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Integrating response shift into health-related quality of life research: a theoretical model

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Abstract

Patients confronted with a life-threatening or chronic disease are faced with the necessity to accommodate to their illness. An important mediator of this adaptation process is 'response shift' which involves changing internal standards, values and the conceptualization of quality of life (QOL). Integrating response shift into QOL research would allow a better understanding of how QOL is affected by changes in health status and would direct the development of reliable and valid measures for assessing changes in QOL. A theoretical model is proposed to clarify and predict changes in QOL as a result of the interaction of: (a) a catalyst, referring to changes in the respondent's health status; (b) antecedents, pertaining to stable or dispositional characteristics of the individual (e.g. personality); (c) mechanisms, encompassing behavioral, cognitive, or affective processes to accommodate the changes in health status (e.g. initiating social comparisons, reordering goals); and (d) response shift, defined as changes in the meaning of one's self-evaluation of QOL resulting from changes in internal standards, values, or conceptualization. A dynamic feedback loop aimed at maintaining or improving the perception of QOL is also postulated. This model is illustrated and the underlying assumptions are discussed. Future research directions are outlined that may further the investigation of response shift, by testing specific hypotheses and predictions about the QOL domains and the clinical and psychosocial conditions that would potentiate or prevent response shift effects. © 1999 Elsevier Science Ltd. All rights reserved.

Keywords: Response shift; Self-report; Quality of life; Theory; Change

Introduction

An orthopaedic surgeon once commented that it must be difficult to study quality of life (QOL) since it not only means different things to different people, but can also mean different things to the same person over a disease trajectory. He recounts the story of a woman who, after hearing her diagnosis of osteosarcoma, told him that if her bone tumor prevented her from being able to walk, life would no longer be meaningful to her and she would prefer euthanasia. When the time came that this woman was confined to a wheelchair, she informed him that life still held value for her but that if she were to become incontinent or bedridden, then life would loose its meaning and she would prefer euthanasia. However, when the time came that she was incontinent and bedridden, the woman stated vehemently that life still held meaning for her and that she

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was not ready for euthanasia. This story illustrates how internal standards, values and the conceptualization of life quality can change over the course of the disease trajectory and that these changes may be inherent to the process of accommodating the illness.

This patient has undergone what is called 'response shift'. The working definition of response shift, adopted in this paper, refers to a change in the meaning of one's self-evaluation of a target construct as a result of: (a) a change in the respondent's internal standards of measurement (scale recalibration, in psychometric terms); (b) a change in the respondent's values (i.e. the importance of component domains constituting the target construct); or (c) a redefinition of the target construct (i.e. reconceptualization) (see also Schwartz and Sprangers, 1999).

Whereas the previous story is anecdotal, there is ample evidence of paradoxical and counter-intuitive findings in the literature which can be interpreted in terms of response shift. For example, patients with a life-threatening disease or disability were found to report a stable QOL (Andrykowski et al., 1993; Bach and Tilton, 1994). Moreover, a number of researchers have documented that people with a severe chronic illness report a level of QOL neither inferior nor better than that of less severely ill patients or healthy people (Cassileth et al., 1984; Stensman, 1985; Breetvelt and Van Dam, 1991; Andrykowski et al., 1993; Groenvold et al., in press). Additionally, health care providers and significant others tend to underestimate patients' QOL as compared to patients' evaluations of their own QOL (Sprangers and Aaronson, 1992; Friedland et al., 1996; Sneeuw et al., 1996). Furthermore, cancer patients are more willing to undergo risky and toxic treatments with minimal chance of benefit than healthy people or people with a benign disease (Llewellyn-Thomas et al., 1989; O'Connor, 1989; Slevin et al., 1990), indicating that patients may have lowered their standards of tolerance and/or changed their values. Perhaps most profound is the discrepancy between clinical measures of health and patients' own evaluations of their health (Daltroy, 1999; Padilla et al., 1992; Kagawa-Singer, 1993). All of these lines of evidence suggest that response shift plays an important yet not explicitly measured role in assimilating illness.

