

The phenomenon of response shift in studies on the health-related quality of life in clinical medicine

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Abstract

A methodological drawback to traditional approaches in studies on the quality of life (QOL) is the omission of dynamic changes in evaluation of various aspects of QOL by patients as well as changes pertaining to the criteria of QOL assessment used by patients, which occur in the process of adjustment to illness or disabilities. These changes affect the results obtained by patients in QOL assessment questionnaires and their effect should be taken into consideration especially in clinical studies taking account of patients' QOL, particularly in longitudinal studies. The aim of the present study is to present in the context of medical sciences the issues of response shift bias (RS), related to the foregoing problem, taking the methods of detecting the RS phenomenon into consideration. The authors develop and promote the conception of QOL as the difference between expectations and the possibility and degree of fulfilling them (gap theory), which offers an interpretation of the phenomenon in question.

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Introduction

In contemporary interpretations, health is perceived as a measure of an individual's biopsychic state [1] and is assessed in clinical studies not only based on "hard" biomedical indicators but is also assessed from the subjective-personal perspective, based on individual experience and assessment made by the patient. The operationalization of this understanding of health is widely explored in clinical medicine as an analytical category: the quality of life (QOL), which, in reference to health issues, is applied in the form of health-related quality of life (HRQOL) [2,3]. The WHOQOL Group experts point out the multi-level nature of the QOL conception and suggest that the constituent elements of QOL embrace not only the physical domain (somatic health) but also the psychological domain (mental health), and social relationships, as well as spirituality/religion/personal beliefs that are part of the scope of the concept [4]. As interpreted by the WHOQOL Group, the HRQOL is understood as

"[...] an individual's 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 and concerns." [5].

The subjectively assessed health condition, operationalized as QOL, utilized as dependent variable in clinical studies, is an element of a tendency to build humanized medicine that takes the patient's perspective into consideration [6,7]. The dynamization of the development of this research approach is the result of the so-called epidemiological shift, which consists in the emergence of dominance of non-communicable chronic diseases (NCD) in the structure of health hazards in developed Western societies, particularly in the context of its second stage, which is that because the therapeutic possibilities of medicine have increased, NCD-related mortality has declined. As a result, a challenge for medicine is to implement treatment efficacy indicators that go beyond the so-called negative health indicators (like mortality, morbidity, etc.) or anatomic end-points, which would enable understanding treatment advantages from the

patients' perspective. Important inspirations for the development of research approaches, taking account of subjective health indicators, come from social sciences, particularly from the sociology of illness, within which, in reference to the theses of humanist sociology, there developed a sociology of illness experience, comprising sociological analyses of human experiences related to being chronically ill [7]. Research on QOL in medicine is also inspired by clinical observations that indicate that patients suffering from many diseases are strongly diversified in terms of QOL, and its components do not always depend on the advanced stage of disease assessed using objectivized clinical methods. For example, in their studies M. Skrzypek and T. Widomska-Czekajska have shown that groups of patients with coronary heart disease, distinguished because of the number of critically narrowed coronary arteries, do not significantly differ in terms of the subjectively assessed health condition, while the angiographic assessment of changes in coronary arteries is not correlated with the patients' QOL. They have also demonstrated that biomedical factors account for only 16% of changes in QOL [8]. Likewise, in the group of atrial fibrillation patients, a low QOL was not related to the severity of the disease assessed using typical clinical criteria, whereas it was associated with the low socioeconomic position of the patients and a greater intensification of depression symptoms [9].

