



Chapitre de livre

2022

Published version

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How to cite

WULFOVICH, Sharon, BUUR, Jeppe, WAC, Katarzyna. Unfolding the Quantification of Quality of Life.
In: Quantifying Quality of Life. [s.l.] : [s.n.], 2022. p. 3–24pp. doi: 10.1007/978-3-030-94212-0_1

This publication URL: <https://archive-ouverte.unige.ch//unige:165994>

Publication DOI: [10.1007/978-3-030-94212-0_1](https://doi.org/10.1007/978-3-030-94212-0_1)

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Chapter 1

Unfolding the Quantification of Quality of Life



Sharon Wulfovich, Jeppe Buur, and Katarzyna Wac

Introduction

There are many ways to define health. Health is defined by the World Health Organization (WHO) as “*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*” [1, 2] This definition has recently been challenged by a team of international experts who suggested that health be defined as “*the ability to adapt and self-manage in the face of social, physical, and emotional challenges.*” [3] Health contributes greatly to quality of life (QoL), and some authors suggest that health-related QoL and QoL can be used interchangeably [4]. However, QoL is more than health, as other factors including work capacity, social support, and the physical environment are also necessary for QoL [5–7]. QoL can be defined in multiple ways through a more global approach (from the psychological, economics, policy, or medical science perspective) [8], a categorical breakdown from an individual perspective (e.g., physical or psychological aspects), or a field-specific definition applied to individuals or specific populations (e.g., Liver QoL) [7, 9].

Across these different definitions, there is some agreement that QoL integrates an individual’s multidimensional evaluation of their own life and total well-being [7]. Furthermore, an individual’s QoL is not merely focused on the individual; it

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encompasses the individual's physical and psychological state, the environment the individual is in, as well as the interaction between the two. The environment includes other individuals; nonmaterial things such as parks and roads; as well as water, air, and access to other resources.

Measuring an individual's QoL allows us to obtain a more holistic assessment of his or her state in the multiple contexts like disease progression (via symptoms), or treatment progress, and to put that in the context of clinical decision making. QoL or well-being has been indirectly assessed since the dawn of the field of medicine. Almost every doctor or physician informally asks the patient about his or her state using questions such as "how are you feeling right now?" or "how are your symptoms?"

With the need to systematically assess QoL in clinical decision making [10], there are two primary ways to capture this information: (1) asking people about different aspects of their lives following subjective self-reporting using validated patient-reported outcomes (PRO) [11] instruments [12]; examples and an overview of the current validated instruments for QoL assessment can be found in the studies of Gill [13] and Linton et al. [14]; and (2) leveraging technologies to objectively capture individuals' biological samples, physiological signals, behaviors, or interactions with the environment [4, 11].

One of the most widely used QoL assessment instruments is the WHO's Quality of Life instrument (WHOQOL), which is used as a framework for organizing this book. The WHOQOL defines QoL as "*individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.*" [15] The WHOQOL-BREF instrument assesses individuals' QoL across four domains: physical health, psychological health, social relationships, and environmental aspects [16]. These four large domains are further broken down into 24 subdomains, denoted by the WHO as '*facets*' [15] (Fig. 1.1). The subdomains embrace subjective and objective aspects of life, are mutually nonexclusive, and potentially intertwine [15]. For example, there is an influence of noise (i.e., environmental aspect) on sleep and rest (i.e., physical health).

The overarching assumption carried throughout this book is that within each of the QoL domains, there are specific daily behaviors that (a) can be accessed objectively through personal technologies or (b) enabled through the use of these technologies. A behavior is defined by the scientific community as "internally coordinated responses (actions or inactions) of whole living organisms (individuals or groups) to internal and/or external stimuli, excluding responses more easily understood as developmental changes," [17] or as "a comportment, or what someone does or how someone acts." [18] Behaviors can be assessed by means of, for example, their frequency, rate, duration, magnitude, and latency [19]. In the scope of this book, we focus specifically on external observable behaviors (or the lack thereof) that may be assessed using technologies. This assumption follows the definition of QoL Technologies (QoLT) as "*any technologies for assessment or improvement of the individual's QoL.*" [20] The variety of designs of QoLT used to assess behaviors in daily life remains unknown, as does their influence on QoL. In this book we focus solely on the approaches using technology-enabled QoL

