

Reexamining the Quality of Life of ALS Patients ——lessons from Previous Studies

Yoshitaro Hotta⁽¹⁾ (Ritsumeikan University) , Michihito Ando⁽²⁾ (Mitsubishi Research Institute) , Yumiko Kawaguchi^(3, 4) (Ritsumeikan University)

Abstract

In this paper previous medical studies of the QOL of ALS patients are surveyed and their contributions and limitations are discussed. The contributions and limitations we focus on are both related to their examination of non-physical and subjective factors of patients' QOL. We argue that it is an important empirical finding that ALS patients' well-being depends heavily on non-physical factors that tend to be undervalued in studies of health-related QOL (HRQL), but a focus on purely subjective or mental QOL may overlook the kind of societal evaluation of patients' circumstances which is crucial to establishing standards for medical and social care. Finally we discuss the potential usefulness of the capability approach to overcome some of the limitations of previous QOL indices.

Keywords: *ALS, QOL, capability, adaptive preference, social care*

1. Objectives

In this paper we review the methods and results of a range of previous studies on the QOL of ALS (Amyotrophic lateral sclerosis ⁽⁵⁾) patients and discuss some of the contributions and limitations of these previous approaches to the assessment of QOL. We then go on to briefly discuss the potential use of the capability approach to address some of these limitations.

2. QOL assessment

2-1. Definitions of QOL

The term “Quality of life” has a range of usages and is difficult to define. For example, the WHOQOL Group (1994) defines 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 [43].

QOL has also been defined in both more subjective and more objective terms, and there is no persuasive reason to choose one particular definition. When discussed in clinical medicine or health economics, however, QOL is generally described in terms of narrowly defined numerical indices because of the requirements of simplicity and quantifiability.

2-2. Generic QOL

We will begin by explaining the basic structures of three prominent generic health-related QOL (HRQL) ⁽⁶⁾ indices and two other QOL indices that are often used for the assessment of well-being of ALS patients. The former are the SIP (Sickness Impact Profile), SF-36 (Medical Outcome

36-Items Short Form) , EuroQol (or EQ-5D) ⁽⁷⁾ and the latter are the SEQoL (Schedule for Evaluation of Individual Quality of Life) and MQOL (MaGill QOL).

SIP is an HRQL measure that attempts to assess patients' self-perceived health status based on their behavior. The effects of health status on everyday activities and participation in society are emphasized over assessments of subjects' cognitive and emotional states, although several questions related to emotional well-being are included in the survey.

SIF-36 is another general HRQL measure and is intended to assess physical, social and emotional functions. It employs thirty six elements to assess eight dimensions of health status, including aspects of both physical and mental health.

EuroQol (EQ-5D) is an HRQL index that put its focus on simplicity and comparability between countries. It assesses five dimensions of health (mobility, self-care, activities in daily life, pain/discomfort and anxiety/depression) with subjects choosing one of three responses to questions in all of these areas. In addition to these questions informants are also asked to indicate their "state of health today" on the visual analogue scale (VAS). EuroQOL has not been used as an index for clinical trials but has been applied to general health evaluation including cost-effectiveness analyses.

Fayers et al. (2000) point out that HRQL may include factors related to overall health, physical capabilities, symptoms caused either by illness or medication, emotional function, cognitive function, social function, sexual function, or existential questions. It is difficult, however, to determine exactly which elements of QOL should be considered "health related" . Also, while nursing and long-term care does not necessarily improve the medical health status of ALS patients it can nonetheless considerably improve their QOL, and such non-medical improvement through non-

medical or quasi-medical intervention is not properly assessed by HRQL indices.

To overcome these limitations, some generic QOL measures aim to evaluate subjects' quality of life beyond a narrowly defined "health status". With SEIQoL, for example, which was developed mainly to evaluate the well-being of people with incurable diseases [23], informants are first required to choose for themselves five factors that they think are important in their own lives. They are then asked to attach weights and scores to each factor. As a result the SEIQoL index describes more subjective informant utilities than other QOL measures.

