# Measuring quality of life in patients with stable coronary artery disease after coronary revascularization

*Advanced analytical methods for measuring changes in HRQoL*

Oreel, T.H.

**Publication date**
2022

# CHAPTER 1

## General introduction

# BACKGROUND

## Initiative to increase our knowledge about quality of life

**Quality of Life and Health programme**. In 2013, the Netherlands Organisation for Scientific Research (NWO) together with the Netherlands Organisation for Health Research and Development (ZonMw) established the Quality of Life and Health programme (https://www.nwo.nl/en/researchprogrammes/quality-life-and-health). In this programme, researchers from both the humanities and medical sciences were invited to collaborate to increase knowledge about quality of life. The concept of quality of life namely plays an important role in healthcare, not only to study the effectiveness of different treatments, but also to decide which treatments should be covered by health insurance, to help patients decide whether or not to start with a certain treatment, or whether expensive life-prolonging treatments provide sufficient benefit to be worthy for collective funding. It was therefore deemed important to have a good understanding of the concept of quality of life and the different ways to measure it.

Quality of life is complex as it is both difficult to conceptualize and to measure. Different people may have different ideas of well-being and health depending on their social background, health problems, and/or living conditions. For example, people with a lower level of education are more inclined to define their health status in negative terms compared with people with advanced education (Stronks et al., 2018). To further exemplify, it has been found that people from Asian cultures are more likely to associate 'energy' with mental health while people from Western cultures are more inclined to associate 'energy' with physical health (Hinton, Sinclair, Chung, & Pollack, 2007; Li, Wang, & Shen, 2003; Thumboo et al., 2013). These group differences in perception of well-being and health should be taken into account when justifying policy or the allocation of resources in healthcare. Hence, research into quality of life would ideally incorporate such differences in the perception of well-being and health status. In doing so, we would not only obtain a more complete insight into the quality of life among different groups of patients, but would also do more justice to the diversity of individual and social situations of different patients.

To address these complexities in the *conceptualization* and *measurement* of quality of life, the previously mentioned research programme Quality of Life and Health focused on: (1) obtaining a better understanding of what quality of life entails (its definition) and (2) improving existing measurement instruments for quality of life and the development of new measurement instruments. To address the differences in quality of life for different groups of patients, special attention was given to psychiatric patients, patients with profound intellectual and multiple disabilities, patients with multiple chronic

morbidities, elderly patients living at home, and people with different socioeconomic status.

**IMPACT study**. Within this programme, we were awarded a project entitled, "Improving the conceptualisation and measurement of quality of life of patients with multiple chronic morbidities, exemplified by patients with cardiac disease undergoing cardiac intervention". The project, called the IMPACT study (www.impactonderzoek.nl/engelstalige-samenvatting/) focussed on improving the conceptualisation and measurement of quality of life of patients with multiple chronic morbidities. We selected patients with coronary artery disease undergoing cardiac revascularization, as those patients typically have multiple morbidities, and are expected to undergo significant changes in HRQoL in a relatively short time period after cardiac revascularization.

The IMPACT study group was a collaboration of researchers from the field of Humanities, including religious studies and medical ethics, and the field of Medical Sciences, including medical psychology, cardiology, oncology, and methodology. Furthermore, the Patient Society of Acquired Cardiac Diseases (https://harteraad.nl/) was also involved in the study.

Following the requirements of the NWO call, the IMPACT study focussed on improving both the *conceptualisation* and *measurement* of quality of life. As such, the study was divided into two parts: a theoretical part and a methodological part. Each part was conducted by a different PhD candidate who worked closely together.

The theoretical part, conducted by Iris Hartog, focused primarily on *improving the conceptualization of HRQoL*. In her dissertation called 'Shattered worlds and new possibilities: How narrative integration of contingent life events influences people's quality of life' (Hartog, 2021) Hartog takes a humanities and religion studies' perspective to study quality of life. Her first aim was to develop a theoretical model that describes how people interpret disruptive life events, such as falling ill, and how this affects their quality of life (Hartog et al., 2020). Her second aim was to operationalize the concepts of this theoretical model into a measurement instrument, called the Reconstruction of Life Events (RE-LIFE) questionnaire. Her third aim was to examine the effect of meaning making interventions that use a narrative approach on quality of life. Finally, her fourth aim was to investigate how personal traits and changes in meaning making of one's illness may influence medical decision making, through their effect on measurements of quality of life (Hartog et al., 2019).

The methodological part pertained to *Improving the measurement HRQoL* and is the focus of this dissertation. This part was initially conducted by Justine Netjes, who developed and executed the study. Justine was succeeded by Tom Oreel, who finished the data collection, performed the data analysis, and reported the results.

**Underlying problem and objective of this thesis**. Health-Related Quality of Life (HRQoL) is a multidimensional concept that includes physical, social, and mental functioning, and general health perceptions. Although the terms quality of life and HRQoL are often used interchangeably, quality of life is a broader concept that captures all aspects of people's life, whereas HRQoL focuses more specifically on the impact of disease and treatment on quality of life (Guyatt et al., 2007). HRQoL is measured by self-report questionnaires in which patients rate their perceived health status and physical, social, and mental functioning (Bullinger, 2004; Guyatt, Feeny, & Patrick, 1993; Ware Jr & Sherbourne, 1992). Such measures aim to provide a comprehensive picture of the perceived impact of disease and treatment on patient's life and are therefore important outcome measures in health care.

