Community Mental Health Journal (2019) 55:1395–1401
https://doi.org/10.1007/s10597-019-00377-w

ORIGINAL PAPER

Lay Perspectives of Quality of Life in Rheumatoid Arthritis Patients: The Relevance of Autonomy and Psychological Distress

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Received: 19 June 2017 / Accepted: 15 February 2019

Abstract
The aim of this study is to increase the understanding of Quality of Life (QoL) in rheumatoid arthritis (RA) patients and explore the personal features of living with the disease. Sixty-two RA patients ($M_{Age} = 56.7$; $SD = 11.2$; female = 83.9%) were interviewed. Assessment included topics on medical condition, functional status (HAQ-DI), and on their perceived difficulties and worries in having RA. Patients' overall definition of QoL was also inquired. Most patients lived with RA for a long period of time ($M = 16.5$ years; $SD = 11.6$) and presented moderate HAQ-DI scores ($M = 1.37$; $SD = 0.75$). Main features of QoL in RA highlight the importance given to physical health, particularly to independence and autonomy. Psychological distress emerged also as an important feature of living with RA, constraining a good QoL. Medical staff should consider the RA patients' emotional needs, expectations, and main perceived determinants of their QoL to better help them.

Keywords Quality of life · Psychological · Autonomy · Rheumatoid arthritis · WHOQoL

Introduction

Rheumatoid arthritis (RA) is a chronic, systemic, inflammatory disorder of unknown aetiology. Outcomes are variable, ranging from the rarely seen remitting disease to severe disease that brings disability and in some patients premature death (Moreland 2008). Without treatment, the majority of patients will experience progressive joint damage and significant disability. Epidemiological data on RA in Portugal is scarce, but a recent population-based study found that rheumatic and musculoskeletal diseases are highly prevalent and that their prevalence is similar to that reported in other countries. According to this study, RA patients are those with the bigger disability (HAQ) and the worse quality of life (EuroQoL-5D) within the rheumatic diseases ("EpiReuma. Estudo Epidemiológico das doenças reumáticas em Portugal," n.d.). RA in Portugal has a prevalence of 0.7% (1.1% for women and 0.3% for men) and available information on these patients point to the fact that there is a different prevalence distribution from region to region.

Presently, great attention is given to Quality of Life (QoL) in chronic health conditions. One of the most accepted definition of QoL is that of the World Health Organization (WHO), which characterises QoL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (Kuyken and The Whoqol Group 1995). Particularly for RA patients, the disease can affect a variety of physical, social and psychological health domains, and QoL measures can provide a broad picture of this impact. Franco-Aguirre and Cardona Arias (2015) and Salaffi et al. (2009) highlight the importance of including QoL as a

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measure of effect on health and as a complementary factor to clinical and epidemiological evaluations in patients with RA. Previous studies have shown that arthritis has a significant impact on multiple dimensions of QoL related to health (HRQOL) (Dominick et al. 2004), and that there is a significant decrease in HRQOL in rheumatic patients when compared with healthy people (Borman et al. 2007; Salaffi et al. 2009). An association between functional disability and quality of life in patients with RA has also been documented (Gong and Mao 2016).

In a literature review conducted by Franco-Aguirre and Cardona Arias (2015) the results showed that the most frequent instruments used for evaluating QoL in RA patients were generic tools, such as the Medical Outcomes Study Short-Form 36 (MOSSF-36) and the Stanford Health Assessment Questionnaire (HAQ). Several studies have emphasized the importance of adequately measuring such an integrative and complex concept (Miranda et al. 2010; Whalley et al. 1997), often emphasizing the need for accurately achieving the patient's own understanding of QoL within the context of their specific disease and living circumstances. This is particularly the case for individuals living under largely impoverished conditions (Schneider et al. 2008) and patients with low educational levels and/or difficulties in understanding complex assessment questionnaires, as they often prefer to openly talk about their RA derived limitations as a way of expressing their QoL constraints and emotional status. Moreover, despite the great variety of available disease-specific QoL instruments (Russell 2008), they are rarely utilized in clinical practice, and may not address important parameters that affect QoL like fatigue and disturbed sleep. Also, generic QoL measures as, for instance, the SF-36, which is thought to be better suited to capture the holistic health of the patient (Tugwell et al. 2008) or the RAQoL, the first RA-specific QoL instrument (Whalley et al. 1997), may be difficult to understand and constrain patients to freely express their worries.