A shortcoming of traditional approaches in QOL studies is to treat QOL as a stable construct, omitting the dynamic changes in the evaluation of different aspects of QOL by patients that occur in the process of adaptation to illness or disability, as well as changes in the criteria of QOL assessment, impacting the results obtained by patients in QOL assessment questionnaires. The aim of the study is to present in the context of medical studies the issues of response shift bias (RS), related to the abovementioned problem. The investigation of these issues was inspired by B. Tobiasz-Adamczyk's suggestion [10], who believes that

"It is not certain whether this aspect is important to the medical circles, for whom what counts first of all is the expectation of a general good assessment of the quality of life by the patient (that is why the change of

standards is not, in many cases, the subject of interest of medical professionals)”

The Conception of QOL as a Gap between Expectations and Reality

K.C. Calman suggested in 1984, in the context of oncology, that QOL should be understood as a gap between the patient's hopes, ambitions and expectations, and their present, actual experience. An integral element of QOL assessment, according to this author, is to take account of the assessment made by patients themselves, which embraces many aspects of life but obligatorily with reference to individual goals, priorities, standards, and internal assessment criteria. It is assumed here that in the process of being ill, in connection with adaptation processes, changes may occur in these areas, the aim of actions taken in medicine being to narrow the discrepancy between the patient's hopes /expectations and reality [11]. Calman emphasizes that

“quality of life [measures] the difference, at a particular moment in time, between the hopes and expectations of the individual and that individual's present experiences” [11].

This approach points out that measures taken to improve QOL may assume the verification of some expectations of patients (or in the case of e.g. a terminal situation, abandoning of some of them) (lowering them) as well as obtaining satisfaction from fulfilling less unreasonable expectations, or an actual improvement in the aspects of life that make up QOL. According to A. Bowling the QOL conception in question (“gap” theory) can be interpreted as an answer to the limitations of strictly functional approaches in studies on QOL, in which attention is only focused on the scope and possibility of functioning of an individual in society. The way of understanding the QOL as introduced by Calman seems to be increasingly accepted at present: for example, in one of the leading studies on QOL, the interpretation based on the “gap

theory” was treated as a priority definition of QOL [12]. This approach enables a right interpretation of the situation in which the present health condition and its constituents meet the patient's expectations. Then the QOL study does not detect the adverse impact of illness on QOL. In contrast, when the current experience of health condition is below expectations, the QOL investigation reveals the adverse impact of illness on QOL. The RS phenomenon, on the other hand, refers to a situation in which a negative experience of health is accompanied by the parallel lowering of expectations: in that situation the measurement of QOL does not reveal the influence of illness despite the objectively poor health condition [12].

Also M. Klocek [13], a clinical cardiologist and expert on QOL studies in Poland, defines QOL as

“the degree of satisfaction with fulfilling needs (physical, mental, social, spiritual) by an individual, i.e. as a difference between expectations and the possibilities and degree of fulfilling them”.

In this sense, “the lower the difference, the higher the quality of life” [13]. Klocek points out that the adoption of this definition of QOL emphasizes that health-related expectations are, on the one hand, a function of environmental influences while on the other hand there may occur “a change of the internal assessment standards” (this is the essence of the RS phenomenon) allowing patients to maintain a high QOL despite illness [13]. This change may occur in the process of adaptation to illness [14]. As part of the change, goal reordering may occur, as a result of which the patient's attention focuses on the aspects of life and functioning that have not been affected by a disease. On the basis of his own research on the QOL of patients after stroke, M. Klocek points out that during the period directly after a stroke episode the QOL of the patient with post-stroke hemiparesis and aphasia is extremely low whereas after the return of the speech function and the possibility of walking with crutches, the patient's QOL may increase to the level of healthy people [13]. The change is not the result of improved condition in objective terms but it stems from the change of the internal standards of

QOL assessment or from changes in the expectations regarding the condition of health.

In A. Bowling's interpretation, QOL should be treated as a construct that is the result of interactions of objective and subjective factors, and furthermore, a dynamic construct influenced by values and ways of assessing different aspects of the life and functioning of individuals, which (values and ways) change in the course of life and in the course of the illness trajectory [5]. It is therefore not right to perceive QOL as a stable phenomenon because the ways of understanding "good health" and its components as well as determinants change in connection with changes of individual frames of reference and internal assessment criteria occurring in the time vector at different stages of the illness trajectory.

