

Quality of Life - Exemplified through Patients Living with Atrial Fibrillation

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Abstract

Background: Health-related quality of life is a frequently assessed patient-reported outcome in the current literature on patients living with atrial fibrillation. Originally, quality of life is an abstract, complex concept, and there is no consensus on a final definition of it. Considering overall quality of life to be assessable using a standardised tool may lead to the loss of valuable knowledge about the patients' individual lived experiences.

Aim: To report how the concept of quality of life is being defined and which arguments are given for using the concept in scientific research papers on patients living with atrial fibrillation.

Method: Systematic literature study based on analysis of 53 scientific research papers on patients living with atrial fibrillation and inspired by Leif Becker Jensen's suggestions on how to perform text analysis on a hermeneutical process described by Hans Georg Gadamar.

Findings: Three ways of defining the concept of quality of life and five preferred ways of giving reasons for using the concept were found. Thirteen of the papers offered no definition of the concept of quality of life, while 19 papers did not offer arguments for using the concept.

Conclusion: Quality of life is seen reduced into assessable parameters like health status. This might lead to the loss of valuable insight into the patients' subjective perception of their lives. To avoid this reduction in future, it is important to call for clear definitions and arguments for assessing quality of life, and to confront a suggested implicit societal agreement within scientific research.

Keywords: Atrial fibrillation; Literature study; Patient-reported outcome; Patients' subjective outcome; Qualitative method; Quality of life

Introduction

Atrial fibrillation (AF) is the most common cardiac arrhythmia, affecting approximately 1-2% of the general population, and more than 6 million Europeans suffer from this arrhythmia [1]. The prevalence of AF is progressing and is expected to at least double within the next fifty years [1].

In a review paper on patient-reported outcomes, Coyne et al. state [2] that health-related quality of life (QOL), together with symptoms due to AF, is the most frequently assessed patient-reported outcome in the current literature on patients living with AF. In a systematic review, Thrall et al. [3] point out that patients living with AF are likely to report a significantly poorer health-related QOL score than healthy controls and patients with coronary heart diseases. According to Engelmann and Godtfredsen [4], the influence on QOL is often captured by using assessable evaluation tools, both generic and disease-specific.

The concepts of QOL and health-related QOL have been widely discussed in the international literature in general for patients suffering from chronic diseases [5-7]. However, this discussion is not new. According to Gill and Feinstein [8], the basis for measuring QOL within the medical literature seems to struggle with the desire to measure things that cannot be measured. Regarding patients living with AF, Jenkins and Bubien also elaborate on issues and difficulties in the usage of the concept of QOL [9]. A clear definition of the concept of QOL is missing, and according to Moons et al. [10] this can lead to confusion in understanding the concept. Bergland and Narum [11] report existence of more than 100 different definitions of QOL. However, they conclude that by nature QOL is versatile and abstract. They therefore suggest defining QOL as an 'umbrella concept' [11]. Moons et al. illuminate [10] six problems related to working with the concept of QOL, as follows; 1. QOL vs. health status and functioning; 2. Objective vs. subjective dimensions; 3. Distinction between indicators and determinants; 4. Changes over time; 5. Negative vs. positive components; 6. Health-related QOL. Moons et al. [10], emphasise that the most appropriate way of defining QOL is by the phrase 'satisfaction with life'. Additionally, according to Kahneman it should be discussed how we can distinguish between general life satisfaction and the patients' subjective assessment of their current physical and emotional state [12]. QOL is defined by the World Health

Organisation (WHO) as; “*..individuals’ perception 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*” [13].

In accordance with this definition, Zachariae et al. state that QOL is multidimensional and consists of objective and subjective aspects, and is rated from the individual’s point of view [14]. Historically, there has been a desire to define QOL as an assessable patient-reported outcome since the World War II (WWII), defining QOL in a materialistic manner to improve living conditions [15]. This is inconsistent with the original content of the concept of QOL, leading back to Aristotle (344-322 BC) who described it as ‘happiness’, and later on, it appears as a socioeconomic concept as ‘the greatest happiness principle’ described by Bentham (1748-1832) [11]. As a socioeconomic concept, the desire was to involve peoples’ perceptions in ethical discussions in the society. In the 1970s, researchers worked on elucidating the original meaning of QOL as a subjective and dynamic concept [11]. In the 1990s, the focus of concern in QOL research was a definition of the concept [11]. Thus, as indicated by Zachariae and Bech [14], there might be a possible sign of a historical duality between a biomedical desire to assess health-related QOL as a patient-reported outcome, and a humanistic desire to focus on the patients’ subjective lived experience and perceptions in regard to the overall QOL. Hamming and Vries [16] explain that QOL contains more subjective elements than health status, which is a patient self-reported evaluation thus emphasising the importance of distinguishing between QOL and health status. The importance of distinguishing between health and QOL is also supported by Moons et al. [10]. According to Chin and Kramer [17], the complexity of a concept requires definitions and argumentation. According to Moons et al. [10], it is crucial to discuss the concept of QOL to minimise ambiguity. In this paper, we will elaborate on the use of QOL in scientific research papers on patients living with AF to illustrate the complexity and context dependency of the concept of QOL.