The aim of this qualitative exploratory study is to increase the understanding of QoL in a group of Portuguese RA patients and explore the personal features of living with RA within the WHOQOL framework which includes six generic domains (physical health, psychological aspects, independence, social relationships, environment and spirituality/religion/personal beliefs) (The Whoqol Group 1998), and within the International Classification of Functioning, Health and Disability (ICF) framework, which describes the complex and multidimensional phenomenon of disability as a difficulty in functioning at the body, person, or societal levels in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors (Leonardi et al. 2006).

Methods

Participants

Participants were selected from a list of patients followed at the Unit of Clinical Immunology (UIC—Unidade de Imunologia Clínica) of the Oporto Hospital Center (Centro Hospitalar do Porto). From a total number of 420 patients with RA according to ACR, an invitation letter was sent to those who were at least 18 years old, had at least 1 year of disease evolution, and lived at no more than 30 km from Porto in order to attend to a lecture on Spa Therapy in RA at the hospital. The only exclusion criterion was having cognitive abnormalities (e.g. psychoses or senile dementia) in the clinical records. A total of 120 patients who fulfilled these criteria were randomly selected and contacted by traditional mail to attend the lecture. Sixty-nine patients acceded to participate in the lecture, and of these 62 acceded to answer to a semi-structured questionnaire on their clinical condition. All these 62 patients signed an informed consent to participate in the study.

Data Collection and Measures

The assessment protocol comprised a set of questions on socio-demographics variables (gender, age, employment status, level of education), and about the disease (e.g. years living with the RA diagnosis). The patients' general functional status at time of the study was assessed using the Steinbrocker Functional Classification (Steinbrocker et al. 1949), which categorizes the patients into 4 functional levels (level I corresponds to complete independence and level IV refers to complete dependence).

Information on the patients' health status was obtained by means of the Portuguese version of the Stanford Health Assessment Questionnaire Disability Index (HAQ-DI) (Bruce and Fries 2005). This instrument assesses the level of functional ability and includes questions on fine movements of the upper extremity, locomotor activities of the lower extremity, and activities that involve both upper and lower extremities. It includes 20 questions in eight categories of functioning, which represent a comprehensive set of functional activities (dressing, rising, eating, walking, hygiene, reach, grip, and usual activities). The stem of each item asks over the past week "Are you able to …" perform a particular task. The patient's responses are made on a scale from 0 (without any difficulty) to 3 (unable to do). The instrument considers if the patient needs some aids or devices for any activity, and the help from another person.

Finally, three open questions were made targeting the patients' difficulties and worries in having RA, and their overall understanding of quality of life: “What is in your perspective QoL?”, “Which areas of your QoL do you feel to be more affected by RA”? and “What are the main physical, psychological and social difficulties associated with RA?”. Data collection was conducted by a physiatrist who has a large experience in working with patients with different kinds of rheumatic diseases. Each interview took on average 40 min and was taped recorded, transcribed and later translated into English.

The study was conducted with the approval of the local Ethics Committee of Centre Hospital of Porto.

Data Analysis

Descriptive statistics were made for sociodemographic information and for health status. Qualitative data was transcribed and translated by the researcher who did the interviews. The transcripts were then analysed for recurrent themes using thematic analysis with the main topics covered in the interviews as starting points. Emergent themes and trends were noted and coded within the WHOQOL and ICF frameworks, i.e., themes were divided according to the WHOQOL six generic domains (physical health, psychological aspects, independence, social relationships, environment and spirituality/religion/personal beliefs) and according to the level of outcome (body, person, societal) described in the ICF. In this paper, independence was explore based on the definition used by Salvador-Carulla and Gasca (2010). These authors defined dependency as a condition related to the loss of autonomy and the need of support by a third person related to an impairment of activities of daily living, specially self-care. Therefore, “autonomy” and “dependency” are here considered a single construct (European-Commission 2003; WHO 2001, 2004; Stucki and Cieza 2004).