The RS phenomenon manifests itself distinctively in the studies on the QOL of patients with disabilities, where a phenomenon is observable which was termed by G. L. Albrecht and P. J. Devlieger as "*disability paradox*": many people with serious disabilities report a high QOL contrary, as it were, to the objective exponents of their health situation. The authors of the conception show that the phenomenon concerns over 50% of people with severe types of disability [15]. Also in other, objectively grave clinical situations, patients do not always report a low QOL, e.g. in oncology [14], which means that not always there is a simple relationship between organic pathology and QOL [12]. The result of such observations were studies meant to identify the factors impacting the ways of assessing QOL, including appraisal frameworks investigating meaning, as well as covering the way of how the flow of time and changes of the circumstances or context of illness model the ways of perception of QOL [16].

In reference to the cited clinical observations and to the "gap" theory, the object of a series of analyses is the processes of modeling expectations of health. The analyses showed that they (expectations) are influenced inter alia by age, gender, socio-economic position (and by other environmental factors), moreover, by personal life, cultural context or the general health condition of an individual (an individual in a generally good health condition will feel a stronger,

destructive effect of relatively less serious health problems) (12).

Definition of the Phenomenon of Response Shift in QOL Studies and Its Interpretation in Terms of Psychological Adaptation to Illness/Disability

The RS phenomenon allows explaining why the results of measurement of QOL, i.e. the scores obtained by patients in the QOL assessment tools may remain stable despite actual changes in patient's QOL [16]. The RS phenomenon consists in that there is "a change in the meaning of one's self-evaluation of the target construct: quality of life", which may, firstly, be a result of recalibration of internal assessment standards of good health, pain and other QOL components (*beta change*). Next, RS may also be a result of the change in the way of evaluating different QOL dimensions (*values*), changes in the way of ranking priorities (*reprioritization*), and may also result from the redefinition by patients of the components of the complex QOL construct (*reconceptualization - gamma change*) [16,17]. The essence of the RS phenomenon is expressed in the definition proposed by B. D. Rapkin and C. E. Schwartz [18], who believe it is the

"recalibration of internal standards of measurement and reconceptualization of the meanings of items".

The object of research is inter alia questions about to what extent/range, in diverse patient groups, there is recalibration of the assessment criteria for individual aspects of QOL. For example, the research by J. Bernhardt et al. [19] has shown that in patients treated for colon cancer randomized to groups receiving different treatment regimens, a greater recalibration of appetite assessment as a QOL component was made by patients receiving more toxic treatment as compared to the group treated using a less toxic method.

Ignoring of the RS phenomenon would thus lead to paradoxical findings concerning QOL, because in those studies more side effects were connected with a paradoxically higher QOL [19]. The occurrence of the foregoing cognitive changes (*beta change, gamma change*) hinder the interpretation of the results of QOL studies and, in traditional approaches ignoring RS, it may prevent treatment advantages associated with QOL [17]. There are, however, not enough data on the scale of the RS phenomenon in specific clinical areas and on its clinical significance. In 2006 Schwartz et al. reported that the largest amount of data on the subject come from studies on the QOL of oncologic patients [20, 21]. It should be added that the ways of evaluating different aspects of QOL differ at different stages of the illness trajectory [16].

According to B. Tobiasz-Adamczyk, when interpreting the results of studies on QOL, account should be taken of the diversity of QOL assessments made by patients in the same clinical situation, arising from differences in standards and aspirations of individual patients, connected with the socio-cultural contexts of individual lives [10]. As Tobiasz-Adamczyk writes

“individual meaning [given to symptoms, changes in health condition – {the authors’ complement}] may be a reflection of ‘meanings’ given to changes in health condition in the broader socio-cultural context” [10].