Studying the impact of disease and treatment on patient's HRQoL is typically performed using longitudinal designs, in which patients' evaluations of their HRQoL is assessed multiple times (e.g., before and after treatment). However, despite apparent changes in health, patients may report surprisingly stable HRQoL over time. This contradictory finding is the key problem of this thesis and two possible causes will be examined. Firstly, most HRQoL questionnaires require patients to recollect their past experiences and combine that information to respond to a HRQoL item. Such *retrospective questions* rely on one's ability to retrieve past experiences (i.e., they are subject to recall bias) and they cannot capture the moment-to-moment variation in experiences (Reis, 2018; Stone, Broderick, Kaell, DelesPaul, & Porter, 2000). These limitations may obscure possible changes in HRQoL over time. A second possible cause examined in this thesis is that changes in health status may evoke changes in the meaning of one's evaluation of HRQoL: a phenomenon called *response shift* (Sprangers & Schwartz, 1999). While response shift can be considered a result of an adaptive process, it may influence one's evaluation of, and consequently one's response to items about one's HRQoL over time (Sajobi, Wang, et al., 2018; Schwartz & Sprangers, 1999). Such response shift effects may lead to an underestimation of the magnitude of change in HRQoL as patients may have adapted to the changed health status, whether it has become poorer or better.

In addressing these two causes – limitations of retrospective questions and the possible influence of response shift -- we aim to enhance the sensitivity and comprehensiveness of HRQoL measurements.

## Patients with coronary artery disease

**Prevalence, symptoms**. Coronary artery disease is the leading cause of death and disability in the Western world (Say et al., 2014) and the most common of the cardiovascular diseases (Abubakar, Tillmann, & Banerjee, 2015). Coronary artery disease is characterized by a reduction of blood flow to the heart muscle due to a build-up of cholesterol-containing plaques in the arteries of the heart. This condition can cause a number of symptoms such as chest pain (angina), shortness of breath, fatigue or other symptoms that may negatively impact one's HRQoL. If left untreated, coronary artery disease can result in heart failure and ultimately death.

**Coronary revascularization procedures**. Symptoms of coronary artery disease can become so severe that patients require a coronary revascularization procedure to alleviate these symptoms and to improve their quality of life (Benzer, Höfer, & Oldridge, 2003; Kulik, 2017). The most common revascularization procedures are percutaneous coronary intervention (PCI) and coronary artery bypass graft (CABG).

*PCI* is a non-surgical procedure that uses a catheter (a thin flexible tube) to place a stent or balloon to open up narrowed arteries of the heart. The stent relieves the narrowing of the blood vessels, which improves the blood supply to the heart, thereby reducing the symptoms and improving patient's HRQoL. PCI is a relatively less invasive procedure compared with CABG. Most PCI procedures are performed in a single day setting with patients being discharged to home on the same day as the PCI procedure. Patient frequently resume their regular activities in approximately three weeks.

*CABG* is a surgical procedure that redirects the blood flow around the narrowed section of the blood vessels to improve blood flow to the heart muscle. This procedure usually involves taking a healthy blood vessel from one's leg, arm or chest and connecting it beyond the narrowed section of the arteries in the heart. The graft creates a new pathway to supply oxygen-rich blood to the heart, thereby reducing the symptoms and improving patient's HRQoL. CABG is a more demanding procedure compared to PCI. Although most patients only stay a few days in the hospital, they need a longer time to recover up to several (2-4) months before one is able to resume regular activities (Blankenship et al., 2013; Loponen et al., 2009; Takousi et al., 2016). During this recovery period, patients' HRQoL is temporarily reduced but will eventually be restored (Krannich, Lueger, Weyers, & Elert, 2007).

*Health recovery after PCI vs CABG*. Depending on the type of procedure, patients' health will generally improve, either abruptly (PCI) or more gradually (CABG), to which they need to adapt (Kulik, 2017; Loponen et al., 2009; Wong & Chair, 2007). Previous

systematic reviews found that, in general, PCI leads to a greater improvement in HRQoL during the first month following the procedure; however, in the long-term (6 months or more), both procedures lead to similar improvements in HRQoL (Blankenship et al., 2013; Takousi et al., 2016).

**Comorbidities**. With an aging population, people are more likely to suffer from multiple comorbidities, which may negatively impact their HRQoL (Fortin et al., 2006). Patients with coronary artery disease are generally older and hence are more likely to suffer from comorbidities which increase the overall disease burden and may negatively impact HRQoL (Barnett et al., 2012; Blankenship et al., 2013; Pettersen, Reikvam, Rollag, & Stavem, 2008; Xie et al., 2008). Moreover, comorbidities also influence how patients recover from cardiac revascularization. For example, previous research found that comorbidities were associated with poorer HRQoL following PCI (Blankenship et al., 2013).

**Gender differences**. Significant differences exist between female and male patients with coronary artery disease; female patients are generally older compared to male patients, are more likely to experience other symptoms (e.g., fatigue, abdominal pain, nausea and vomiting), tend to have more comorbidities, and report a higher comorbidity burden (Bute et al., 2003; Chandra et al., 1998; EUGenMed et al., 2016; Hochman et al., 1999; Lawton, 2011; Maas & Appelman, 2010). Coronary artery disease mostly affects men (Finegold, Asaria, & Francis, 2013), but the different presentation of complaints in female patients may underestimate the risk of coronary artery disease among women (Maas & Appelman, 2010) and current treatment protocols are based primarily on studies among men (Lawton, 2011). This may lead to less optimal (evidence based) treatment in female patients compared with their male counterparts (Davis et al., 2015).

Previous research found that female patients with coronary artery disease report poorer HRQoL than male patients with coronary artery disease following PCI (Blankenship et al., 2013). Gender differences in the prevalence of comorbidities and symptomology may (in part) explain why female patients report poorer HRQoL than male patients (Norris et al., 2004; Norris et al., 2008). However, possible interactions between gender and comorbidity burden and their effect on HRQoL after coronary revascularization procedures may also occur but are mostly unknown. Insight into such possible interaction effects would enable a more individualized, gender-specific approach and support shared decision-making regarding the choice for coronary revascularization, which is especially important as the main goal of planned revascularization is to reduce symptoms. Hence, the question arises whether there are gender differences regarding the impact of comorbidity burden on HRQoL after coronary revascularization procedures.