The concept of response shift has its foundation in research on educational training interventions (Howard et al., 1979b) and organizational change (Golembiewski et al., 1976). Whereas Howard and colleagues defined response shift in terms of changes in internal standards of measurement, Golembiewski and colleagues introduced the component of reconceptualization in addition to this scale recalibration. While changes in values are inherent in Golembiewski's description of reconceptualization, the working definition adopted in this paper includes this as a separate third component that is relevant to the change in the meaning of one's self-evaluation. Making it a distinct third aspect will thus highlight its importance and emphasizes the need to measure it carefully.

The extent to which the three components of response shift are distinct or interconnected is still unknown. It may be the case that these aspects of response shift are ineluctably intertwined. Alternatively, changes in internal standards, values or conceptualization may only reflect response shift when they occur in pairs. For example, changes in internal standards may only reflect response shift when they are coincident with changes in values or changes in conceptualization. The interconnection may also reflect a hierarchical nature. For example, Golembiewski and colleagues adopted the following hierarchy, where reconceptualization needs to be ruled out before changes in internal standards can be detected. This approach makes sense since changes in internal standards of measurement will have lost their meaning if the construct itself has changed over time. Conversely, it is difficult to imagine that changes in internal standards might occur without affecting the conceptualization of the construct. Thus, while clearly distinguishing the three aspects of response shift is needed to elucidate the concept, recognizing their interconnectedness is also necessary to acknowledge the complexity and richness of the phenomenon (see also Schwartz and Sprangers, 1999).

Since response shift refers to a change in the meaning of one's self-evaluation, it may occur in any field where self-reports are required (Howard et al., 1979b). The focus of this paper will be on response shifts that may take place in the area of health-related QOL, as a result of changes in health status. Integrating response shift into health-related QOL research would enhance the sensitivity and relevance of this line of research. Understanding response shift requires a sound theoretical model. In this paper, a theoretical model is proposed to clarify and predict the occurrence or absence of response shift effects and how response shift may affect perceived QOL (Fig. 1). Additionally, future research directions are outlined that may further the investigation of the response shift phenomenon, by testing specific hypotheses and predictions about the QOL domains and the clinical and psychosocial conditions that may yield response shift effects.

Theoretical model

The proposed model addresses how response shift may affect health-related QOL as a result of changes in health status. It has five major components: (1) a catalyst, (2) antecedents, (3) mechanisms, (4) response shift and (5) perceived QOL. The *catalyst* in QOL

research would refer to a change in the respondent's health status, that may or may not result from a treatment. The *antecedents* refer to stable or dispositional characteristics of the individual. Examples of such antecedents include sociodemographics (e.g. gender, education) and personality (e.g. optimism, self-esteem, sense of control, mastery) (Ormel, 1983; Costa and McCrae, 1980; De Haes, 1988; Scheier et al., 1989), expectations (Scheier and Carver, 1987), or spiritual identity. *Mechanisms* will refer to behavioral, cognitive, and affective processes to accommodate the catalyst. Examples of such mechanisms include using coping strategies (Lazarus and Folkman, 1984; Folkman, 1997); initiating social comparisons (Taylor and Lobel, 1989; Van Der Zee et al., 1995; Gibbons, 1999); seeking social support (Cohen and Wills, 1985; Sarason et al., 1985; Taylor et al., 1986); reordering goals (Rapkin and Fischer, 1992); reframing expectations (Heyink, 1993; Allison et al., 1997) and engaging in spiritual practice (Park et al., 1990; Koenig, 1997; Richards and Folkman, submitted for publication). The working definition of *response shift* is a change in the meaning of one's self-evaluation of QOL as a result of changes in internal standards, values and the conceptualization of QOL. *Perceived QOL* may be defined as a multidimensional construct incorporating at least three broad domains — physical, psychological and social functioning (Siegrist and Junge, 1989; Cella and Tulsky, 1990; McMillen Moinpour et al., 1990). Beyond this core set of QOL domains, additional issues may be more salient for some individuals (e.g. spirituality and intimacy) or more relevant for specific patient groups depending on the functional domains affected by the disease (e.g. sexuality and body image).