Results

Descriptive statistics of the RA patients’ demographic profile and health status is presented in Table 1. Most patients were female (52; 83.9%), with a mean age of 56.7 years old (SD = 11.2). The youngest patient was 31 years old and the oldest was 79 years old. When analysing participants by age groups, most participants reported advanced age: 13.64% (n = 22) were between 60 and 69 years old and 13.02% (n = 21) between 50 and 59 years old. Most patients (55; 88.7%) had low educational levels (i.e. 4 years of school). In what concerns their employment status, 29.0% (n = 18) were unemployed due to the presence of disability; and 27.4% (n = 17) were retired earlier due to the disability. Most participants had low-income professional backgrounds: Housemaids (15) farmers (13) and an important number of women never had a paid work (25). People with higher educational levels maintained their occupational activities with the support from their employer entities by means of ergonomic adaptations in the workplace. Regarding functional status, the mean score of HAQ-DI was 1.37 (SD = 0.75), with 62.9% (n = 39) patients corresponding to the level II.

Table 1 Characteristics of the sample

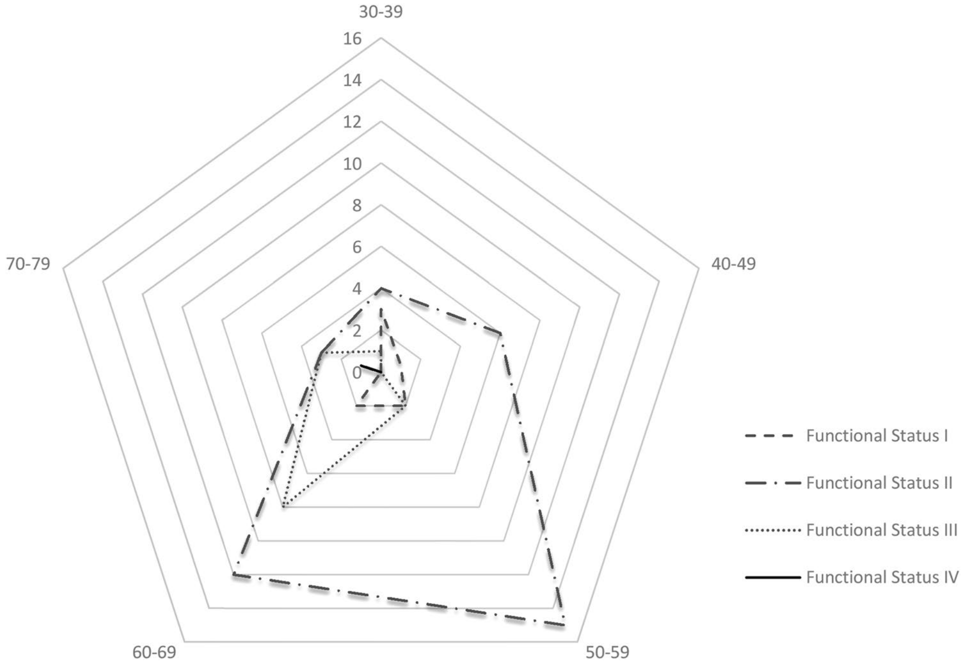
Characteristics	n (%)
Gender	
Female	52 (83.9)
Male	10 (16.1)
Age, mean (SD), years	56.7 (11.2)
Employment status	
Employed	15 (24.2)
Sick leave	3 (4.8)
Disabled	18 (29.0)
Retired	17 (27.4)
Unemployed	8 (12.9)
Level of education	
Primary school	55 (88.7)
Secondary school	1 (1.6)
University	6 (9.7)
Duration of disease, mean (SD), years	16.5 (11.6)
Functional status	
I	8 (12.9)
II	39 (62.9)
III	14 (22.6)
IV	1 (1.6)
HAQ-DI, mean (SD)	1.37 (0.75)

The functional status was analysed according to the age group (Fig. 1). The results revealed that participants with more advanced ages showed a moderate functional level (level II).