## Assessing the dynamic nature of HRQoL

**HRQoL questionnaires with retrospective questions**. HRQoL is commonly measured using questionnaires in which patients are asked to complete *retrospective questions* referring to the past week(s) or month(s). Such retrospective reports require patients to recollect past experiences and combine that information to respond to the question, thereby providing a combined evaluation of their past HRQoL. For example, item 20 of the Short Form Health Survey (McHorney, Ware, & Raczek, 1993) reads: "During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?". To answer such items, patients need to remember different situations over a four-week period and be able to reactivate how physical health and/or emotional problems interfered with their social activities. Such retrospective HRQoL questions may be limited by one's inability to give a complete and accurate recollection of past experiences, i.e., they are subject to recall bias (Reis, 2018; Stone & Shiffman, 2002). For example, whenever individuals are asked to recall past experiences they have the tendency to judge past experiences by the most intense and/or recent experience instead of the average of all past experiences ("peak-end effect" and "recency effect"; Kahneman, Fredrickson, Schreiber, & Redelmeier, 1993; Solhan, Trull, Jahng, & Wood, 2009; Stone et al., 2000). Even when all information can be retrieved perfectly, different experiences over the past four weeks must still be aggregated into an average score ranging from 1 ("all of the time") to 5 ("none of the time"). By combining these experiences into a summarizing score, moment-to-moment variations in experiences are lost (Fredrickson, 2000).

**HRQoL questionnaires with momentary questions**. Alternatively, one can assess HRQoL using Ecological Momentary Assessment (EMA). EMA comprises the repeated assessment of patients' momentary HRQoL in their natural environment (Barge-Schaapveld, Nicolson, Delespaul, & deVries, 1997; Shiffman, 2009; Verhagen, Simons, van Zelst, & Delespaul, 2017). EMA questionnaires are usually administered using smart phone applications, which repeatedly present patients with *momentary questions* about their current mood, feelings, symptoms and/or information of the momentary context (e.g., location, activity, social circumstances of that moment). Because such momentary questions assesses patients' currently experienced HRQoL, it is able to capture the moment-to-moment variation in experiences and is therefore less susceptible to recall bias than retrospective questions (Shiffman, 2009). However, due to the need for frequent and repeated assessments, EMA questionnaires are also time consuming, burdensome and intrusive for the patients (Conner, Tennen, Fleeson, & Barrett, 2009).

**Measuring change in HRQoL using retrospective versus momentary questions**. EMA questionnaires have rarely been applied to measure changes in HRQoL among patients

with a chronic disease of a predominant somatic nature, such as cardiovascular disease. Consequently, there is limited evidence of the validity of measuring change in HRQoL using EMA in this context. Furthermore, previous studies primarily investigated the validity of EMA within one assessment period, e.g., a week (Csikszentmihalyi & Larson, 2014; Everhart, Smyth, Santuzzi, & Fiese, 2010; Maes et al., 2015; Mareva et al., 2016; Sherman, Eisen, Burwinkle, & Varni, 2006), not the validity of measuring changes in HRQoL over multiple assessment periods (Maes et al., 2015; Mareva et al., 2016). Moreover, it is unknown whether retrospective and momentary questions of HRQoL yield the same levels of validity when measuring changes in HRQoL in a somatic context. The question therefore arises how retrospective and momentary questions relate to each other with respect to the validity of measuring change in HRQoL over two assessment periods in cardiac patients following coronary revascularization.

## New methods for analysing the dynamic nature of HRQoL

**Within-person dynamics of HRQoL**. HRQoL is a dynamic construct (Allison, Locker, & Feine, 1997). Momentary questions of HRQoL allow us to capture the moment-to-moment fluctuations in moods, symptoms, and other HRQoL domains at both group level and individual level. Such momentary measurements allow the examination of the dynamics within individual's HRQoL, in other words, how different moods, symptoms, and other HRQoL domains influence each other or themselves over time (Csikszentmihalyi & Larson, 2014; Maes et al., 2015; Reis, 2018; van der Krieke et al., 2017).

**HRQoL as a network model**. A new method to explore, visualize and analyse such dynamics in momentary measurements is network analysis (Bringmann et al., 2013; Snijders, 2009). In network analysis, a specific construct (e.g., HRQoL) is represented as a network of causally interacting variables (Barabási, 2011; Borsboom & Cramer, 2013; Fried et al., 2017; Kossakowski et al., 2016). With respect to HRQoL, network analysis allows us to investigate how different HRQoL domains influence each other and/or themselves over time at both group level and individual level. This enables us to analyse patterns that are lost in static (group level) index scores (Fisher, Medaglia, & Jeronimus, 2018; Howe, Bosley, & Fisher, 2020). For example, the centrality (i.e., importance) of symptoms within the network might be used to identify symptoms that require additional treatment; improvement of a highly central symptom will likely improve other symptoms as well.

To our knowledge, network analysis has not yet been applied to momentary HRQoL data of patients with cardiovascular disease. The question then arises whether network analysis can be used to examine the dynamics within patient's HRQoL using

momentary data of patients with stable coronary artery disease scheduled for coronary revascularization.

## Experience of contingency and narrative integration on changes in HRQOL

**Integration of life events and changes in HRQoL**. As described above, people's evaluations of HRQoL vary with time and experience (Allison et al., 1997). A disruptive life event, such as the diagnosis of coronary artery disease, may change people's life narratives through the process of narrative meaning making and thereby influencing their HRQoL (Kruizinga, Hartog, Scherer-Rath, Schilderman, & Van Laarhoven, 2017). Hartog et al. (2020) proposed a theoretical model that describes how people interpret such disruptive life events and how this may affect their HRQoL.

**Reconstruction of Life Events questionnaire.** The concepts of the theoretical model have been operationalized into a measurement instrument, called the Reconstruction of Life Events questionnaire (RE-LIFE). The RE-LIFE aims to assess the process of narrative meaning making of one important life event in general (as chosen by the respondent), and of being diagnosed with coronary artery disease and undergoing revascularization, in particular. Given this newly developed questionnaire, its reliability and validity need to be established, before it can be used in research and practice to provide a comprehensive account of the underlying processes of changes in HRQoL. The question then arises, what is the psychometric performance of this newly developed RE-LIFE questionnaire?