Changes in an individual's health status may prompt behavioral, cognitive and affective processes necessary for accommodating illness. These processes have the potential to change an individual's standards, values or conceptualization of QOL and this response shift will thus influence perceived QOL. The kind of mechanisms that an individual will engage in as well as the magnitude and type of the resulting response shift (i.e. changes in standards, values or conceptualization) will be dependent on dispositional characteristics. Thus, the antecedents are postulated to have both indirect and direct effects on potentiating response shift. Perceiving a suboptimal QOL may lead the individual to reinitiate established or new mechanisms. This feedback loop is aimed at maintaining or improving the perception of QOL. Clearly, this process is iterative and dynamic by definition.

Illustration

Three examples are provided to elucidate this preliminary model. Imagine three women, Jane, Ann and Mary, all of whom are diagnosed with Stage 3 breast cancer. Jane expects that she is able to control important features of her day-to-day life, and thus has a generalized expectancy of an internal locus of control. When confronted with her diagnosis, Jane would seek to maintain a sense of control. However, her focus remains on controlling disease-specific domains which are not currently within her control. Consequently, she experiences frequent episodes of helplessness, frustration, and depression because she is not able to accomplish her usual level of work and other activities. Jane's behavior is not likely to result in response shift because she has not changed her internal standards, has not changed her values, nor has she reconceptualized QOL. Consequently, her perceived QOL will be worse than her QOL prior to diagnosis.

In contrast to Jane, Ann has the tendency to expect that powerful others exert control over her day-to-day life. When confronted with her diagnosis, she would seek to engage in spiritual practice that might include prayer and reading religious texts. She might engage in

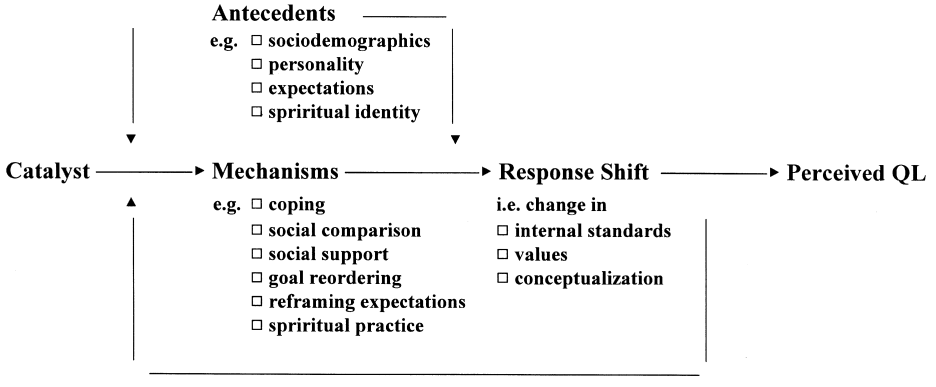

Fig. 1. A theoretical model of response shift and quality of life (QOL).

downward social comparison, by talking with and supporting less fortunate other people with a similar diagnosis. These behaviors might induce response shift due to changes in *internal standards*, since her idea of poor functioning may now be anchored at a much lower level than previously conceived. Additionally, by engaging in spiritual practice and by developing a role of helping other people whose conditions are worse, she may create a new sense of purpose in life which may modify her *conceptualization of QOL*. Thus, Ann might experience a similar level of QOL to that experienced prior to diagnosis.

Like Jane, and in contrast to Ann, Mary has always tended to perceive herself as being able to control important features of her day-to-day life. When confronted with this diagnosis, she would seek to maintain an internal sense of control by reordering her goals and engaging in upward social comparison. For example, since health is no longer controllable to her and her energy level may not allow her to work as she used to, she might focus her attention on developing more intimate family relationships rather than professional accomplishments, which had been her focus prior to diagnosis. She might also seek positive role models, such as women who have succeeded in overcoming a similar disease. These behaviors may induce response shift that results in the first place from changes in *values*, i.e. in the relative importance of QOL domains as family life gained in importance relative to a professional career. Additionally, by changing her focus to other role models, she might perceive overcoming the disease as within her power, and might develop an appreciation of her social and emotional resources (Bach and Tilton, 1994). This appreciation might result in a change in her *conceptualization of QOL*. Thus Mary might experience a level of QOL similar to or better than one which she had experienced prior to diagnosis.