We therefore suggest that the terms health-related QOL and health status only cover a part of the individual persons overall QOL, and thereby that it is important to distinguish between the terms, which has also been emphasised earlier by Guyatt et al. [18], Apers et al. [19] and Moons [20]. Related to the context of patients living with AF the prefix of ‘health-related’ to QOL, is often considered. We therefore suggest a potential for a conflict between the way QOL is being used in science and research today and the original understanding of the concept as a multidimensional concept capturing the individual’s perception and experience of their position in life. The aim of this

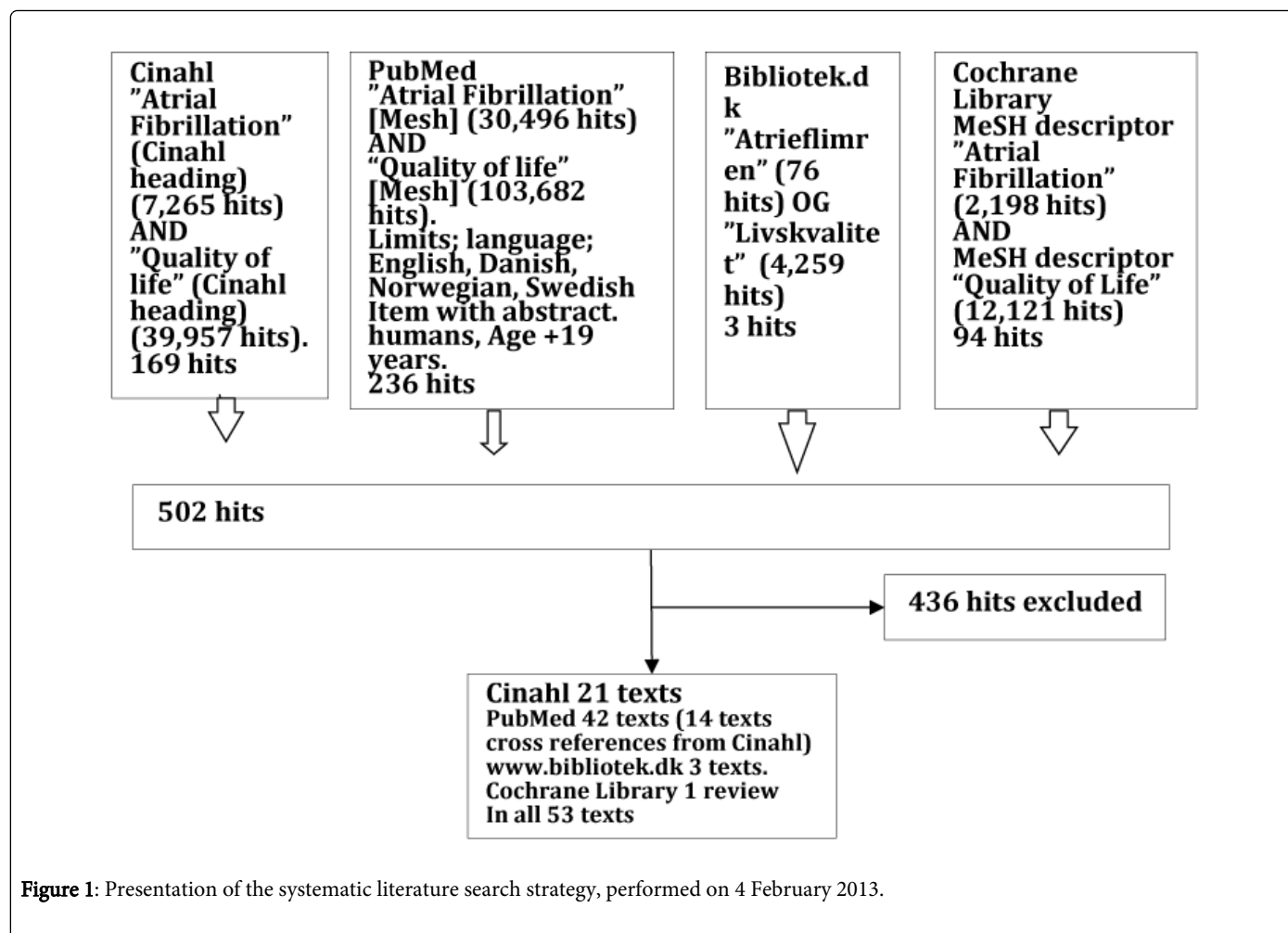
paper is to report how QOL has been defined and the reasons that have been given for using it in scientific research papers on patients living with AF.

Material and Method

The specific research questions for the study were; ‘How is the concept of quality of life defined?’ and ‘what reasons are given for using the concept of quality of life?’. We used the literature study method based on text analysis to guide our analysis on scientific research papers on patients living with AF. According to Silverman [21], it is important to describe why and how text analysis is used. In this study, we used the text analysis to examine the above mentioned expected contradictory and hidden content, applying QOL. As suggested by Koch and Vallgård [22] text analysis can elaborate on issues of hidden and contradictory contents in texts. The analysis was carried out based on the Danish scholar Leif Becker Jensen’s suggestions on how to perform text analysis [23] as a hermeneutical process described by the German philosopher Hans Georg Gadamar [24]. We started our analysis by reading all the included papers to get an overall impression. We then repeatedly read the papers keeping an open mind and trying to understand them from the perspective of the author. In our analysis, we considered major limitations of space, and requirements by editors and readers to stick to the point when one is describing research whose measured outcome is health-related QOL in scientific papers. We followed the three levels of text analysis suggested by Becker Jensen [23]. The *text close analysis level* enabled us to identify the content, the *communicative level* aimed to recognise where and why the text was written, and finally the *societal level*, which allowed us to elucidate the influence of societal factors [23]. To make it possible to report the result of our analysis, we used a schedule with the following issues; Author, publication year, purpose, design, context/country, definition of QOL, reasons for using QOL and findings.

Search strategy

The literature search, following Stoltz et al. [25], and Polit and Becks’ [26] recommendations for literature search was performed on 4 February 2013. We wanted to identify research papers on patients living with AF, where the concept of QOL was included. Of 502 possible hits, 53 texts were included in the study [2-4,27-75]. Details on the systematic literature search in Cinahl, PubMed, The Danish National Library Database and the Cochrane Library are demonstrated in Figure 1.