## Response shift in HRQoL after coronary revascularization

**Response shift.** Changes in HRQoL after coronary revascularization are usually measured by comparing scores on HRQoL questionnaires before and after the revascularization procedure. However, revascularization procedures may induce response shift. Response shift can be defined as a change in the meaning of patients' self-evaluation due to a change in internal standards (recalibration), a change in the relative importance of the components of HRQoL (reprioritization), and/or a change in the meaning of the target construct (reconceptualization) (Sprangers & Schwartz, 1999). Although they may be adaptive for the patient, response shift effects may affect comparisons of HRQoL scores over time. Changes in HRQoL after coronary revascularization are therefore more accurately measured when these possible response shift effects are taken into account (Sajobi, Brahmbatt, Lix, Zumbo, & Sawatzky, 2018; Schwartz & Sprangers, 1999).

**Response shift among different groups of patients**. Response shift in HRQoL has been found among different groups of patients. For example, among patients with multiple

sclerosis (Ahmed, Mayo, Scott, Kuspinar, & Schwartz, 2011; King-Kallimanis, Oort, Nolte, Schwartz, & Sprangers, 2011), cancer patients (Anota et al., 2014; Brinksma et al., 2014; Hamidou, Dabakuyo, & Bonnetain, 2011; Tessier, Blanchin, & Sébille, 2017), epilepsy patients following surgery (Sajobi, Fiest, & Wiebe, 2014), patients with HIV/aids (Li & Rapkin, 2009), and patients with osteoarthritis undergoing total knee replacement surgery (Sajobi et al., 2014). Most importantly, response shift effects have also been detected among patients with cardiovascular disease. For example it has been found that hypertensive patients with coronary artery disease experienced a response shift in HRQoL over a 1-year period (Gandhi, Ried, Huang, Kimberlin, & Kauf, 2013), and among cardiac patients taking part in a rehabilitation program (Friedrich, Karoff, & Hinz, 2019).

**Structural equation modelling (SEM) approach**. Different methods for detecting response shift exist, each with their own strengths and limitations (Sébille et al., 2021). In this thesis response shift is investigated using structural equation modelling (SEM) (Oort, 2005). The SEM approach has the advantage that it can detect the different types of response shift effects (i.e., recalibration, reprioritization, reconceptualization), and that it can investigate the influence of the different response shift effects on the assessment of change in HRQoL. SEM models the associations between observed scores (e.g., scores of the Short Form Health Survey 36 and Seattle Angina Questionnaire questionnaires) and the underlying construct of interest (generic and disease-specific HRQoL) in a factor model. By fitting a factor model to the data at different moments in time, change in model parameters can be used to statistically investigate the three types of response shift effects.

**Response shift after coronary revascularization**. The positive changes in health after coronary revascularization may prompt changes in patients' views of their HRQoL over time. However, it is unknown whether such response shifts actually occur after coronary revascularization, if controlling for possible response shift effects results in better estimates of change, and if possible response shift effects are related to patient characteristics, i.e., sociodemographic, clinical and/or psychosocial variables. The question therefore arises whether (1) response shift occurs among patients with coronary artery disease following coronary revascularization, (2) whether the assessment of changes in HRQoL, controlled for response shift, yield more valid estimates of changes in HRQoL, and (3) whether possible occurrences of response shift are related to patient characteristics.

## Impact study

**Design of the Impact study**. A total of 320 patients with coronary artery disease were included in this study, with 195 patients receiving PCI, 54 patients receiving CABG and

71 patients receiving neither PCI nor CABG but a diagnostic procedure instead. Patients were eligible if they were 18 years or older, had stable coronary artery disease and were scheduled for CABG or PCI. Patients had to have at least one comorbidity and were excluded if they were unable to complete questionnaires due to language or cognitive problems. Patients were administered questionnaires at four assessment periods: one before the intervention and at three follow-up periods after the intervention (see Table 1). Patients completed questionnaires on HRQoL at each assessment period, but other questionnaires were administered at different time points (see Table 1). Demographic and clinical information was collected at baseline. Patients completed the questionnaires on paper or online dependent on their preference.

**EMA sub-study**. From the total sample, 37 patients also participated in the EMA sub-study. 27 patients underwent PCI, eight patients underwent CABG and two patients underwent a diagnostic procedure only. Additional inclusion criteria for participation in the current add-on study on momentary assessments were being experienced smart phone users (indicated at their own discretion), and having a functional Wi-Fi connection at home to enable daily transfer of data to a central server to avoid data loss. Patients completed the HRQoL questionnaire with momentary questions at three assessment periods, at baseline and two follow-up measures after the intervention. The follow-up time points differed per vascularization procedure due to the expected difference in recovery, i.e., two weeks (for PCI), three months (for PCI and CABG), and six months (for CABG) following revascularization (see Table 1). Momentary questions were assessed over the course of seven days. Patients received an iPod for the duration of the assessment period with the PsyMate™ application installed (www.psymate.eu). PsyMate™ was programmed to give nine beeps during daytime, at random moments within predefined time slots (maximally 2 hours apart).