McGill QOL (MQOL) is another QOL measure that is often used to assess the QOL of ALS patients. MQOL is not a perfectly generic QOL measure but has been developed to assess the QOL of patients with life-threatening or terminal illness [9, 10, 11, 12, 13] In its 1996 version, MQOL has 16 questions and consists of physical, mental, existential and support-related questions.

2-3. Disease-specific QOL

The SIP/ALS-19 (Sickness Impact Profile ALS-19) and ALSAQ-40 (ALS-specific QOL) indices were created as HRQL measures designed specifically for the assessment of ALS patients' QOL, and an index called ALSSQOL (ALS-specific QOL) was constructed as a QOL measure that puts a particular emphasis on non-physical aspects of quality of life based on the MQOL index.

SIP/ALS-19 is a QOL index which has only 19 questions that are selected for their simplicity and ease of use from those found in the SIP index. These questions were chosen based on the statistical correlations between the scores of each question and the TQNE (Tufts Quantitative Neuromuscular Exam) index that measures the neuromuscular capability

papers are discussed with a focus on non-physical aspects of QOL and the QOL of family caregivers.

3-1. Assessment of non-physical aspects of the QOL of ALS patients

Ten out of eighteen papers attempted to assess non-physical aspects of the QOL of ALS patients [5, 7, 15, 17, 21, 30, 32, 34, 37, 38] and nine of these papers (De Groot et al. (2007) [15] was the exception) used non-physical subject-based QOL measures such as MQOL or SEIQoL instead of a HRQL measure.

All of these studies pointed out that patients' subjective QOL scores do not necessarily decrease along with the progress of their physical disorder.

The most commonly stated reason for focusing on the non-physical aspects of the QOL of subjects in these studies is that patients' subjective QOL tends to be different from their QOL as measured by indices whose primary concern is the physical capabilities of informants. Another reason given in some cases is that a non-physical QOL assessment is required in order to evaluate the quality of medical and social-care provided to ALS patients [7, 32].

Many studies that we reviewed cited spirituality and religiosity as essential non-physical factors of informants' QOL. In particular the studies done by the ALSSQOL group emphasized spirituality and religiosity as important components of QOL [34, 37, 38]. Although only one paper analyzed the importance of social support using an independent evaluation [5], several papers indicated that social support is among the essential factors in improving the QOL of ALS patients [21, 30, 38].

3-2. Studies comparing the QOL of patients and caregivers

Another major subject in our review is comparative studies of the

subjective QOL of patients and caregivers. Seven papers [4, 19, 20, 28, 30, 39, 40] can be classified in this group. Six focused on the QOL of patients and family caregivers and one (Van den Berg et al. (2005) [40]) focused on patients and professional caregivers.

When it comes to the relation between the progress of the disease and the QOL of patients and caregivers, five of the papers indicated that while the QOL of ALS patients did not clearly decrease as their physical capabilities deteriorated, the QOL of caregivers did have a statistically significant positive correlation with the physical capabilities of the ALS patients. Brooks et al. (1996) and Ganzini et al. (1998) reported that the negative impact on subjective QOL caused by the progress of ALS is much greater for caregivers than for patients [3, 18]. Gauthier et al. (2007) also mentioned that “caregivers’ overall psychological well-being worsened over time, whereas the patients’ remained relatively stable” [19]. Kaub-Wittemer et al. (2003) evaluated ALS patients with ventilators, both invasive and non-invasive, and both studies pointed out that the degree of satisfaction with the use of ventilators is higher for patients than for family caregivers [28]. Trail et al. (2003) states that patients tend to estimate the QOL of caregivers to be higher than their empirically assessed QOL and that caregivers tend to estimate the QOL of patients to be lower [39]. This study also discusses the differences between the attitudes of patients and caregivers toward medical treatment. In particular, regarding the use of a Non-Invasive Ventilator (NIV), caregivers tended to be much more negative than patients; only 3 % of patients but 32 % of caregivers have negative attitudes toward the use of NIV.

Lo Coco et al. (2005) reported different results regarding the subjective or non-physical QOL of patients and caregivers: as the disease progressed both the patients’ and caregivers’ SEIQoL scores decreased and there was no clear difference between them [30].