In these three examples, the antecedents and mechanisms are differentially effective in inducing response shift, and consequently in reducing, maintaining or improving QOL. These examples also illustrate that this process can implicate more than one aspect of response shift. For the sake of simplicity, we have used only a limited number of antecedents and mechanisms, but this is not to imply that only one or two of these variables should be considered in modeling response shift.

Discussion of the model

Conceiving the proposed model as a single process would be overly simplistic and would do injustice to the complex, multifaceted, and dynamic reality of psychological adaptation to illness. Rather, the model is meant as a framework which may guide the conceptualization and measurement (Schwartz and Sprangers, 1999) of QOL over time. Additionally, this model is not new from clinical (Wilson, 1999) or theoretical perspectives. For example, it has similarities with control theory's approach to the understanding of self-regulating systems. The central aspect of control theory is the feed-back loop aimed at reducing sensed discrepancies from a comparison value to explain how people maintain an acceptable level of health, well-being or any other self-definition (Powers, 1978; Carver and Scheier, 1982; Leventhal and Nerenz, 1983). The proposed model is not meant to replace such or other (derived) theories that purport to explain health-related QOL, including adaptation theories (Helson, 1964; Brickman and Campbell, 1971; Taylor, 1983; Parducci, 1995), discrepancy theories (Calman, 1984; Michalos, 1985), uncertainty in illness theory (Mishel, 1988, 1990; Padilla et al., 1992), or stress-coping theories (Lazarus and Folkman, 1984). Rather, to the extent that response shift is demonstrated to have explanatory power, its incorporation is recommended in such existing theories. While all these theories make important and convincing attempts to explain perceived well-being from different angles and with different foci, none of them takes response shift explicitly into account.

The strength of including response shift is first that it conceptualizes three salient aspects of change. Making these aspects explicit in the model will allow a better understanding of how QOL is affected by changes in health status, as well as by medical or psychosocial interventions. Second, elucidating these aspects will direct the development of reliable and valid measures for assessing change in QOL (see Schwartz and Sprangers, 1999).

For example, according to the cognitive theory of stress and coping (Lazarus and Folkman, 1984) and its recent modification (Folkman, 1997), people are constantly appraising their interactions with their environment. Interactions that are appraised as stressful (e.g. a cancer diagnosis) require coping to accommodate the stressor. Coping processes lead to an event outcome which may be positive, negative or may not yield a resolution. Emotion is generated throughout the processes of appraisal, coping and event outcomes. This model may gain in explanatory power when response shift is postulated prior to event and emotional outcomes, thus rendering it consistent with the proposed model. By explicitly addressing changes in internal standards, values and the conceptualization of outcome, the subtlety and complexity of the adaptation process will be more comprehensively captured.

A second example might be past research which suggests no or minimal effectiveness of a psychosocial

or medical intervention on perceived QOL. If such studies were to integrate response shift in their evaluations, they might be more responsive to the full treatment impact. Indeed, response shift can be viewed as an important component of a treatment effect, or alternatively of the longitudinal trajectory of perceived QOL. It may be the case that treatments that induce a response shift are more tolerable and result in better treatment adherence than those which do not. For example, an important factor of treatment adherence might be the extent to which a medical treatment challenges values that are central to a person. To illustrate, young women with lupus, whose self-esteem is highly dependent on body image, would be less likely to be able to tolerate side effects of steroids (e.g. facial disfiguration) because they are unable to change that central value. Conversely, these same women might be better able to tolerate the comparatively severe gastro-intestinal side effects of methotrexate because their self-image is not challenged. Given their values and preferences they might be more committed to maintaining the methotrexate therapy and might consequently shift their internal standards of gastro-intestinal discomfort to maintain an acceptable level of QOL.