| Questionnaires and procedures | Assessment periods | | | |
|---|---|---|---|---|
| | T1* | T2* | T3* | T4* |
| **HRQOL questionnaires** | | | | |
| Disease specific HRQOL (SAQ7) | X | X | X | X |
| EMA questionnaire (one week time frame)* | X | X | X | X |
| Overall health status (EQ5D) | X | X | X | X |
| Overall HRQoL (SF36) | X | X | X | X |
| **Criterion Measures** | | | | |
| Physical functioning (NYHA) | X | X | X | X |
| Subjective Change in HRQoL (SSQ) | 0 | X | X | X |
| **Background measures** | | | | |
| Demographic (age and gender) | X | 0 | 0 | 0 |
| Clinical (intervention type and comorbidities) | X | 0 | 0 | 0 |
| Emotionality and Agreeableness (HEXACO-SPI) | 0 | 0 | X | 0 |
| Reconstruction of Life Events questionnaire (RE-LIFE) | 0 | 0 | X | X |
| Posttraumatic Growth Index (PTGI) | 0 | 0 | X | X |
| **EMA Sub-study*** | | | | |
| PCI patients (EMA) | X | X | X | 0 |
| CABG patients (EMA) | X | 0 | X | X |

**Table 1. Questionnaires used in the IMPACT study (X = assessed; 0 = not assessed)**. Notes: * *T1* = baseline measure, one week before revascularization; *T2* = follow-up measure, two weeks after revascularization; *T3* = follow-up measure, three months after revascularization; *T4* = follow-up measure, six months after revascularization; *EMA Sub-study* = all patients who participated in the EMA sub-study completed EMA assessments during 3 weeks: PCI patients completed EMA during T1-T3 and CABG patients during T1 and T3-T4; *SAQ7* is the Seattle Angina Questionnaire (Chan, Jones, Arnold, & Spertus, 2014); *EMA questionnaire* was based on an earlier version developed by Maes and colleagues (Maes et al., 2015); *EQ5D* is the EuroQol 5D (Group, 1990); *SF36* is the Dutch version of the Short Form Health Survey 36 (Ware Jr & Sherbourne, 1992); *NYHA* is New York Heart Association functioning classification system (Levin, Dolgin, Fox, & Gorlin, 1994; Schoormans, Mager, Oort, Sprangers, & Mulder, 2012); *SSQ* is the Subjective Significance Questionnaire (Osoba, Rodrigues, Myles, Zee, & Pater, 1998); *HEXACO-SPI* is the HEXACO Simplified Personality Inventory (De Vries & Born, 2013); *RE-LIFE* is the Reconstruction of Life Events Questionnaire (Hartog et al., 2020); PTGI is the posttraumatic growth index (Tedeschi & Calhoun, 1996).

## OUTLINE OF THE THESIS

**In chapter two**, we present the study on gender differences in HRQoL among patients with coronary artery disease following coronary revascularization. We investigated the impact of comorbidity burden on the change in HRQoL following coronary revascularization in female patients versus male patients. Generic and disease-specific HRQoL data from all four time points were used to measure change in HRQoL (see Table 1). Patients' comorbidity conditions were identified using the hospitals' electronic medical records.

**In chapter three**, we present the study in which we compare the criterion validity of momentary questions of change in HRQoL and retrospective questions of change in HRQoL. We compare the associations between the momentary and retrospective change scores following cardiac revascularization with the corresponding criterion measures of changes in HRQoL. For a more detailed description of the questionnaires used in this study see Table 1.

**In chapter four**, we describe the study on network analysis for analysing HRQoL among patients with coronary artery disease. Here we illustrate the use of network analysis to examine momentary HRQoL data. Momentary data at baseline were used to estimate network models at group-level and at individual level.

**In chapter five**, we describe the study in which we investigate the psychometric properties of the RE-LIFE questionnaire as administered three months following revascularization. The scale structure, internal consistency reliability and the validity of the RE-LIFE questionnaire will be presented.

**In chapter six**, we present the findings of our study in which the SEM approach was used to investigate the occurrence of response shift in HRQoL after coronary revascularization and whether the assessment of change in HRQoL, controlled for response shift, yield more valid estimates of changes in HRQoL. We used the SF-36 and SAQ7 data collected at baseline and at three months after treatment. Criterion measures of change were measured with the SSQ and change in NYHA class.

**In chapter seven**, we discuss the extent to which we have succeeded in examining the possible causes of stability and how our results may enhance the sensitivity and comprehensiveness of HRQoL measurements.

**In chapter eight**, we summarize our findings.

**In chapter nine**, we summarize our findings in Dutch.

## REFERENCES


Abubakar, I., Tillmann, T., & Banerjee, A. (2015). Global, regional, and national age-sex specific all-cause and cause-specific mortality for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet, 385*(9963), 117-171.

Ahmed, S., Mayo, N., Scott, S., Kuspinar, A., & Schwartz, C. (2011). Using latent trajectory analysis of residuals to detect response shift in general health among patients with multiple sclerosis article. *Quality of Life Research, 20*(10), 1555-1560.

Allison, P. J., Locker, D., & Feine, J. S. (1997). Quality of life: a dynamic construct. *Social science & medicine, 45*(2), 221-230.

Anota, A., Bascoul-Mollevi, C., Conroy, T., Guillemin, F., Velten, M., Jolly, D., Mercier, M., Causeret, S., Cuisenier, J., & Graesslin, O. (2014). Item response theory and factor analysis as a mean to characterize occurrence of response shift in a longitudinal quality of life study in breast cancer patients. *Health and quality of life outcomes, 12*(1), 1-18.

Barabási, A.-L. (2011). The network takeover. *Nature Physics, 8*(1), 14.

Barge-Schaapveld, D., Nicolson, N. A., Delespaul, P., & deVries, M. W. (1997). Assessing daily quality of life with the experience sampling method. *Quality of life in mental disorders*, 95-107.

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet, 380*(9836), 37-43.

Benzer, W., Höfer, S., & Oldridge, N. B. (2003). Health-related quality of life in patients with coronary artery disease after different treatments for angina in routine clinical practice. *Herz, 28*(5), 421-428.

Blankenship, J. C., Marshall, J. J., Pinto, D. S., Lange, R. A., Bates, E. R., Holper, E. M., Grines, C. L., & Chambers, C. E. (2013). Effect of percutaneous coronary intervention on quality of life: a consensus statement from the Society for Cardiovascular Angiography and Interventions. *Catheterization and Cardiovascular Interventions, 81*(2), 243-259.

