = 326$). Professional carers, blinded to self-reports, provided EuroQol-5D scores from two perspectives: their own perspective (proxy–proxy) of the patients' HRQoL and the estimation of the patient's view (proxy–patient).

Results: The interrater gap varied linearly in both DSC and somatic patients from proxy scores overestimating low self-reports to proxy scores underestimating high self-reports. This attenuation tendency existed for both proxy–proxy and proxy–patient perspectives. The interrater gap tended to be smaller for the proxy–patient perspective.

Conclusions: Proxies (professional carers) tend to attenuate self-reports in NH patients with and without dementia toward moderate scores rather than report systematically poorer HRQoL. A proxy–patient perspective may be preferable to a proxy–proxy perspective for the purpose of estimating self-reports. Further research into other populations is needed to understand whether the attenuation tendency is a general phenomenon. © 2016 Elsevier Inc. All rights reserved.

Keywords: Attenuation tendency; Bias; Proxy score; Quality of life; Nursing home; Assessment

1. Introduction

Valid and reliable measures of health-related quality of life (HRQoL) in patients with severe chronic conditions

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* Corresponding author. Tel.: +31-45-576-2504; fax: +31-45-576-2800

E-mail address: roeslan.leontjevas@ou.nl (R. Leontjevas).

and limited expectations of cure are essential for determining the benefits of health care interventions [1]. Cost-utility analyses based on HRQoL outcomes are often conducted to prioritize interventions [2]. Because quality of life reflects personal experiences, the patients are essential informants in their HRQoL assessments [3]. However, self-reporting can be impeded or its validity can be questioned in frail patients such as those with severe cognitive impairments and communication deficits. In such cases, family members or health professionals can be asked to act as a proxy and to report on behalf of the patient [1]. Insight into the disparity between proxy reports and self-reports is important both for the estimation of unavailable

What is new?

Key findings

- Proxies attenuate self-reports toward moderate scores rather than report systematically poorer quality of life in patients with and without dementia.
- The interrater gap between proxy reports and self-reports tends to be smaller when proxies estimate the perspective of the patient than when proxies report from their own perspective on patients' quality of life.

What this adds to what was known?

- Our study adds to the very limited knowledge about the attenuation tendency bias and about the use of different proxy perspectives by confirming the existence of the attenuation tendency for two proxy perspectives in patients with and without dementia.

What is the implication and what should change now?

- Researchers and clinical professionals should take the attenuation tendency into account when using proxy reports.

self-reports and for combining information from different sources.

A growing number of studies show that proxies report worse HRQoL as compared to self-reports, especially in dementia [4–9]. However, for the estimation of self-reports, adding an average value of the interrater gap (the difference between proxy reports and self-reports) to the proxy score might be a faulty strategy. Research into acute lung injury survivors revealed that the interrater gap varied from positive to negative numbers across the range of self-reports. The proxies, who were blind to patients' scores, reported worse HRQoL when patients exceeded a certain cutoff point, whereas proxies tended to provide higher scores than self-reports when self-reports were below such a cutoff score [10,11]. If this attenuation tendency is a universal phenomenon across different patient populations, researchers and clinical professionals should always take the tendency into account when using proxy reports to estimate self-reports.

In addition to the attenuation tendency in proxy scores, it is important to consider that proxies may use different perspectives in evaluating HRQoL. For example, proxies may respond from the patient's perspective (proxy–patient), which involves a belief about which answer the patient would give. A second possibility is that proxies may report

from their own perspective (proxy–proxy) and supply what they believe to be the most accurate answers [12,13]. A study of geriatric rehabilitation patients revealed that in patients with impaired cognition (Mini–Mental State Examination [MMSE] score of ≤ 23), the patients' own responses (self-reports) were in good agreement with proxy–patient responses [13]. In contrast, there were lower levels of agreement between self-reports and proxy–proxy responses. Therefore, when self-reporting is considered essential in HRQoL taxations, it can be tempting to recommend the use of a proxy–patient perspective in patients who cannot or do not want to report. However, to the best of our knowledge, sound empirical support for this recommendation is lacking. Furthermore, it is not clear whether the attenuation tendency of proxies exists for both proxy–patient and proxy–proxy perspectives.

The aim of this study conducted in nursing home (NH) units in the Netherlands was twofold. First, we aimed to examine the mean interrater gap—the extent to which the two proxy perspectives of HRQoL diverge from self-reports. Dutch NHs provide patients with self-contained living space located within specific “wards” (units) staffed with regular teams of professional carers. Dementia special care (DSC) units are designed for patients with dementia and are staffed with personnel trained to deal with specific dementia-related behavioral and psychological problems. Somatic units provide care from a medical-somatic approach without specialization in dementia care, although patients with dementia may also reside in these units if they do not require DSC. Because somatic and DSC units differ in patient characteristics, and in the training of the staff, we explored the differences in the interrater gap for somatic and DSC units. Second, across the whole range of self-reports, we wanted to explore whether there was an attenuation tendency in proxy–reports from both proxy–patient and proxy–proxy perspectives, and whether this differed for DSC units as compared to somatic NH units. NHs provide care for patients with limited expectations of cure who have severe chronic disorders including progressive conditions such as dementia. Many patients in NHs cannot be interviewed, especially those patients with dementia. Their proxies may be the only available information sources in HRQoL assessments. Research in the heterogeneous NH population may contribute to understanding whether the attenuation tendency is a universal phenomenon that needs to be accounted for in patients' assessments.

2. Methods

2.1. Participants and design

The sample for this cross-sectional study was obtained from a longitudinal effectiveness study of the multidisciplinary care program that was aimed at improving depression management in NH patients [14]. The Nijmegen

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