According to the patients’ perspectives, key aspects of QoL in RA include overall physical functioning (43.7%) and independence (32.95%). This last aspect was often embedded in the concept of autonomy. Common illustrative sentences include “*being able to normally do the activities of daily living, by my own*”, “*feeling autonomous and free to do everyday chores*”, “*being able not to rely on others*” and “*doing everything without restrictions*”. When crossing WHOQOL established domains with the participants’ definitions of QoL, “physical health” and “level of independence” accounted for 76.70% of the emergent themes (Fig. 2). Within these two major domains, affected areas include specific physical symptoms (joint discomfort, pain), overall feelings of being physically unhealthy, and not being able to perform daily routines (work, ADLs).

When a more detailed analysis was conducted on the main physical, psychological and social difficulties associated with RA, main concerns referred to the level of

Fig. 1 Functional statue versus age



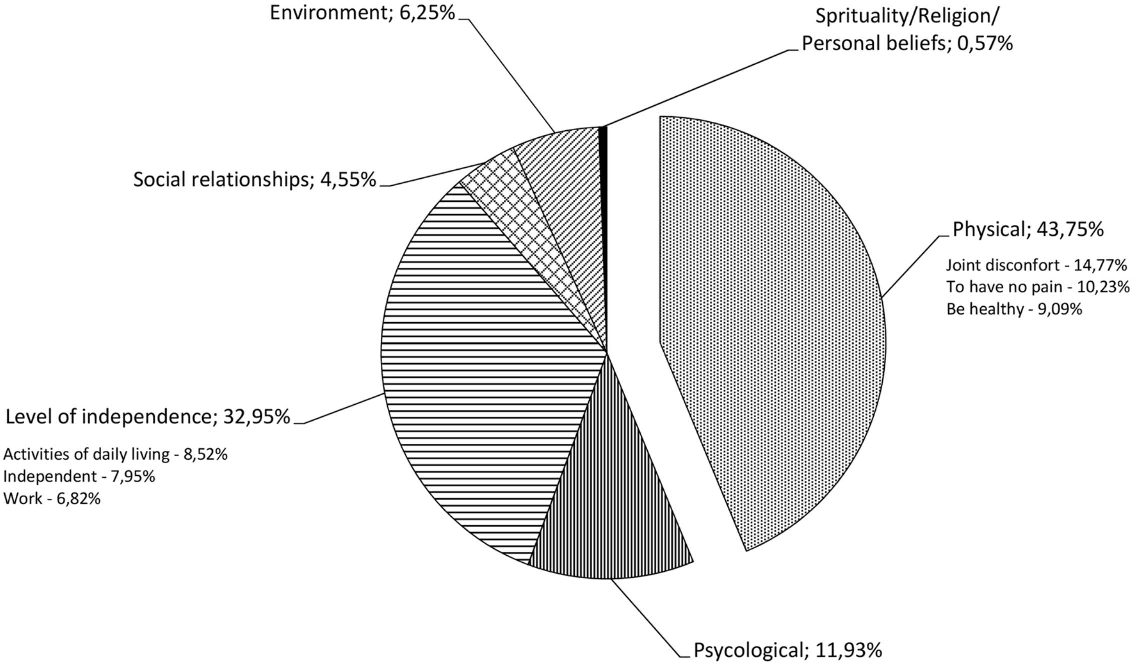


Fig. 2 Patients' perspective of QoL according to 6 domains WHOQoL

independence (59.65% of emergent themes), followed by psychological aspects (23.98%) which include fearing the future, depressive symptoms and feeling unwell / emotionally distressed (Fig. 3).