Borsboom, D., & Cramer, A. O. (2013). Network analysis: an integrative approach to the structure of psychopathology. *Annual review of clinical psychology, 9*, 91-121.

Brinksma, A., Tissing, W. J., Sulkers, E., Kamps, W. A., Roodbol, P. F., & Sanderman, R. (2014). *Exploring the response shift phenomenon in childhood patients with cancer and its effect on health-related quality of life.* Paper presented at the Oncology Nursing Forum.

Bullinger, M. (2004). Measuring health related quality of life. *Adamantiades-Behçet's Disease*, 113-122.

Bute, B. P., Mathew, J., Blumenthal, J. A., Welsh-Bohmer, K., White, W. D., Mark, D., Landolfo, K., & Newman, M. F. (2003). Female gender is associated with impaired quality of life 1 year after coronary artery bypass surgery. *Psychosomatic medicine, 65*(6), 944-951.

Chan, P. S., Jones, P. G., Arnold, S. A., & Spertus, J. A. (2014). Development and validation of a short version of the Seattle angina questionnaire. *Circulation: Cardiovascular Quality and Outcomes, 7*(5), 640-647.

Chandra, N. C., Ziegelstein, R. C., Rogers, W. J., Tiefenbrunn, A. J., Gore, J. M., French, W. J., & Rubison, M. (1998). Observations of the treatment of women in the United States with myocardial infarction: a report from the National Registry of Myocardial Infarction-I. *Archives of internal medicine, 158*(9), 981-988.

Conner, T. S., Tennen, H., Fleeson, W., & Barrett, L. F. (2009). Experience sampling methods: A modern idiographic approach to personality research. *Social and personality psychology compass, 3*(3), 292-313.

Csikszentmihalyi, M., & Larson, R. (2014). Validity and reliability of the experience-sampling method *Flow and the foundations of positive psychology* (pp. 35-54): Springer.

Davis, M., Diamond, J., Montgomery, D., Krishnan, S., Eagle, K., & Jackson, E. (2015). Acute coronary syndrome in young women under 55 years of age: clinical characteristics, treatment, and outcomes. *Clinical Research in Cardiology, 104*(8), 648-655.

De Vries, R. E., & Born, M. P. (2013). De Vereenvoudigde HEXACO Persoonlijkheidsvragenlijst en een additioneel interstitieel Proactiviteitsfacet. *Gedrag & Organisatie, 26*(2), 223-245.

EUGenMed, Group, C. C. S., Regitz-Zagrosek, V., Oertelt-Prigione, S., Prescott, E., Franconi, F., Gerdts, E., Foryst-Ludwig, A., Maas, A. H., & Kautzky-Willer, A. (2016). Gender in cardiovascular diseases: impact on clinical manifestations, management, and outcomes. *European heart journal, 37*(1), 24-34.

Everhart, R. S., Smyth, J. M., Santuzzi, A. M., & Fiese, B. H. (2010). Validation of the Asthma Quality of Life Questionnaire with momentary assessments of symptoms and functional limitations in patient daily life. *Respiratory Care, 55*(4), 427-432.

Finegold, J. A., Asaria, P., & Francis, D. P. (2013). Mortality from ischaemic heart disease by country, region, and age: statistics from World Health Organisation and United Nations. *International journal of cardiology, 168*(2), 934-945.

Fisher, A. J., Medaglia, J. D., & Jeronimus, B. F. (2018). Lack of group-to-individual generalizability is a threat to human subjects research. *Proceedings of the National Academy of Sciences, 115*(27), E6106-E6115.

Fortin, M., Bravo, G., Hudon, C., Lapointe, L., Almirall, J., Dubois, M.-F., & Vanasse, A. (2006). Relationship between multimorbidity and health-related quality of life of patients in primary care. *Quality of Life Research, 15*(1), 83-91.

Fredrickson, B. L. (2000). Extracting meaning from past affective experiences: The importance of peaks, ends, and specific emotions. *Cognition & Emotion, 14*(4), 577-606.

Fried, E. I., van Borkulo, C. D., Cramer, A. O., Boschloo, L., Schoevers, R. A., & Borsboom, D. (2017). Mental disorders as networks of problems: a review of recent insights. *Social Psychiatry and Psychiatric Epidemiology, 52*(1), 1-10.

Friedrich, M., Karoff, J., & Hinz, A. (2019). Response shift effects in patients' assessments of their quality of life after cardiac rehabilitation. *Quality of Life Research, 28*(9), 2609-2620.

Gandhi, P. K., Ried, L. D., Huang, I.-C., Kimberlin, C. L., & Kauf, T. L. (2013). Assessment of response shift using two structural equation modeling techniques. *Quality of Life Research, 22*(3), 461-471.

Group, T. E. (1990). EuroQol-a new facility for the measurement of health-related quality of life. *Health policy, 16*(3), 199-208.

Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of internal medicine, 118*(8), 622-629.

Guyatt, G. H., Ferrans, C. E., Halyard, M. Y., Revicki, D. A., Symonds, T. L., Varricchio, C. G., Kotzeva, A., Valderas, J. M., Alonso, J. L., & Group, C. S. C. M. (2007). *Exploration of the value of health-related quality-of-life information from clinical research and into clinical practice.* Paper presented at the Mayo Clinic Proceedings.

Hamidou, Z., Dabakuyo, T. S., & Bonnetain, F. (2011). Impact of response shift on longitudinal quality-of-life assessment in cancer clinical trials. *Expert Review of Pharmacoeconomics & Outcomes Research, 11*(5), 549-559.

Hartog, I., Scherer-Rath, M., Kruizinga, R., Netjes, J., Henriques, J., Nieuwkerk, P., Sprangers, M., & van Laarhoven, H. (2020). Narrative meaning making and integration: Toward a better understanding of the way falling ill influences quality of life. *Journal of health psychology, 25*(6), 738-754.