The process of inclusion and exclusion was performed by reading titles and abstracts of the total number of hits. Inclusion criteria were; patients with AF, the concept of QOL was included in the text, and the text was a scientific research paper. Exclusion criteria were; treatment-specific texts, patients with pacemakers, editorial comments and children (under 18 years). A librarian from the Danish National Library of Health Sciences was consulted during the systematic literature search.

Results

The text close analysis level

The findings are presented in Table 1, and the structure of this analysis is reported in Figure 2.

As shown in Figure 2, a clear definition of the concept of QOL was lacking in 13 of the 53 selected papers, even though the concept was used as the outcome of the study described in the paper. In relation to this, abbreviations like QOL, HRQOL (health-related QOL) and HS (health status) were used without defining or differentiating between them in eight of the papers [46,49,55-57,60,66,74]. In 29 of the papers,

QOL or health-related QOL was defined as an evaluating and assessable parameter. For example, Valderrama et al. [68] referred to other studies using Short Form-36 (SF-36) as a research outcome. In eight of these studies, we found argument for measuring QOL or health-related QOL, referring to SF-36 as the most valid and widely applied tool [27,35,46,53,54,61,75,76]. In six of the papers [4,28,33,36,46,57], QOL or health-related QOL was defined as a multidimensional concept with subjective elements which was hard to assess and use as outcome in clinical trials. Furthermore, these papers also emphasised the importance and difficulties in working with the concept. Five of the papers used the WHO definition [3,31,32,38,60], and multidimensional aspects were also included in their arguments. The paper written by McCabe et al. [73] exemplified the importance of including qualitative descriptive perspectives as well, when working with the concept of QOL. Five of the papers called for a new tool for integration in clinical practice and clinical trials [51,55,57,62,74]. The limitations of assessing the patient's subjective perspective using a generic tool were emphasised. In six of the papers without definition of QOL, arguments for use of the concept of QOL were also missing [39,40,43,48,65,67].

Author	Pub. Year	Design	Definition of quality of life	Arguments for using the concept of quality of life
Kang and Bahler [31]	2004	Cross sectional study	Health-related quality of life defined by the World Health Organisation. (W)	Focus on the concept as multidimensional and subjective. Critical regarding use of the concept in other studies and the random use of abbreviations and labels for the concept. Critical regarding the use of the concept as an effect outcome in studies. Emphasises the importance of the individual perception of the concept and involving physiological aspects of the concept. (M)
Kang[32]	2006	Cross sectional study	Health-related quality of life defined by the World Health Organisation. (W)	Critical regarding the use of health-related quality of life as an effect goal. Argues that health-related quality of life is important to use and investigate even though it is hard to work with. (M)
Maryniak et al. [38]	2006	Questionnaire study	Cites the World Health Organisation's definition of quality of life -"individuals' perception 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 and standards". (W)	Emphasises the importance of humans' subjective evaluation of quality of life. Uses a symptom checklist together with the SF-36 questionnaire. (M)
Thrall et al. [3]	2006	Systematic literature study	<i>"Patient-related issue"</i> Refers to the historical evolution of the concept going back to the 1940's where the World Health Organisation extended the definition of health to <i>"encompass the presence of physical, mental and social well-being"</i> . Quality of life has been more and more important as an outcome in research since 1980's. (W)	Emphasises quality of life as an important parameter instead of just focusing on mortality and morbidity related to different treatment strategies. Assessments of quality of life have been used in many settings e.g. to screen for psychological morbidity, to prioritise patients for various treatment, to determine the choice of treatment, to monitor patients' progress, and as an outcome measure in clinical trials. Relates to methodology weaknesses in the use of the concept (small sample size, no control group, short term follow-up periods and non-validated tools to assess quality of life). Emphasises the need for studies focusing on atrial fibrillation and its influence on people in a more general way. Quality of life is particularly relevant to treatment of chronic conditions. (M)
Paquette et al. [27]	2000	Double-blinded randomised multicenter study	Quality of life assessed as a parameter. Short Form 36 and Toronto Atrial Fibrillation Severity scale. Duke activity status index, Symptom Checklist. (P)	Short Form 36 is used because it is the most valid tool. (T)
Engelmann and Pehrson [29]	2004	Literature study	Health-related quality of life as an effect parameter. (P)	Emphasises problems of using quality of life as an effect goal. Health-related quality of life can be affected by many different factors and is multidimensional by nature. (M)
Suzuki and Kasanuki [30]	2004	Questionnaire study	Quality of life can be assessed as a parameter. Quality of life is assessed by Scale of Disease and quality of life. (P)	Arguments related to the importance of psychosocial aspects in the multidimensional concept quality of life instead of just focusing on somatic aspects as seen in earlier studies. (M)
Van den Berg et al. [35]	2001	Questionnaire study	Measuring quality of life from Short Form 36. (P)	Justifies the use of Short Form 36 as a standardised and valid generic questionnaire. Gives a short description of the elements of the questionnaire but does not further justify the selection of tool. (T)
Lünderitz and Jung [36]	2000	Literature study	Defines the concept as a multidimensional construction. Highlights a consensus regarding "quality of life is measurable on basis of four parameters". (M)	States that working with quality of life is important, and that this work can be complicated. Validity in earlier studies is lacking. (M)
Hegbom et al. [75]	2006	Intervention study	Defines health-related quality of life and uses the Short Form 36 questionnaire as measurement. (P)	Refers to other studies where Short Form 36 has been used. Uses Short Form 36 because it is a valid generic tool. (T)