The great majority of patients (58; 93.5%) revealed throughout the interviews having negative thoughts on a daily basis, particularly when performing their daily routines and/or professional activity. Pain was not the main concern, but rather its conjoint psychological difficulties. Sadness, the recurrent need for antidepressant drugs, and a clear perception of being disabled (in the sense of losing autonomy and independence) recurrently emerged as important themes while expressing more common aspects related to RA symptoms (e.g. pain). A small proportion of participants (4; 6.5%)

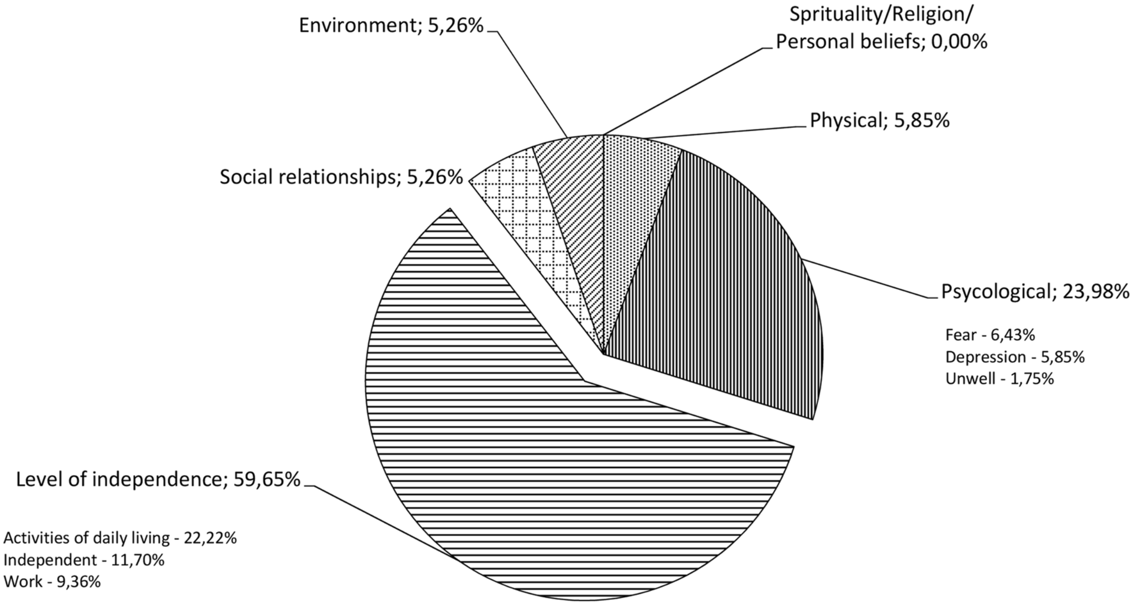


Fig. 3 Main difficulties associated with RA according to 6 domains of WHOQoL

expressed their resignation with their medical condition and knew how to cope with the limitations, either by living each day at a time, or by emphasising the available functionality. The great majority expressed in a clear way their wish to have better quality of life—living better (51; 82.4%) rather that an extended life—living longer.

Discussion

When thinking about RA symptoms/consequences, pain usually comes first as it is a core aspects of the disease; nevertheless, due to its progressive nature and impact, physical difficulties often come together with expressed needs of feeling autonomous and independent. Such needs relate to several psychological aspects as depressive symptoms and difficulties in coping with the disease's consequences in terms of functionality, which emerged as significant facets of living with RA. In fact, both the perceived level of independence/autonomy and psychological aspects constitute the major worries of the patients included in this study, highlighting its importance for QoL. Both aspects also reinforce how the loss of the ability to carry out daily functions owing to RA can be associated with the onset of depressive symptoms, and how "having control" and "self-management" may be important facets of dealing with RA in daily life (Flurey et al. 2015, 2014).