Hartog, I. D. (2021). *Shattered worlds and new possibilities. How narrative integration of contingent life events influences people's quality of life.* [Sl: sn].

Hartog, I. D., Willems, D. L., van den Hout, W. B., Scherer-Rath, M., Oreel, T. H., Henriques, J. P., Nieuwkerk, P. T., van Laarhoven, H. W., & Sprangers, M. A. (2019). Influence of response shift and disposition on patient-reported outcomes may lead to suboptimal medical decisions: a medical ethics perspective. *BMC medical ethics, 20*(1), 1-7.

Hinton, D. E., Sinclair, S. J., Chung, R. C.-Y., & Pollack, M. H. (2007). The SF-36 among Cambodian and Vietnamese refugees: An examination of psychometric properties. *Journal of Psychopathology and Behavioral Assessment, 29*(1), 38-45.

Hochman, J. S., Tamis, J. E., Thompson, T. D., Weaver, W. D., White, H. D., Van de Werf, F., Aylward, P., Topol, E. J., & Califf, R. M. (1999). Sex, clinical presentation, and outcome in patients with acute coronary syndromes. *New England Journal of Medicine, 341*(4), 226-232.

Howe, E., Bosley, H. G., & Fisher, A. J. (2020). Idiographic network analysis of discrete mood states prior to treatment. *Counselling and Psychotherapy Research, 20*(3), 470-478.

Kahneman, D., Fredrickson, B. L., Schreiber, C. A., & Redelmeier, D. A. (1993). When more pain is preferred to less: Adding a better end. *Psychological science, 4*(6), 401-405.

King-Kallimanis, B. L., Oort, F. J., Nolte, S., Schwartz, C. E., & Sprangers, M. A. (2011). Using structural equation modeling to detect response shift in performance and health-related quality of life scores of multiple sclerosis patients. *Quality of Life Research, 20*(10), 1527-1540.

Kossakowski, J. J., Epskamp, S., Kieffer, J. M., van Borkulo, C. D., Rhemtulla, M., & Borsboom, D. (2016). The application of a network approach to Health-Related Quality of Life (HRQoL): introducing a new method for assessing HRQoL in healthy adults and cancer patients. *Quality of Life Research, 25*(4), 781-792.

Krannich, J.-H., Lueger, S., Weyers, P., & Elert, O. (2007). Health-related quality of life two days before, ten days and one year after coronary artery bypass graft surgery. *The Thoracic and cardiovascular surgeon, 55*(05), 288-292.

Kruizinga, R., Hartog, I. D., Scherer-Rath, M., Schilderman, H., & Van Laarhoven, H. (2017). Modes of relating to contingency: an exploration of experiences in advanced cancer patients. *Palliative & supportive care, 15*(4), 444.

Kulik, A. (2017). Quality of life after coronary artery bypass graft surgery versus percutaneous coronary intervention: what do the trials tell us? *Current opinion in cardiology, 32*(6), 707-714.

Lawton, J. S. (2011). *Sex and gender differences in coronary artery disease.* Paper presented at the Seminars in thoracic and cardiovascular surgery.

Levin, R., Dolgin, M., Fox, C., & Gorlin, R. (1994). The Criteria Committee of the New York Heart Association: Nomenclature and Criteria for Diagnosis of Diseases of the Heart and Great Vessels. *LWW Handbooks, 9*, 344.

Li, L., Wang, H., & Shen, Y. (2003). Chinese SF-36 Health Survey: translation, cultural adaptation, validation, and normalisation. *Journal of Epidemiology & Community Health, 57*(4), 259-263.

Li, Y., & Rapkin, B. (2009). Classification and regression tree uncovered hierarchy of psychosocial determinants underlying quality-of-life response shift in HIV/AIDS. *Journal of clinical epidemiology, 62*(11), 1138-1147.

Loponen, P., Luther, M., Korpilahti, K., Wistbacka, J.-O., Huhtala, H., Laurikka, J., & Tarkka, M. R. (2009). HRQoL after coronary artery bypass grafting and percutaneous coronary intervention for stable angina. *Scandinavian Cardiovascular Journal, 43*(2), 94-99.

Maas, A., & Appelman, Y. (2010). Gender differences in coronary heart disease. *Netherlands Heart Journal, 18*(12), 598-603.

Maes, I. H., Delespaul, P. A., Peters, M. L., White, M. P., van Horn, Y., Schruers, K., Anteunis, L., & Joore, M. (2015). Measuring health-related quality of life by experiences: the experience sampling method. *Value in Health, 18*(1), 44-51.

Mareva, S., Thomson, D., Marenco, P., Estal Muñoz, V., Ott, C. V., Schmidt, B., Wingen, T., & Kassianos, A. P. (2016). Study protocol on ecological momentary assessment of health-related quality of life using a smartphone application. *Frontiers in psychology, 7*, 1086.

McHorney, C. A., Ware, J. E., & Raczek, A. E. (1993). The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *MEDICAL CARE-PHILADELPHIA-, 31*, 247-247.

Norris, C. M., Ghali, W. A., Galbraith, P. D., Graham, M. M., Jensen, L. A., & Knudtson, M. L. (2004). Women with coronary artery disease report worse health-related quality of life outcomes compared to men. *Health and quality of life outcomes, 2*(1), 21.

Norris, C. M., Spertus, J. A., Jensen, L., Johnson, J., Hegadoren, K. M., & Ghali, W. A. (2008). Sex and gender discrepancies in health-related quality of life outcomes among patients with established coronary artery disease. *Circulation: Cardiovascular Quality and Outcomes, 1*(2), 123-130.

Oort, F. J. (2005). Using structural equation modeling to detect response shifts and true change. *Quality of Life Research, 14*(3), 587-598.

Osoba, D., Rodrigues, G., Myles, J., Zee, B., & Pater, J. (1998). Interpreting the significance of changes in health-related quality-of-life scores. *Journal of clinical oncology, 16*(1), 139-144.