Badia et al. [37]	2007	Literature study and validation of a disease-specific questionnaire	Defines health-related quality of life as it can be assessed from a parameter. (P)	Emphasises that working with development of a disease specific tool can reduce the individuality in the patients' perceptions, and points out that it is important to involve patients in the process. (M)
Lane and Lip [28]	2009	Literature study	Mentions that quality of life is a multidimensional construction but also that it is assessable using different scales. (M)	Emphasises methodology weaknesses in studies concerning quality of life. Emphasises that quality of life is being misused in the meaning of health. States that patients' perspective on the concept is an important outcome which can give important information in clinical trials. (M)
Reynolds, Ellis and Zimetbaum [33]	2008	Literature study	A subjective phenomena based on humans' individual perception and created through experiences, beliefs and expectations. (M)	Emphasises multidimensional aspects regarding the phenomena and discusses the roles of these aspects included when working with the concept. Critical regarding usage of quality of life as a measurement in the body of a standardised questionnaire and as an effect goal for a treatment. (M)
Engelmann and Godtfredsen [4]	2004	Literature study	Multidimensional concept. (M)	Emphasises the importance of working with the concept, but also that the concept is subjective and therefore can be difficult to work with. (M)
Siaplaouras et al. [39]	2005	Effect study	No definition of the concept. Uses a questionnaire with a scale 1-5. (N)	No arguments for using the concept quality of life as an effect parameter. (N)
Härden et al.	2009	Validation of a disease-specific questionnaire	No definition. Uses health-related quality of life. (N)	No further reasoning for using the concept than the concept is important to take into account in clinical practise. (N)
Dorian et al. [34]	2009	Validation of a scale to assess subjective assessment of quality of life	No definition of the concept. (N)	Important to use the concept of quality of life in clinical practise to reach understanding of the patients' subjective and specific perception of their situation. (I)
Ong. et al. [41]	2006	Questionnaire study	No definition of the concept. No differentiation between health-related and non-health-related quality of life. The two concepts are assimilated. (N)	Refers to results from other studies related to impaired quality of life among patients suffering from atrial fibrillation. Assimilates health status and quality of life. Splits up quality of life into mental and physical parts, referring to Short Form 36. Emphasises the importance of focusing on human factors with influence on quality of life instead of only focusing on disease-related factors. (M)
Sears et al. [43]	2005	Questionnaire study	No definition of the concept. Assimilates health-related quality of life with general quality of life. (N)	No arguments for working with the concept except for reference to other studies where the concept has been included. (N)
Dagres et al. [65]	2007	Cohort study	No definition of the concept. Quality of life is measured by EQ-5D and EQ-VAS. (N)	Usage of the two scales is not discussed, and no reasons are given (N)
Funk et al. [66]	2007	Literature review	No definition of the concept. Health-related quality of life is used as an effect outcome. Health-related quality of life and quality of life are used randomly. (N)	Emphasises that quality of life is an important "outcome" for assessing the effect of an intervention. Criticises the huge occurrence of tools which makes it difficult to compare study outcomes. Emphasises the desire to increase the stringency in working with assessing health-related quality of life. (I)
Dorian et al. [72]	2000	Questionnaire study	No definition. Mentions health-related quality of life but uses the abbreviation "QOL". Mentions global quality of life which is subjective and can be expected to be affected by chronic diseases. (N)	Elucidates that different tools are used for measuring patients' quality of life. Emphasises problems related to the non-existence of a specific questionnaire which can assess subjective aspects of quality of life and mentions that it might be a problem to measure these aspects. (I)
Thrall et al. [67]	2007	Questionnaire study	No definition of the concept. (N)	Emphasises methodology weaknesses in earlier quality of life studies. Gives no reasons for using the concept. (N)

Pontoppidan et al. [69]	2009	Prospective study	Measuring quality of life from Short Form 36. (P)	No arguments for using Short Form 36 are giving. (N)
Kang [70]	2009	Descriptive comparative study	Quality of life measured from Short Form 36. (P)	Describes the concept in details, but gives no reasons for using it. (N)
Lane et al. [28]	2009	Questionnaire study	Measuring health-related quality of life from Short Form 36. (P)	No reasons for using the concept are given. (N)
Ong et al. [41]	2006	Cross sectional study	Measuring quality of life by Short Form 36. Uses health-related quality of life and quality of life randomly. Assimilates the two concepts but only defines health-related quality of life. (P)	No further arguments for using the concept. (N)
Valderrama, Dunbar and Mensah [68]	2005	Literature study	Refers to other studies, using Short Form 36. (P)	No arguments for using the concept. (N)
Palm Johansen et al. [44]	2012	Literature review	No definition of the concept. Uses the Danish term "Livskvalitet" – "quality of life". Refers to studies where the concept has been used. (N)	Describes quality of life as an important measurement when wanting to obtain knowledge on patients' perceptions of living with atrial fibrillation. (I)
Bohnen et al. [45]	2011	Questionnaire study	Quality of life assessed by four scales: Physical condition, Psychological wellbeing, Social activities and Everyday activity. Quality of life is described as a parameter. A specific questionnaire designed to include both patients and their spouses has been developed. (P)	No direct argument for assessing quality of life. Refers to other studies where quality of life has been used as an assessable effect parameter (N)
Reynolds et al. [74]	2010	Randomised controlled trial	Uses the abbreviation QOL. Describes that quality of life can be assessed as an effect parameter. Uses Short Form 36 and Symptom Severity Checklist. (P)	Refers to other studies where quality of life has been seen as an assessable effect parameter. Short Form 36 is used because it is an extensively validated generic measure. Short Form 36 has been used in many other studies regarding patients living with atrial fibrillation. (T)
Perret- Guillaume et al. [46]	2010	Cross sectional study	Using the concepts of health status and health-related quality of life. Defines quality of life as a multidimensional concept, based on the patients' perception. Differs between quality of life and health-related quality of life. Uses two instruments; MOS –SF- 36 and Duke Health profile. (M)	Uses generic measures to be able to compare the participants, without regard to a specific disease. Emphasises that the selected instruments have been validated and used by others. (T)
McCabe et al. [73]	2011	Qualitative descriptive interview study	No direct definition of the concept of quality of life. Refers to other studies, where quality of life has been assessed from surveys. Emphasises that qualitative studies are needed to describe patients' experiences of living with atrial fibrillation. Impaired physical functioning and mental health in patients living with atrial fibrillation have earlier been reported. The authors emphasise the question "but how?". (N)	The concept of quality of life is not used directly in this study, but the importance of descriptive studies to obtain knowledge of patients' perception is being emphasised. (Q)
Spertus et al. [47]	2010	Development and validation of a disease-specific health status questionnaire. Prospective observational literature and interview study	Health-related quality of life is assessed as health status, in a questionnaire. The abbreviations used are explained. No final definition of quality of life. Refers to other studies which have shown decrease in patients' quality of life in regard to atrial fibrillation. (P)	Health status is an important outcome to use in clinical or research purposes, to get insight in patients' evaluation and to improve quality of treatment for atrial fibrillation. "Quantifying patients' perceptions of their disease with patient-reported outcomes is becoming an increasingly important method for defining the efficacy of new treatments and determining the quality of healthcare" (I)
Pappone et al. [48]	2011	Randomised controlled trial	No final definition of quality of life. Assessing quality of life from Short Form 36. (N)	Refers to other studies, which have shown that quality of life can be impaired in patients with atrial fibrillation. (N)