The associations of RA/QoL and RA/ psychological aspects have been documented in the scientific literature. Results from Dominik et al. (2004), for instance, show that arthritis has a significant impact on multiple dimensions of QoL, and that particularly older adults with RA report poorer general health, physical health, mental health, and sleep, as well as more activity limitations and pain, compared to those without arthritis. In the EpiReumaPt study, RA was significantly and independently associated with worse QoL in the Portuguese population, but there wasn't found a significant association with depression and anxiety symptoms (Branco et al. 2016). However, several studies have previously shown a significant association with these psychological symptoms and QoL in RA patients (e.g. Rogers et al. 2015; Nas et al. 2011), and have also highlighted the role of social aspects as the perceived social support in the management of depression and anxiety symptoms (Zyrianova et al. 2006). Higher depression and anxiety symptoms may increase the deterioration in QoL, and considering our findings, getting a deeper picture of the emotional status (both at a clinical and subclinical level) of RA patients is of great importance, as it is getting an in-depth insight of both medical and social resources that might be affecting/constraining independence and control.

Despite the availability of different medical treatment for RA, the detrimental effect of this chronic illness on many areas of life, as mood and emotions, elicit the need for psychological interventions. The psychological well-being of patients with RA has been recognized as an important issue (Gettings 2010; Ryan 2014), so along with treating RA signs and associated medical evolution, medical staff should also consider the patients' needs from a psychological point of view. Bearing in mind such a need, and considering that assessing psychological support for RA patients has been shown to be inconsistent and haphazard (Gettings 2010), an important step forward may be to explore the perceived determinants of quality of life within a multidisciplinary team approach. The presence of psychological distress could be then adequately recognized, and complementary therapies with proven benefits (e.g. cognitive behavioural therapies, meditation) be encouraged and conducted alongside conventional treatments.

Based upon our findings, demand for psychological support should be high; however, no clear information could be obtained on the rate of support on this matter (either pharmacological or psychotherapeutic). Previous research, however, has revealed that less than a quarter of patients report being asked about social and emotional issues, suggesting a gap between needs and psychosocial care provision (Dures et al. 2014). Such information reinforces the importance of having an in-depth understanding of what constitutes QoL for each patient, particularly among those with low educational levels and in impoverished conditions. This may be the way for accurately capturing the features of living with RA (Schneider et al. 2008) and its psychological consequences.

A special note is to be made on this study sample's characteristic and on the research methodological limitations. First of all, participants were mostly middle-aged/old and presented overall low educational levels. This finding is line with the Portuguese population in general: between 2013 and 2015, in Portugal the life expectancy at birth was 80.4 years for both men and women (77.4 and 83.2 respectively) (INE, 2016). In the same year, Portuguese residents with 50 + years represented 41.1% of the total population. Regarding to education, 8.3% of the Portuguese population never attended school and 23.5% had only 4 years of education. Older population showed the highest levels of illiteracy, with 27.7% of people with 65 + years old never attended school and 50.7% only attended 4 years. Second, the mean of duration of the disease found in our sample was 16.5 years. Although high, living so long with the disease did not seem to be associated with a higher level of dependency, once the majority of the participants showed a moderate functional level (level II of HAQ). The disease aggressiveness seems to be more relevant for the functional level than the duration of the disease. As for the study limitations, the methodology of using open questions does not allow the comparison with others studies in this field of research that assess QoL through a quantitative lens (e.g. SF36—short form (36) form health survey; EQ5D—European Quality of life Questionnaire) (Rodrigues et al. 2015). We believe, however, that a qualitative approach can give a deeper insight on the psychological features of living with RA, particularly among old individuals with low educational levels, as it is the case of this study patients. When crossing the items of the tables WHOQOL, ICF-RA and HAQ-DI we found several gaps, suggesting the need for better homogenization of coding between them in order to make them more integrative in clinical practice.

Conclusion

This study explored the personal features of living with RA within the WHOQOL and ICF frameworks in a group of RA patients. Main results reinforce the weight of feeling independent and autonomous, and support that along with RA's physical symptoms and associated functional limitations, psychological aspects are of great value to these patients' QoL. These aspects must be pursued as a crucial aim in clinical practice and highlight the importance of connecting the traditional approach, which is based on the exclusive use of clinical and laboratory evaluation, with the assessment of the patients' perspective on their health needs and care provision. The psychologist's role in assessing and treating psychological distress in RA should also be a priority.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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