Van den Berg et al. (2005) investigated the effect of multidisciplinary ALS care and mentioned that patients with multidisciplinary care had a better mental QOL than patients who were provided with general care but no significant difference were found in caregivers QOL.

4. Discussion

4-1. Contributions and limitations of QOL indices

One important contribution of these QOL studies on ALS patients is that they have empirically clarified that non-physical factors are essential to the QOL of ALS patients. Though the elements that are evaluated with HRQL are generally considered to be crucially important, recent studies on the QOL of ALS patients have revealed that the subjectively perceived QOL of ALS patients that is represented by SEIQoL or MQOL scores is not as low as their QOL as measured with HRQL. Several studies even indicated that while the progress of physical disability reduced family caregivers' subjective QOL it did not greatly impact that of the patients themselves.

While QOL studies on ALS patients using subjective QOL indices such as SEIQoL or MQOL have made important contributions towards understanding the well-being of patients with physical disabilities and incurable diseases, this approach is also not without its limitations. Subjective QOL indices provide only a measure of informants' feelings and do not precisely reflect more objective circumstances that the society and societal values can affect through medical and social care programs. This lack of objective factors also prohibits the consideration of “adaptive preference⁽⁸⁾”, since any such analysis would require consideration of an objective environment that restricts the subjects' preferences. This is problematic; to ignore adaptive preference when assessing the QOL of ALS patients (and when using such assessments in the formulation of

health care programs) is to disregard the fact that the limitations imposed on ALS patients' daily activities may influence their preferences.

Many studies on ALS patients employing the SEIQoL index have indicated that family and spirituality are important factors in the patients' QOL and as a result that doctors and policymakers need to pay more attention to these dimensions. But these studies do not examine why patients have placed importance on these dimensions of their QOL . The concept of adaptive preference suggests that these patients may have emphasized these dimensions of their QOL because their physical disability has caused them to give up on trying to achieve high well-being in other dimensions such as taking part in society.

This suggests that the areas where treatment and social support are most needed may in fact not be the ones patients have themselves indicated are important to their quality of life. In other words, the fact that patients may be able to adapt to their limitations and thereby report high QOL benefits from dimensions such as spirituality and family life does not mean that well-being in dimensions such as taking part in society should be seen as less important for ALS patients to be given the capability of achieving. Subjective QOL measures obviously cannot properly address this problem. More objective measures such as HRQL are also inadequate as they fix the dimensions of QOL assessment a priori and may ignore factors that play an important role in patients' QOL. .

4-2. Applicability of the capability approach to the assessment of QOL

These issues have received little attention in previous research specifically focused on ALS, but there have been several more general studies whose results can be applied to the assessment of the QOL of ALS patients. One potentially useful method is the capability approach that has been developed mainly by Amartya Sen [35, 36]. The capability approach

of patients [31].

ALSAQ-40 is another disease-specific measure that was created to assess the HRQL of ALS and other motor neuron diseases patients. According to Jenkinson et al. (2000), this measure is based on detailed interviews with ALS patients following which forty questions were selected that were deemed to express “the most salient and central concerns of patients” [24]. These questions cover five areas or dimensions related to patients’ health status: physical Mobility, ADL/Independence, Eating and Drinking, Communication, and Emotional Functioning.

ALSSQOL is another disease-specific measure that was developed to more generally assess the QOL of ALS patients, including its non-physical aspects. According to Simmons et al. (2006), the SIP/ALS-19 and ALSAQ-40 indices cannot evaluate the QOL of ALS patients comprehensively because their questions focus mainly on physical capabilities of ALS patients, while SEIQoL, which is sensitive to non-physical factors, cannot be used for surveys with large sample sizes [38]. ALSSQOL is presented as an index that does not ignore important non-physical factors that are essential to the QOL of ALS patients. It was developed based on MQOL and its complete version has fifty nine items, forty six of which are broken up into six factors: negative emotion, interaction with other people and the environment, intimacy, religiosity, physical symptoms, and bulbar function [38].

