Quality of Life in Long-Term Forensic Psychiatric Care: Comparison of Self-Report and Proxy Assessments

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A B S T R A C T

Objective: To compare quality of life (QoL) ratings of long term forensic psychiatric care patients with the ratings of psychiatric nurses, in which the nurses indicate how they think the patient would answer.
Methods: Agreement on QoL-scores according to the Forensic inpatient Quality of Life Questionnaire (FQL) was investigated for seventy- seven pairs of patients and psychiatric nurses from two forensic psychiatric long-care facilities where QoL is seen as an important treatment goal. This study also examined whether the amount of agreement was related to specific patient characteristics and characteristics of the patient- psychiatric nurse relationship.
Results: On group level, only small and mostly non-significant differences were found between patients' and psychiatric nurses' mean QoL scores. However, pairwise comparisons revealed poor agreement between patients' and nurses' QoL scores for half of the domains and moderate agreement on the other half of the domains, except for Leave, which was the only domain on which patients and their nurses had similar scores. Patient characteristics such as type of offence and type of psychopathology were negligibly related to the level of agreement. However, characteristics of the patient-nurse relationship such as age of the nurse and length of the patient-nurse relationship did influence the amount of consensus between patients' and proxies' QoL-scores significantly.
Conclusions: Nurses were not sufficiently able to accurately estimate their patients' QoL experience and could probably benefit from a training aimed at assessing QoL of their patients and how to support their patients in optimizing their QoL themselves.

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Quality of life (QoL) has become an important health outcome in general psychiatric settings for both in- and outpatients. In forensic psychiatry, there is growing attention as well for QoL as an outcome measure (van Nieuwenhuizen, Schene, & Koeter, 2002) and also as a variable in the assessment of predicting criminal recidivism (Bouman, Schene, & de Ruiter, 2009).

According to several studies, a significant proportion of mentally disordered offenders require long term, in some cases life-long, forensic psychiatric care (Melzer et al., 2004; Shaw, Davies, & Morey, 2001; Vorstenbosch, Bouman, Braun, & Bulten, 2014). These so-called long-care patients are characterized by complex psychopathology, non-compliance in therapy and a high risk of criminal recidivism. In contrast to general forensic psychiatry, treatment of long-care patients is often no longer aimed at returning to society and risk reduction, but at psychiatric and medical care, acceptance of stay and optimising quality of life.

Due to the lack of perspective and because of basic human rights, QoL should be a very important theme in long term forensic psychiatric care.

However, in a specific long-care forensic context, QoL has a different meaning compared to in society in general. Setting-specific aspects (i.a. mandatory stay in a closed environment) (Coid, 1993; Walker & Gudjonsson, 2000) and disease-specific aspects (i.a. having severe and complex psychopathology) (American Psychiatric Association, 2000; Long, McLean, & Boothby, 2008) influence many parts of the lives of these patients. Generic instruments which assess QoL, such as The World Health Organisation Quality of Life (The WHOQOL Group, 1998), and instruments which assess QoL of psychiatric patients in general, such as The Lancashire Quality of Life Profile (Oliver, Huxley, Priebe, & Kaiser, 1997), do not fully address these aspects. A setting- and disease-specific questionnaire has therefore been developed: the Forensic Inpatient Quality of Life questionnaire (FQL) (Vorstenbosch, Bulten, Bouman, & Braun, 2007; Vorstenbosch et al., 2014). The FQL is based on the Social Production Function Theory (SPF) (Lindenberg, 1996; Ormel, Lindenberg, Steverink, & Vonkorf, 1997), patients' and forensic psychiatric nurses' experiences and their perceptions on quality of life (Vorstenbosch, Bulten, Bouman, & Braun, 2010). The SPF states that psychological well-being is influenced by social well-being and physical well-being, and that it can be improved by five instrumental goals: stimulation, comfort, status, behavioral confirmation and

affection (Ormel et al., 1997). The SPF-theory assumes that, in order to reach these goals and improve subjective QoL, different resources can be used, patients can substitute between resources and are able to set up buffers for the negative effect of loss of resources (Lindenberg, 1996; Ormel et al., 1997).

Additionally, Vorstenbosch and colleagues (Vorstenbosch et al., 2007) developed a proxy version of the FQL, which consists of exactly the same questions, but then rephrased as to how the forensic psychiatric nurse assigned to the patient (henceforth: case manager) thinks the patient would answer. Proxy measures are important because research has repeatedly shown that there are inconsistencies when comparing QoL ratings made by psychiatric patients and their case manager or a family member, for example among patients with dementia (Banerjee et al., 2009; Moyle, Murfield, Griffiths, & Venturato, 2012), schizophrenia (Becchi, Rucci, Placentino, Neri, & de Girolamo, 2004) and adolescents with autism spectrum disorders (Sheldrick, Neger, Shipman, & Perrin, 2011). According to these studies, proxies generally underestimate the patients' QoL.