Pettersen, K. I., Reikvam, A., Rollag, A., & Stavem, K. (2008). Understanding sex differences in health-related quality of life following myocardial infarction. *International journal of cardiology, 130*(3), 449-456.

Reis, H. T. (2018). Why researchers should think "real-world": A conceptual rationale *Relationships, Well-Being and Behaviour* (pp. 249-271): Routledge.

Sajobi, T. T., Brahmbatt, R., Lix, L. M., Zumbo, B. D., & Sawatzky, R. (2018). Scoping review of response shift methods: current reporting practices and recommendations. *Quality of Life Research, 27*(5), 1133-1146.

Sajobi, T. T., Fiest, K. M., & Wiebe, S. (2014). Changes in quality of life after epilepsy surgery: the role of reprioritization response shift. *Epilepsia, 55*(9), 1331-1338.

Sajobi, T. T., Wang, M., Awosoga, O., Santana, M., Southern, D., Liang, Z., Galbraith, D., Wilton, S. B., Quan, H., & Graham, M. M. (2018). Trajectories of health-related quality of life in coronary artery disease. *Circulation: Cardiovascular Quality and Outcomes, 11*(3), e003661.

Say, L., Chou, D., Gemmill, A., Tunçalp, Ö., Moller, A.-B., Daniels, J., Gülmezoglu, A. M., Temmerman, M., & Alkema, L. (2014). Global causes of maternal death: a WHO systematic analysis. *The Lancet Global Health, 2*(6), e323-e333.

Schoormans, D., Mager, Y. L., Oort, F. J., Sprangers, M. A., & Mulder, B. J. (2012). New York Heart Association class assessment by cardiologists and outpatients with congenital cardiac disease: A head-to-head comparison of three patient-based versions. *Cardiology in the Young, 22*(1), 26-33.

Schwartz, C. E., & Sprangers, M. A. (1999). Methodological approaches for assessing response shift in longitudinal health-related quality-of-life research. *Social science & medicine, 48*, 1531-1548.

Sébille, V., Lix, L. M., Ayilara, O. F., Sajobi, T. T., Janssens, A. C. J., Sawatzky, R., Sprangers, M. A., & Verdam, M. G. (2021). Critical examination of current response shift methods and proposal for advancing new methods. *Quality of Life Research*, 1-18.

Sherman, S. A., Eisen, S., Burwinkle, T. M., & Varni, J. W. (2006). The PedsQL™ present functioning visual analogue scales: preliminary reliability and validity. *Health and quality of life outcomes, 4*(1), 1-10.

Shiffman, S. (2009). Ecological momentary assessment (EMA) in studies of substance use. *Psychological assessment, 21*(4), 486.

Solhan, M. B., Trull, T. J., Jahng, S., & Wood, P. K. (2009). Clinical assessment of affective instability: comparing EMA indices, questionnaire reports, and retrospective recall. *Psychological assessment, 21*(3), 425.

Sprangers, M. A., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. *Social science & medicine, 48*(11), 1507-1515.

Stone, A. A., Broderick, J. E., Kaell, A. T., DelesPaul, P. A., & Porter, L. E. (2000). Does the peak-end phenomenon observed in laboratory pain studies apply to real-world pain in rheumatoid arthritics? *The Journal of Pain, 1*(3), 212-217.

Stone, A. A., & Shiffman, S. (2002). Capturing momentary, self-report data: A proposal for reporting guidelines. *Annals of Behavioral Medicine, 24*(3), 236-243.

Stronks, K., Hoeymans, N., Haverkamp, B., den Hertog, F. R., van Bon-Martens, M. J., Galenkamp, H., Verweij, M., & van Oers, H. A. (2018). Do conceptualisations of health differ across social strata? A concept mapping study among lay people. *BMJ open, 8*(4), e020210.

Takousi, M. G., Schmeer, S., Manaras, I., Olympios, C. D., Makos, G., & Troop, N. A. (2016). Health-Related Quality of Life after Coronary Revascularization: A systematic review with meta-analysis. *Hellenic Journal of Cardiology, 57*(4), 223-237.

Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of traumatic stress, 9*(3), 455-471.

Tessier, P., Blanchin, M., & Sébille, V. (2017). Does the relationship between health-related quality of life and subjective well-being change over time? An exploratory study among breast cancer patients. *Social science & medicine, 174*, 96-103.

Thumboo, J., Wu, Y., Tai, E.-S., Gandek, B., Lee, J., Ma, S., Heng, D., & Wee, H.-L. (2013). Reliability and validity of the English (Singapore) and Chinese (Singapore) versions of the Short-Form 36 version 2 in a multi-ethnic urban Asian population in Singapore. *Quality of Life Research, 22*(9), 2501-2508.

van der Krieke, L., Blaauw, F. J., Emerencia, A. C., Schenk, H. M., Slaets, J. P., Bos, E. H., de Jonge, P., & Jeronimus, B. F. (2017). Temporal dynamics of health and well-being: a crowdsourcing approach to momentary assessments and automated generation of personalized feedback. *Psychosomatic medicine, 79*(2), 213-223.

Verhagen, S. J., Simons, C. J., van Zelst, C., & Delespaul, P. A. (2017). Constructing a Reward-Related Quality of Life Statistic in Daily Life—a Proof of Concept Study Using Positive Affect. *Frontiers in psychology, 8*, 1917.

Ware Jr, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical care*, 473-483.

Wong, M. S., & Chair, S. Y. (2007). Changes in health-related quality of life following percutaneous coronary intervention: a longitudinal study. *International journal of nursing studies, 44*(8), 1334-1342.

Xie, J., Wu, E. Q., Zheng, Z.-J., Sullivan, P. W., Zhan, L., & Labarthe, D. R. (2008). Patient-reported health status in coronary heart disease in the United States. *Circulation, 118*(5), 491-497.