3. Previous studies on the QOL of ALS patients

For this review we selected sixteen papers based on the results of a PUBMED search [44]. The papers were chosen based on their primary concern being ways of assessing the QOL of ALS patients. These papers consist of six studies conducted in the US, three in Italy, two in Germany, two in Ireland and two in Holland. one in U. K. In the next section these

can potentially shed light on what is missing in existent subjective QOL instruments.

The capability approach tries to overcome the problems mentioned above by introducing not only purely subjective or mental but also non-subjective societal values in the assessment of QOL. What societal values are and how they should be addressed are topics that are debated in moral philosophy and are beyond the scope of this paper. But when it comes to the assessment of ALS patients' QOL, the capability approach seems to be more appropriate than purely subjective or mental QOL assessment.

For example, suppose there are two ALS patients (X and Y) who have severe physical disabilities and cannot move their bodies at all. X has a special wheelchair to move around and paid care workers take care of her 24 hours a day and Y has neither wheelchair nor care workers and is thus bedridden. As it turns out, they both enjoy their lives because X happens to like going out in her wheelchair and Y happens to prefer reading books in bed. Their SEIQoL scores are the same because X puts a high weight and high score on the “going out” dimension and Y does the same on the “reading books” dimension.

At first it may seem appropriate to evaluate their QOL based on their own subjective values determined through the SEQoL index. However, from the standpoint of the capability approach, X has higher capability and is considered to enjoy higher well-being. The reason is that X is capable of both going out in her wheelchair and reading books in bed but Y is only capable of doing the latter. In our example Y is lucky because she happens to prefer (or at least is able to adapt herself to) spending all her time reading books in bed. But if Y happens to be someone who likes going out and can't stand staying at home in bed, X's situation is obviously preferable to Y's: X can enjoy her life regardless of her own preferences, but Y's well-being depends on her incidental preference and ability to

adapt herself to the situation. Major QOL indices, whether of HRQL or subjective QOL, do not illuminate this difference between X and Y's situations.

5. Conclusion

As Coast et al. (2007) indicates, the application of the capability approach to the field of health care is still being worked out [8] and needs to be developed further to make it a viable alternative to existent QOL instruments . The potential usefulness of the capability approach in the field seems to be apparent but there have been few empirical analyses carried out based on the approach. At least in the field of medical and social care, the intuitive potential of the idea of capability has yet to be turned into a concrete measure of QOL based on significant numbers of empirical studies.

Notes

- (1) Ritsumeikan University, Graduate School of Core Ethics and Frontier Sciences
- (2) Mitsubishi Research Institute, INC. Email: anmichi1981@hotmail.com
- (3) President of Care Support MOMO and director of the Japan ALS Association and Non-Profitable Organization SAKURA. Care Support MOMO currently employs 43 care givers and provides a 24 hour personal assistant service for 10 ALS patients in Tokyo. Every month NPO SAKURA provides training courses for over 20 new caregivers each from different organizations.
- (4) Ritsumeikan University, Graduate School of Core Ethics and Frontier Sciences
- (5) According to the *Journal of the American Medical Association, JAMA*:
"Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig disease, involves progressive loss of motor neurons (a type of nerve cell controlling muscle movements) in the brain and spinal cord. ALS is a progressive, disabling, and ultimately fatal disease of unknown cause. Walking, speaking, swallowing, breathing, and other basic functions become impaired with time" [47].
- (6) The word "generic" here expresses the applicability of QOL measures to not only patients with a particular disease but also healthy people or the population as a whole. The opposite is "disease-specific". Health-related QOL (HRQL) is an

individual's QOL measured in terms of elements that are related to their health status.

- (7) Our explanation of these three HRQL measures here is based on Fayers et al. (2000) [16].
- (8) "Adaptive preference" refers to the adaptation of preferences to the feasible alternative set. For discussions of what kinds of adaptive preference should be viewed positively, see Nussbaum's (2000) criticism of Elster (1983) [16, 34]. The adaptive preferences of ALS patients are discussed in Ando et al. (2007) [1].

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