However, there is a lack of knowledge about the agreement between patients and proxies within forensic psychiatric settings. This topic has never been studied before. This study aims to fill this gap by investigating the level of agreement on QoL ratings of long-care patients made by the patients themselves and by their case managers. Furthermore, this study aims to determine whether the level of agreement between patients and case managers is associated with the length of patient-case manager relationship. Becchi and colleagues (Becchi et al., 2004) found a higher agreement between schizophrenic patients and a proxy who was a relative in comparison with schizophrenic patients whose proxy was a nurse or friend. This might suggest that the length of patient-case manager relationship may be positively related to the amount of agreement on their QoL-ratings. Also, the relationship between the level of agreement and patient characteristics such as type of offence and type of psychopathology will be investigated in this study. Although this specific relationship has never been studied before, previous studies in forensic psychiatry did find a relationship between patient reported QoL and psychiatric diagnose (Bouman, Van Nieuwenhuizen, Schene, & de Ruiter, 2008; Draine & Solomon, 2000; Hansson, 2006; Masthoff, Trompenaars, van Heck, Hodiamant, & de Vries, 2006; Trompenaars, Masthoff, van Heck, Hodiamont, & de Vries, 2006) and type of offence (Bouman, de Ruiter, & Schene, 2008). These findings suggest that patient characteristics could potentially influence the level of agreement between patient's and case manager's QoL-scores as well.

The present study may provide important input for case managers. Being aware of discrepancies in QoL ratings could potentially help case managers to intervene on the most appropriate QoL domains and enable them to facilitate an optimal quality of life for their patients.

MATERIAL AND METHODS

Subjects

The study has been conducted in two high secure long-care forensic psychiatric facilities in the Netherlands. Between 2011 and 2013, 77 unique pairs of patients and their case managers completed the FQL. This was 51% of the total population (N = 151) of the long-care wards at the times of measurement. Every patient and case manager was asked to participate in the study, except for patients who were unable to complete the questionnaire due to a psychotic episode and/or major chance of decompensation, insufficient mastery of the Dutch language or seclusion, which was about 13% of the total population (N = 19). For 10% (N = 15) of the patients, no proxy-scores were available, because their case manager didn't participate in the study. Forty patients (26%) refused to participate in the study. Those patients mainly refused because they 'did not feel like participating' or thought it made no sense to participate because 'life in long-care is only getting worse'.

Demographic and clinical characteristics of the participating patients and case managers are shown in Table 1. All 77 participating patients were male and were diagnosed with one or more diagnoses on Axis I and/or Axis II defined according to the Diagnostic and Statistical Manual of Mental Disorders, version IV-TR (American Psychiatric Association, 2000). On average the participating case managers on had been working for over four years at the LFPC-wards (Table 1). The case managers generally had a vocational education which was often but not necessarily related to (forensic) psychiatric care. However, all case managers were specifically trained in working with forensic psychiatric patients.

The demographic and clinical variables as included in Table 1 did not differ significantly from the patients who did not participate in this study ($p = .06$–$p = .926$).

Procedure

Data were collected as part of an on-going longitudinal study in which the quality of life at two long-care forensic psychiatric facilities in the Netherlands was assessed. The data which were used in this study were gathered between 2011 and 2013. Participation by the patient was rewarded with payment equal to two working-hours.

The case managers (forensic psychiatric nursing staff) or a researcher asked the patients to fill in the questionnaire; case managers were approached by the researcher. In case a patient suffered from illiteracy or poor concentration, completion of the questionnaire was assisted by a researcher who read the questions. The case managers (every member of the nursing staff was linked to specific patients) completed the questionnaire themselves, mostly within a few days and up to two weeks after their patients completed the questionnaire.

Forensic Inpatient Quality of Life Questionnaire

Quality of life was measured using the Forensic inpatient Quality of Life questionnaire (FQL), a disease- and setting-specific instrument for QoL-assessment in long-care forensic psychiatry, developed by Vorstenbosch and colleagues (Vorstenbosch et al., 2007). The FQL consists of 114 subjective items which cover 15 domains: Activities, Leave, Residence, Nutrition, Hygiene, Health, Sexuality, Social Relations, Other Residents, Daily Staff, Affection, Autonomy, Self-actualisation, Finances and Religion. These domains are briefly described below. Because patients were forced to stay in the long-care, the FQL also contains an item about their acceptance of stay. The items were rated on

Table 1
Demographic and Clinical Characteristics of the Participants (N = 77).

Characteristic	
	Patients
Gender: male (%)	77 (100%)
Age, years: mean (s.d.; range)	52 (9,3; 35–77)
Length of stay in long-care, years: mean (s.d.; range)	6,4 (3; 0–14)
Length of stay in forensic psychiatric system, years: mean (s.d.; range)	17 (5,9; 4–34)
Main diagnosis, axis (%):	
Axis I	34 (44%)
Axis II	43 (56%)
Offense which led to mandatory stay in long-care, category (%):	
Homicide or attempted homicide	31 (40%)
Sexual offense	31 (40%)
Other	15 (20%)
	Case managers
Gender: male (%)	45 (60%)
Age, years: mean (s.d.; range)	41 (9,8; 22–57)
Length of employment at long-care wards, months: mean (s.d.; range)	52 (28; 3–120)
Length of patient-case manager relationship, months: mean (s.d.; range)	13 (17; 0–94)