Guedon-Moreau et al. [49]	2010	Randomised controlled trial	Uses Short Form 36 as a health status questionnaire, later on describes that quality of life is measured using the two selected questionnaires. (P)	Refers to other studies where quality of life has been used as measurements. (N)
Mohanty et al. [50]	2012	Prospective study	Uses quality of life as an assessable outcome from Short Form 36 to evaluate the impact of metabolic syndrome in patients undergoing catheter ablation for atrial fibrillation. (P)	Refers to earlier studies which have shown that metabolic syndrome and atrial fibrillation, as stand alone conditions, have been seen to trigger physical, mental and psychological problems which greatly impair quality of life. (N)
Coyne et al. [2]	2005	Literature review	Measuring health-related quality of life as a patient-reported outcome measure. (P)	Measuring health-related quality of life is an important outcome to assess patients' evaluation on how atrial fibrillation symptoms and treatment impact their lives. It is very important to be aware of what a questionnaire is assessing e.g. a symptom questionnaire alone cannot assess health-related quality of life. (I)
Peinado et al. [51]	2010	Prospective observational multicenter study	Assesses health-related quality of life from a disease-specific questionnaire (AF-QOL). No final definition of the concept. Refers to other studies where the concept of health-related quality of life has been used. (P)	Development and validation of a new disease-specific questionnaire have been missing, and assessment of patients' health-related quality of life from generic measures has not been giving clear results. (O)
Lamori et al. [52]	2012	Retrospective observational study	Health-related quality of life is assessed by Short Form 12. Describes Short Form 36 as a standard measurement of quality of life. Refers to earlier studies where quality of life has been seen as impaired by dyspepsia. (P)	Emphasises that quality of life has been assessed in earlier studies. No direct argument for using the concept. (N)
Reynolds et al. [74]	2010	Prospective observational registry study	Health-related quality of life assessed by Short Form 12 and Atrial Fibrillation Symptom Checklist. No final definition. (N)	Refers to other studies where health-related quality of life has been assessed. Emphasises that health-related quality of life is important to work with, and that there is a need for a disease specific questionnaire. (O)
Jaber et al. [53]	2010	Quasi experimental questionnaire study	Individual perceptions of quality of life are assessed by Short Form 36. No further definition of the concept. (P)	Uses Short Form 36 to quantify individual perceptions of health and wellbeing because it is a previously validated and used tool. (T)
Groenveld et al. [54]	2011	Randomised controlled trial	Quality of life is assessed by Short Form 36. (P)	Short Form 36 is a validated and frequently used questionnaire in arrhythmia studies. Furthermore, Short Form 36 has been translated into Dutch. (T)
Gehi et al. [55]	2012	Prospective cohort study	General health status and wellbeing assessed by Short Form 12, by PCS and MCS component scores. Disease-specific questionnaire used: University of Toronto Atrial Fibrillation Severity Scale (AFSS) and Atrial Fibrillation Effect on QualiTY-of- Life (AFEQT), Canadian Cardiovascular Society Severity of Atrial Fibrillation Scale (CCS-SAF). Refers to other studies where the concept of quality of life has been used. (P)	Development of a disease specific tool regarding this group of patients is very important. "A <i>general quality of life scale may not reflect symptoms particular to AF</i> ". (O)
Fichtner et al. [56]	2012	Prospective quasi experimental study	Assesses quality of life from seven validated and tailoured questionnaires, both disease-specific (3) and generic (4). (P)	Disease-specific tools are important and more reliable to assess quality of life in patients living with paroxysmal atrial fibrillation. (I)
Dabrowski et al.	2010	Prospective quasi experimental study	Quality of life assessed using the Nottingham Health Profile questionnaire. Definition: " <i>determinants of positive functioning assessment (quality of life) include 1) Objective factors such as health status (and the results of medical tests), socioeconomic status (home, work, income) and social relationships (their quantity and quality)</i> "	Indicates hope for development of a better tool to evaluate patients' perceptions as an endpoint in clinical trials. (O)