This means that the meaning-creative activity of patients, occurring in the process of being ill, is related to culture and society, which constitute a specific reservoir of meanings of symptoms and other consequences of illness and being ill. A significant role is also played here by a stage of the life cycle. The elderly are known to demonstrate similar QOL assessments like younger people, which can be interpreted either as a result of the impact on QOL of factors other than health or as a result of lower expectations of life among the elderly [10]. According to B. Tobiasz-Adamczyk, the interpretation of the results of studies on QOL should also take account of the fact that they may indicate the effectiveness of the process of disease normalization, within which the symptoms of organic pathology may be treated as “constant’ routine indicators [...]of the functioning [of

the patient]” [10]. Also Schwartz et al. suggest that the RS phenomenon may be interpreted as a result of adaptation work aimed at restoring balance between expectations and the experience of illness reality, consisting in the modification of expectations and self-image [16]. According to I. Heszen-Niejodek [14]:

“Even in people with an experience of severe and life-threatening diseases, after the period of adaptation, neither high nor permanently lower mental well-being is reported. Many studies have found for example that cancer patients assess the quality of their life similarly to carefully selected control groups of healthy subjects”.

From the clinician’s perspective it is essential to understand that some interventions, for example in the field of rehabilitation, particularly psychosocial, can be in fact oriented towards producing the RS phenomenon in patients as part of adaptation to illness in order to improve QOL in objectively serious clinical situations [16].

Methods of Detecting the RS Phenomenon and Its Methodological Implications in Studies on QOL

The RS phenomenon concerns the aspects of QOL that are contained in the questionnaire questions classified as evaluation-based items. In the questions of this type the patient makes a subjective assessment/judgment based on idiosyncratic criteria [Schwartz 2007], i.e. those that may significantly differ in the case of various persons. The RS phenomenon, in turn, is not observed, as indicated by Schwartz et al., regarding questions concerning objective functional indicators (performance-based items), in which giving an answer does not involve a subjective judgment but an objective measurement of the phenomenon. These are for example questions about the duration of performance of specific tasks or daily activities [16].

The RS phenomenon particularly strongly influences the results of longitudinal studies on QOL. In

the situation when, with time, patients lower their expectations in the process of adaptation to illness, and the experience of health deteriorates concurrently, QOL may not change (scoring in the questionnaires remains unchanged) despite the worsening of the objective health condition. We will dwell longer on methodological problems associated with the longitudinal assessment of QOL at two time points: at the beginning and at the end of intervention, e.g. in the studies on the effect of a specific way of treatment on QOL (the “pre and post” approach). In traditional approaches of this type it is assumed that the internal standards of QOL assessment in patients are stable. As has been said above, this is not the case because of adaptation processes taking place in the course of illness, which causes changes in the prospective assessment to reflect not only the actual change in experiencing health but one resulting from recalibration of standards of the patient’s own health situation (*beta change*). The detection of the RS phenomenon effected by *beta change* is possible owing to the application of the “then-test approach”, consisting in that at the beginning of an intervention an initial assessment (pre-test) is made, and after the completion of the intervention – a final assessment (post-test) and at the same time a repeated, retrospective assessment of the pre-test (then-test). [17,18,20,22]. The application of this approach, involving the retrospective assessment of the pre-test, consists therefore in that the subjects fill in a QOL assessment test regarding that which is now (after treatment – post-test), and directly afterwards one regarding that which was before treatment (pre-test). (At this point we will not discuss other methods of RS detection. For more, see [22]). In these circumstances the assessment standard is the same in relation to the results of treatment and the situation prior to treatment. In this analytical approach, the RS will be the difference between the pre-test and the then-test. It will be also possible to discern the actual change in QOL: this is the difference between the post-test and the then-test. Observe that the traditional approach ignoring the RS phenomenon wrongly assumes that the patient uses the same criteria when assessing the situation before and after intervention. It is then assumed that the QOL change is a simple difference between the

pre-test and the post-test [17]. To emphasize the methodological approach in question, we will once again specify the rules applied [23]:

**TRADITIONAL CHANGE:
POST-TEST VS. PRE-TEST
RESPONSE SHIFT:
PRE-TEST VS. THEN-TEST
ACTUAL CHANGE:
POST-TEST VS. THEN-TEST**

We will additionally point out the limitations of the “*then-test approach*”. Firstly, it is the difficulty with remembering of that which was. In the case of a small time interval between the post and pre assessment the subjects will remember what they wrote in the test at the beginning of the study and can repeat their assessment (recall bias) [20,23]. There may also be a tendency to show one’s own improved well-being in order to fulfill the researcher’s expectations: the subject will then lower the QOL assessment in the past (social desirability bias) [24]. A situation is also possible that the subject demonstrates an improved QOL to justify before themselves the effort connected with participation in the treatment (effort justification bias) [24] or to please the doctor [23]. It should be remembered that the assessment with the “*then-test approach*” methodology covers only those subjects who completed the whole cycle of treatment/intervention. As the study covers the subjects who completed the treatment program, it is possible to overestimate the success of the treatment assessed [24].

It should be added that changes occurring in QOL over time also depend on in relation to which moment in the illness trajectory the patient compares the present health condition. It is well-known that an improvement in health condition will be subjectively assessed as greater when the point of reference is the health situation characterized by greater deterioration than the situation when the change occurs from the point closer to the condition of normalcy [16].

The RS phenomenon – the result of changes concerning the mental and cognitive sphere in patients, which occur in the course of illness, emphasizes the significance of individualized (hermeneutic) approaches in studies on QOL. As part of it, there are

suggestions that open-ended items should be introduced into QOL assessment questionnaires: such questions enable the subjects to indicate and rank the meaning of QOL aspects included in a questionnaire [5]. An interesting option, albeit one that implies interpretation difficulties, is also the question about other QOL aspects, not included in a given questionnaire, which are essential to patients in a particular clinical or health situation

The identification of the RS problem in QOL studies also emphasizes, in a more general perspective, the drawbacks and deficiencies of quantitative approaches based on standardized research questionnaires, and the advantages of qualitative approaches (inter alia, the Individual In-Depth Interview technique is used as part of them), which enable identification of QOL determinants resulting from work on personal identity, and of the consequent redefinition of oneself and one's life situation as well as changes in patients' values and priorities [25]. For that reason, QOL studies based on the methodology of social sciences may be a valuable complement to qualitative questionnaire surveys that are subject to limitations typical of all studies based on survey techniques: they present only that which was written in the questionnaire. The essential advantages of social qualitative studies on QOL are that patients themselves point out the areas that constitute their understanding of QOL, moreover, they can express their opinions about the meaning and the level of satisfaction with each of the areas in the context of their life situation. Emphasis is laid here on the patient who, as an active and acting subject makes an effort to interpret that which is around. Patients perceive the conditions of their life in health or illness in a definite way, experience accompanying emotional states, and as a result they attribute specific meanings to them from the QOL perspective. Qualitative strategies enable identification of changes in the conceptualization of what is "quality of life" and "health" as well as to find the motives behind these changes, which we are unable to learn using quantitative research methods.

Conclusions

1. The quality of life in medicine as presented by the "gap theory" is understood as a difference between the patient's expectations and their current experience of health.
2. Diverse weightings attributed to individual aspects of QOL by different patients should have methodological consequences consisting in that different QOL aspects specified by the individual subscales of QOL assessment questionnaires should be assigned different weightings according to their diverse meanings to the studied groups of patients.
3. Modeling of expectations regarding health is a significant goal of programs of supporting people with chronic diseases and of psychological support that influences the improvement of QOL. Lowering of expectations and their adjustment to the realities of a disease enables obtaining higher assessments of QOL.
4. Ignoring of the RS phenomenon associated inter alia with the change of expectations regarding health in the longitudinal assessment of QOL may cause an erroneous interpretation of research results. The inclusion of the RS phenomenon is perceived as a requirement in the new generation of studies on QOL in medicine.

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