An initial recognition of response shift came in the context of the lack of change in perceived QOL despite clinical or objective deterioration (Andrykowski et al., 1993; Bach and Tilton, 1994). Thus, one crucial assumption of this model is that people want to feel as good as possible about themselves, either in the past or present. With its roots in control theory, response shift is thus directed toward maintaining or regaining homeostasis. The corollary assumption is that the model is dynamic. In the face of continuous change, such flexibility would be necessary to maintain or regain an acceptable perceived level of QOL. For example, if health status improves dramatically but transiently, the individual might shift his or her internal standards, values and the conceptualization of QOL to adjust to this changing level. If the individual were unable to adjust to subsequent deterioration and maintained those higher standards that were appropriate when his or her health was better, then the initial response shift becomes maladaptive. It is thus critical that the aspects of response shift be continuously and flexibly readdressed over the course of the disease trajectory.

At this early stage in model development, our understanding of the dynamics which may lead to response shift is limited to those situations where response shifts seem adaptive. Thus, our examples are teleological as we are postulating response shift as a mechanism by which perceived QOL does not deteriorate in the face of deteriorating health status. Indeed, the most obvious examples of research or anecdotal evidence are more suggestive of the adaptive than of the maladaptive potential of response shift. For example, response shift might serve as a buffer of the stressful impact of deteriorating health on psychological well-being (Schwartz et al., 1995). It is conceivable, however, that response shift would be maladaptive in some contexts. The example provided above pertained to an individual's inability to adapt adequately to changes in health status. Another example may refer to an individual who has a health condition that requires problem-focused vigilance. It would be maladaptive to change internal standards of his/her symptoms or functional limitations if this shift were to prevent him or her from utilizing appropriate health care services or treatment regimens. Furthermore, the model does not require that response shift be a conscious process. The consciousness or intentionality of response shift may differ across individuals.

Clearly, not all changes or lack of changes in QOL are driven by response shift. By definition, response shift is not at stake when patients' internal standards, values, or conceptualization of QOL remain unaffected. However, given the preliminary stage of model development and the scarcity of empirical data, the identification or prediction of the situations where response shift does not play a role is necessarily tentative. For example, one might expect that the occurrence of response shift will be less likely in areas of behavioral change, instrumental coping, and learning appropriate compensatory or preventive skills (e.g. walking with a cane, caring for a stoma, cooking according to dietary restrictions). Clearly, such activities may be of paramount importance in accommodating the illness, but may not necessarily affect the internal standards, values or conceptualization of QOL. Additionally, one might hypothesize that response tendencies such as social desirability, effort justification and cognitive dissonance reduction may induce changes in reported QOL, without actually affecting internal standards, values or the conceptualization of QOL. For example, patients with symptomatic gallstones who were randomized to either laparoscopic cholecystectomy with day care or laparoscopic cholecystectomy in the hospital, preferred retrospectively the treatment they had received, independent of the treatment actually received (Keulemans et al., 1997). This retrospective preference may be viewed as an example of cognitive dissonance reduction rather than response shift. However, such response tendencies may also potentiate response shift. For example, Diener et al. (1991) demonstrated that social desirability may not be a response artifact, but rather a personality characteristic that may help people to assimilate illness and enjoy a higher level of QOL.

Future research directions

There are many aspects of this theoretical model that need to be developed in future research. The components of the model, including the catalyst, antecedents, mechanisms and perceived QOL, would benefit from investigations which highlight or identify the specific conditions which would potentiate or prevent response shifts. Regarding the *catalyst*, it would be important to identify what parameters of health state changes or interventions would initiate the response shift process. Parameters that would merit attention include the rate of onset of the health status change (i.e. sudden or gradual), its duration, severity, pervasiveness and direction (i.e. improvement or deterioration). Finally, it is conceivable that response shifts occur merely with the passage of time, without clear changes in health status and/or the underlying pathology. Time does change patients, if only because there is a longer past with disease and a greater number of experiences that occur in the interim that may affect internal standards, values, and the conceptualization of life quality. Thus, an additional question is related to the extent that response shift may be elicited by the mere passage of time or by entering new developmental stages in life (Erikson, 1963).