			2) <i>Subjective factors: Physical (capacity, complaints), mental (anxiety, depression, self-perception) interpersonal (social support, interactions with other persons) and social (satisfaction from work, financial situation and social position)</i> ". No reference to this definition is mentioned except from referring to other studies which have shown impaired quality of life in patients with atrial fibrillation. (M)	
Cha et al. [58]	2011	A prospective cohort study	Quality of life assessed using Short Form 36. (P)	No arguments for using the concept. Refers to other studies, which have shown impairment in patients' quality of life in regard to atrial fibrillation. (N)
Ariansen et al. [59]	2010	Case-control study	Uses "QOL" as designation on quality of life. Mentions health-related quality of life (mixes up designations). Assesses quality of life from Short Form 36 and the disease-specific questionnaire Symptom Checklist, Frequency and Severity. (P)	No arguments for using the concept. Refers to other studies where it has been used. (N)
Almeida et al. [60]	2011	Cross sectional study	Defines quality of life from the definition provided by the World Health Organisation in 1947. <i>"Quality of life is a wide concept involving several factors affecting the life of a person, such as social condition, health, economical status, satisfaction and welfare."</i> <i>"Quality of Life is related to the subjective perception, on health status and on how a disease affects the persons life, involving both physical, functional, emotional and social aspects"</i> Describes that quality of life was evaluated from two questionnaires – one generic (Short Form 36) and one disease-specific Duke Anticoagulation Satisfaction Scale. (W)	Refers to the importance of evaluating the subjective perception from the patients' perspective. States that quality of life has been evaluated in a few earlier studies. Both selected instruments were easy to use and self-explanatory. Emphasises that both instruments have been validated in Brazil. (M)
Steg et al. [62]	2012	International, observational, cross sectional survey	Quality of life assessed by the questionnaire EQ5D. (P)	Refers to other studies assessing quality of life. EQ5D is validated in different languages. Discusses the need for at disease-specific questionnaire and that the existing disease-specific questionnaires, related to atrial fibrillation, were not available at the time, when the study was performed. (O)
Rådholm et al. [63]	2011	Population-based survey study	Assesses self-estimated health related quality of life from EQ-5D index value and Vas scale. (P)	No arguments for using the concept. Refers to prior studies, which have indicated impaired quality of life in patients with atrial fibrillation. (N)
Suleiman et al. [64]	2012	Randomised control trial	Quality of life assessed by Atrial Fibrillation Symptom Frequency and Severity Checklist. (P)	No arguments for using the concept. (N)
Ahmed et al. [61]	2010	Randomised controlled trial	Measuring general health-related quality of life, using the generic Short Form 36 and other disease-specific measures. (P)	Short Form 36 is the most widely used tool to assess health-related quality of life in arrhythmia studies. (T)

Table 1: Presentation of the 53 selected scientific research papers.

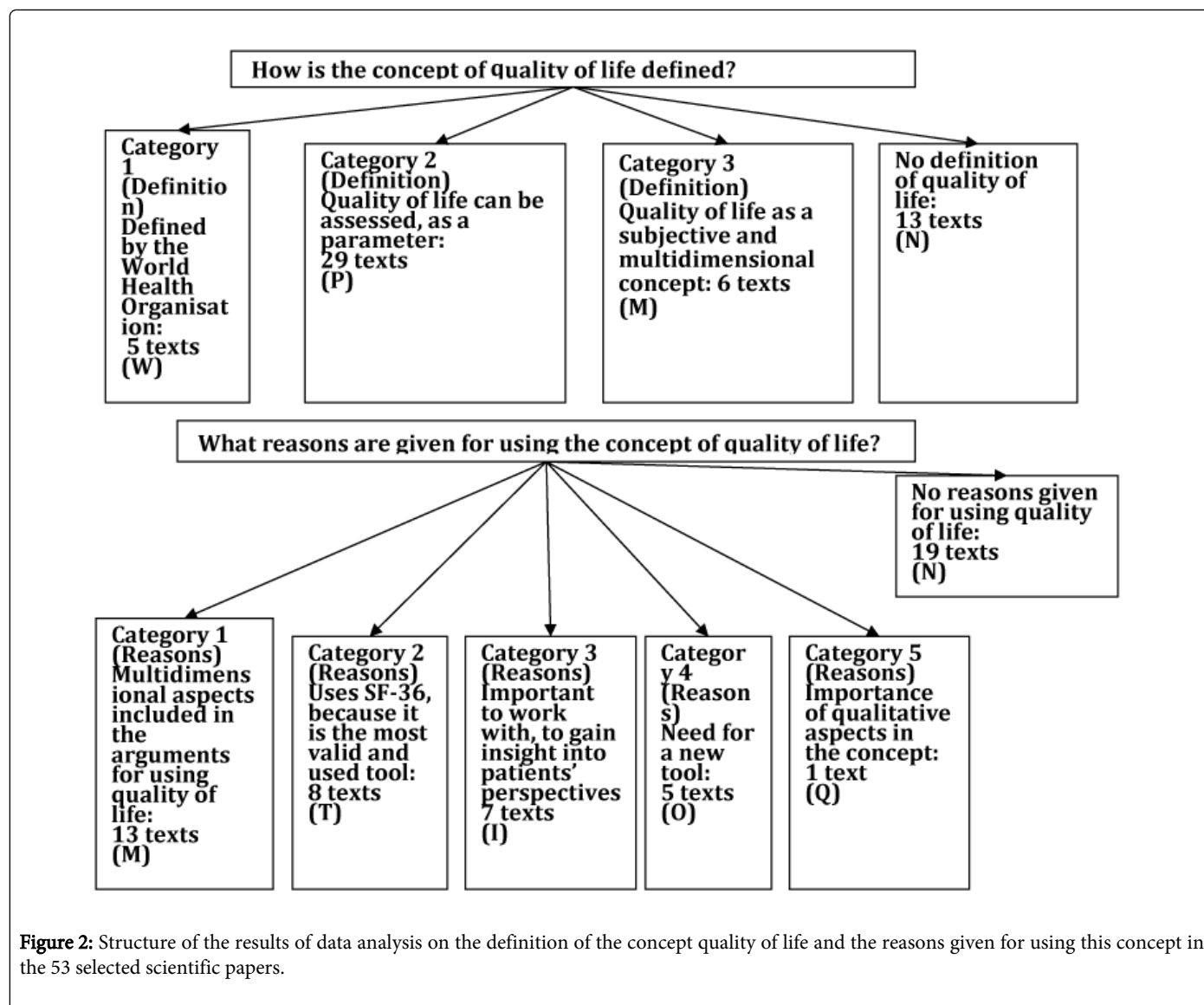


Figure 2: Structure of the results of data analysis on the definition of the concept quality of life and the reasons given for using this concept in the 53 selected scientific papers.

The communicative analysis level

Most of the papers were written by physicians with the exception of four that were written by nurses [31,32,44,73]. Two were written by nurses and doctors in collaboration [45,64], and one paper was written by a psychologist [30]. The target population of all the papers was health care professionals. The papers were mainly questionnaire studies, literature reviews and one qualitative interview study.

The societal analysis level

The papers were published from 2000 to 2012 and were published in various countries: Japan, France, Italy, UK, US, South Korea, Israel, Canada, Spain, Poland, Norway, Sweden, Germany, the Netherlands, Brazil and Denmark.

Discussion

This section of the paper is based on three subjects which occurred during the analysis, regarding reflections on the utilisation of the concept of QOL.

Sign of an implicit societal agreement

Missing definitions and reasons for using the concept of QOL were elucidated in this study. Furthermore, it showed a “mix up” in the abbreviations that did not seem to be concise as the authors seem to fail to distinguish between QOL, health-related QOL and health status. This issue might lead to concept confusion and reduction of the original meaning of the concept, as stated by Moons et al. [10] who emphasised the crucial issue of reflecting on the use of the concept of QOL. We are aware that patients’ perspective is taken into account in the design and validation of questionnaires. However, considering overall QOL equal to health-related QOL and health status may lead to risk of reducing the individuals lived experiences included in overall QOL as lived experiences are context dependent and situation oriented and part of the individual person’s life [77].

According to Becker Jensen [23], implicit meanings of concepts may be a result of a societal agreement and thus no direct demands for a final definition are made by society when using the concept. This may be exemplified by arguments stating that SF-36 is a valid and widely applied tool [27,35,46,53,61,74-76]. This kind of argumentation

might be what Becker Jensen [23] describes as 'tricks of arguments'. Becker Jensen defines 'tricks of arguments' as a special type of argument characterised by being a reliable argumentation but not necessarily valid [23] (p.81). Compared to Toulmin's model of arguments (1958), 'tricks of arguments' might be regarded as the warrant in a chain of argumentation, consisting of three elements, claim, support and warrant. Lack of documentation is frequently seen within 'tricks of arguments', and justification relies on the recipient. According to Becker Jensen, 'tricks of arguments' appear in different types, for example; expert arguments, authority arguments, and genetic arguments [23] (p.81-82). Expert arguments meaning that if experts state that something is right, it is considered right and can serve as a warrant in the chain of argumentation, without demand for relevant documentation. For example in a conversation between a patient and a medical doctor, the patient believes that the doctor is right due to his education and position and does not demand further documentation. Authority arguments meaning reference to a respected authority (person or institution) can serve as a warrant for a claim, without demand for documentation of the warrant. According to Becker Jensen, one of the largest authorities in Denmark is social agreements that are likely to be implicit. In other words, the majority in a society can decide what is right. Genetic arguments meaning to conclude about the nature of something based on a description of it, for example stating: most women are stay-at-home wives, ergo women prefer to be housewives taking care of their families [23] p. 82. In this study where authors claim that SF-36 can be used as an expression of the subjective overall concept of QOL, without further definition and reflection or argument for the claim, it may be considered as what Leif Becker defines as an "expert argument" or an "authority argument" [23] (p.81-82). The use of 'tricks of arguments' might be a result of the earlier mentioned 'implicit societal agreement' stating that it is valid to consider the overall concept of QOL to be assessed using a standardised tool like SF-36.

The issue of academic writing and existence of an implicit societal agreement

With regard to academic writing where, according to Eriksson [78], Chin and Kramer [17] and Hanestad and Wahl [15], arguments and definitions play a central role for the transparency, rigour and clarity of the text, this issue of an implicit societal agreement is crucial. It underlines the importance of the author's responsibility to reflect on the concepts used.

In academic writing, a clear and transparent reasoning is commonly recommended. According to Dahlager and Fredslund [79], the reader's opportunity to gain understanding of the use of the concept is minimal, if the author does not explicate the pre-understanding including the definition and arguments for the concept used. Using the concept of QOL without explicit considerations on the concept and its connection to health status may lead to less attention on the individual's subjective lived experience. By this paper, we want to highlight the importance of arguments and definitions in scientific research.

Potential consequences of not confronting an implicit societal agreement

The findings of the societal and communicative levels of the analyses performed in the 53 selected scientific papers indicated that these results were evident in different countries and professional contexts, ranging from psychologists and doctors to nurses. It is

difficult to define the contexts in which the problem of hidden societal agreement is most dominant. Moons et al. [10] point out that the discussion regarding the content of the concept of QOL (especially in the 1990s) has mostly been ongoing within humanistic research [10], which perhaps is the reason why the influence is less established within the field of biomedical research. However, Gill and Feinstein [8] comment on this issue by saying that the usage of QOL within medical literature seems to aim at the wrong target by requesting to measure something that cannot be measured. More research is required to determine relationships regarding this issue in different contexts.