Regarding the *antecedents*, research is needed to address which dispositional characteristics play a role in the response shift process. For example, personality characteristics such as self-esteem or optimism might promote response shift, while depression or locus of control might impede it. Additionally, people may have different thresholds for recognizing or tolerating health status change, an extreme example of a low threshold being somatization disorder. The characteristic feature of somatization is the rigidity by which these patients conceptualize their symptoms and their resistance to efforts to change these dysfunctional cognitions (Wilson, 1999) Alternatively, people with a high level of tolerance for symptoms, may not feel the need to engage in adaptive strategies. Consequently, both people with lower or higher thresholds are hypothesized to be less inclined to undergo response shifts, albeit for different reasons. Additionally, future research should examine whether different characteristics are implicated at different stages of the disease trajectory. For example, one might hypothesize that sociodemographic factors might be implicated early on and that different personality characteristics might play a significant role at subsequent phases of the disease trajectory. The rationale for this hypothesis is that sociodemographic characteristics, such as gender, age, level of education and ethnic background may affect early presentation of symptoms (i.e. patient's delay). Personality characteristics, such as optimism and mastery, are related to coping mechanisms (Pearlin and Schooler, 1978; Scheier and Carver, 1987) and by definition may play a role at a later stage in the disease trajectory.

With respect to the *mechanisms*, research is needed that will clarify how these mechanisms relate to response shift, how they relate to each other, how they are moderated by the antecedents, and how they may be influenced by the illness trajectory. For example, since it is easier to change one's cognition (e.g. aspiration level) than affect (e.g. emotional well-being) (Campbell et al., 1976, De Haes et al., 1992), it is hypothesized that in early stages of the disease trajectory cognitive coping strategies will be initiated, while emotion-focused coping will be adopted later on. This model would be best served by empirically examining the interrelationships and feedback loops. Subsequent work might then enumerate additional mechanisms.

With respect to *perceived QOL*, response shift is expected to be more prevalent in domains which are more cognitive (e.g. satisfaction, achievement of life goals and cognitive ability) rather than affective (e.g. emotional well-being, mood and distress) (Campbell et al., 1976, De Haes et al., 1992). Additionally, one might hypothesize that response shift is more likely to occur in those domains which are subjective (e.g. pain, fatigue and interpersonal relationships) rather than objective (e.g. physical functioning, role performance and work disability). While one might predict that response shift would occur in more global assessments of QOL domains, future research should evaluate whether specific assessments of the same QOL domains will reveal comparable response shift effects. Similarly, behaviorally-anchored items might be less prone to response shift than affectively- or cognitively-worded items, although research in educational interventions found response shift effects in both types of questions (Howard et al., 1979a).

While the proposed model postulates a dynamic *feedback loop*, investigating this process is complicated by time-dependent parameters that are currently undefined. For example, it is unknown how long it takes for response shifts to occur. Thus accurately tracking this process will be facilitated when the desired interval for data collection is known.

While all of the above components merit considerable investigation, perhaps the most fundamental work on response shift is related to broader questions about the overall significance of this model. Specifically, the contribution of response shift to QOL research will depend on whether it increases the explained variance in both objective health status and subjective well-being measures (see Daltroy et al., 1999). Additionally, its contribution would be supported if it facilitates better prediction of future QOL. Of related importance would be investigations which clarify which aspects of response shift highlight or attenuate longitudinal or

intervention effects. For example, interventions aimed at changing cognitions (e.g. aspiration level) might induce changes in internal standards of measurement, while interventions focusing on affect (e.g. psychological well-being) might result in changes in values and the conceptualization of QOL. Additionally, stress-management interventions as well as effective doctor–patient communication may actually 'teach' response shifts by training people to change their internal standards, values or the conceptualization of QOL.

This complex unfolding might well be investigated in longitudinal research with multiple time points, incorporating standardized assessments of selected antecedents, mechanisms and perceived QOL, as well as additional measures of response shift (see Schwartz and Sprangers, 1999). To capture fully the impact of response shift in QOL research, such investigations should preferably be conducted in a large range of acutely and chronically ill patients whose illness differs in stage, severity and pervasiveness. Revealing the full impact of response shift may be critical for research which aims to evaluate QOL over time in observational studies comparing different patient groups, or in intervention studies of adaptation to illness.

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