In 29 of the 53 selected papers we found indication of a desire to assess QOL or health-related QOL as a measurement, a parameter. The desire to assess health-related QOL and the evaluation of measurements, disease-specific scales, generic scales, and questionnaires can be seen historically in the development of the concept. For example, Bergland and Narum write that in the post WWII period, researchers wanted to measure 'welfare' and to improve living standards [11]. It is reported in the *Annals of Oncology* in 1995 that for the first time the U.S. Food and Drug Administration's Guidelines approved a drug primary based on results on patient-reported health outcome [80]. Additionally, it is reported by both Zacharia [81] and the user manual of the SF-36 questionnaire [82] that inclusion of patient reports on health-related QOL is requested when a new drug is being tested. This is a case of a 'silent demand' to the pharmaceutical industry, to assess health-related QOL as an 'effect goal'. A reason for assessing the patient's health-related QOL has been given by Zachariae as 'involving the patients in their own treatment'. Patients' lived experiences are by definition and explicitly taken into account in the very design, validation, and use of disease specific health-related questionnaires, and thereby a crucial foundation for the design and validation of questionnaires. Thus, trying to assess the patients' lived experiences from a standardised questionnaire may be problematic, when we consider lived experiences as context dependent and situation oriented. Hamming and Vries [16] recommend that it is important to state what is being assessed, e.g. health status, instead of denominate it all QOL. From the 53 selected papers we found that a definition of the concept of QOL was missing in 13 of the papers, and arguments for using the concept were missing in 19 of the texts. This indicates a potential for improvement and precision on what is being assessed and for what purpose in research involving the concept of QOL in the context of patients living with AF.

In their deliberations, the authors seem to fail to distinguish between QOL, health-related QOL and health status. From our point of view, this is what Moons et al. [10] state by emphasising the crucial issue of reflecting on the utility of the concept of QOL.

To articulate the implicit societal agreement within scientific research, we wish to stress the importance of reflecting on and facing these issues regarding the concept of QOL, and consequently elucidating the problems.

Limitations

Several of the selected scientific papers were based on a quantitative methodology, which is important to be aware of in understanding QOL from a hermeneutical perspective, which by nature, is qualitative. We have been attentive and open to this fact in our interpretations. QOL is complex and multidimensional and has been a popular subject in scientific research; exemplified by being included in numerous texts (see Figure 1 - 103,682 hits in the search in Pub Med on 'quality of

life'). The aim of this study was not to clarify all aspects of the concept of QOL, but to elaborate on how QOL has been used and arguments for using it. However, specific details regarding the concept of QOL may be lost. Moreover, the aim of this study has not been to elaborate on the specific results from the selected scientific papers. This kind of study would have called for another approach e.g. a systematic review approach. Performance of this kind of study is considerable for future study plans. Additionally it may add important and valuable knowledge to the field of patient reported outcome in patients living with AF. Hermeneutical interpretation requires the researcher to be open and aware of his/her pre-understanding in order to let the text speak for itself. There is a risk of misunderstanding hidden meanings in the papers, but we have tried to be aware of this risk during the entire interpretation process, by rereading the papers several times and reminding each other and ourselves how and where the papers were written and by whom. We have tried to stay aware of the agenda and purpose of the papers. Hermeneutical interpretation is subjective and can therefore not be generalised, but according to Delmar [83] 'generalisability' in qualitative studies can be seen as 'recognition', which means a way of expressing something familiar or common. Therefore, the findings of this study cannot necessarily be transferred directly into contexts of other diseases. However, because QOL is a popular universal and widely used human concept, our findings may disclose some familiar and common things about the concept, which can be relevant to investigate in relation to other diseases. In addition, perhaps the issues related to the potential existence of an implicit societal agreement in a research field can be seen in relation to other diseases, as generic tools to assess health status such as SF-36 have also been used in other fields than patients living with AF. Therefore, there may be a potential for the existence of what is described by Becker Jensen [23] as 'implicit societal agreements' and 'tricks of arguments' in other research areas, similar to the ones found in this study.

Implications for future studies

In this study, we found that the patients' subjective lived experiences are at risk of being condensed into outcomes in standardised evaluation assessments if the concept of QOL is used unreflected without definition and argument. We find it important to elucidate this risk, to prevent reduction of the patients' subjective lived experiences in future studies. However, we also find it important to emphasise the importance of developing disease-specific questionnaires for the specific disease that the patient suffers from, as described by both Zachariae and Beck [14], Pedersen and Kupper [84] and Spertus et al. [47]. A disease-specific questionnaire must cover the specific symptoms and problems concerning the specific disease. Taking patients' experience of symptom burden into account is especially important within the population of patients living with AF, as this is a highly heterogeneous group in reference to symptom burden, age and gender, as described by Camm et al. [85] as well as by McCabe [73]. However, we would suggest including qualitative as well as quantitative approaches to focus also on the patients' subjective lived experiences in future studies. The study performed by McCabe et al. [73] is an example of a qualitative approach. Most importantly, we suggest reflecting upon the concepts being used. A newly published paper by Eriksen and Risør [86] reflects upon the concept of 'symptom', which is also a central issue in future studies on the population of patients living with AF. Furthermore, Dijkers comments that a continuous discussion on QOL is needed [87].

Conclusion

Assessing the concept of QOL from a standardised assessment tool might lead to reduction of valuable insight into the patients' subjective lived experiences if left standing alone. To avoid this reduction in scientific research concerning patients living with AF, it is important to call for a clear definition and reasoning for using the concept, and to be aware of the aspects of QOL that can be assessed using a tool and the ones that cannot. Without challenging the suggested implicit societal agreement regarding the ability of calculating patients' subjective lived experiences, the ambiguities in the use of QOL will continue.

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