QoL Domains	QoL Subdomains
<i>Physical Health</i>	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work capacity
<i>Psychological</i>	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality/religion/personal beliefs Thinking, learning, memory and concentration
<i>Social Relationships</i>	Personal relationships Social support Sexual activity
<i>Environment</i>	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation/leisure act. Physical environment (pollution / noise / traffic / climate) Transport

Fig. 1.1 WHOQOL Instrument Domains and Subdomains [16]

assessments. We therefore assume that QoLT enable behavior assessments and as a result the assessment of QoL in individuals [11].

This book presents QoLT leveraged for QoL assessment and draws from the WHOQOL, providing a way to categorize behaviors and QoL aspects. As a result, the WHOQOL instrument presented here serves as the organizational method for this book.

The remainder of this chapter is organized as follows: First, we present the WHOQOL instrument in detail (Sect. 2), and then we present the ‘quantified-selves’, who leverage daily life technologies to assess their own behaviors and daily life (Sect. 3). Lastly, we conclude with a discussion further motivating the vision for this book (Sect. 4).

This book follows the WHOQOL instrument, and its chapters are organized along the WHOQOL subdomains. The following chapter discusses conclusive remarks and future directions for the field of QoL assessment. Finally, the last chapter discusses the current state of the subjective assessment of QoL by summarizing

a set of validated instruments and scales for assessing daily life behaviors in the context of QoL, also organized along the variables in the WHOQOL instrument.

The WHOQOL Instrument

The WHO developed its first edition of an international QoL assessment approach in 1995 [15]. The development of the WHOQOL consisted of many stages: (i) QoL concept clarification; (ii) qualitative pilot; (iii) development pilot; and (iv) field test [15]. Due to the multidimensional essence of QoL, the WHOQOL divided QoL into six broad domains: (1) physical domain; (2) psychological domain; (3) level of independence; (4) social relationships; (5) environment; and (6) spirituality/religion/personal beliefs [15], embraced within the original 100-question instrument referred to as the WHOQOL-100 [21]. Later, the WHO developed a WHOQOL-BREF QoL assessment [16, 22], a shorter version of the original WHOQOL-100, which defines four broad domains: (1) physical health; (2) psychological health; (3) social relationships; and (4) environment [16, 22]. This shorter version, used as the assessment model throughout this book, was developed to minimize respondent burden and unnecessary detail when approaching QoL assessment in the general population [16, 22]. The WHOQOL-BREF instrument has been demonstrated to have “*good to excellent psychometric properties of reliability*” and to perform “*well in preliminary tests of validity*.” [22]

The WHOQOL-BREF, its four domains, and the 24 subdomains are outlined in Fig. 1.1. The paragraphs below provide a working definition for each of the four domains and 24 subdomains of the WHOQOL-BREF. We use the titles of the WHOQOL-BREF and have adapted the definitions of the WHOQOL User manual [23] accordingly, as the WHOQOL-BREF does not have its own manual.

Domain I: Physical Health

1. *Activities of Daily Living*: “a person’s ability to perform usual daily living activities.”
2. *Dependence on Medicinal Substances and Medical Aids*: “a person’s dependence on medication or alternative medicines for supporting his/her physical and psychological well-being.”
3. *Energy and Fatigue*: “the energy, enthusiasm and endurance that a person has in order to perform the necessary tasks of daily living, as well as other chosen activities such as recreation.”
4. *Mobility*: “the person’s view of his/her ability to get from one place to another, to move around the home, move around the workplace, or to and from transportation services.”
5. *Pain and Discomfort*: “unpleasant physical sensation experienced by a person and the extent to which these sensations are distressing and interfere with life.”
The topics include pain control.
6. *Sleep and Rest*: problems getting enough sleep and rest.

7. *Work Capacity*: “a person’s use of his or her energy for work.” “Work” is defined as any major activity in which the person is engaged.

Domain II: Psychological Health

8. *Bodily Image and Appearance*: “the person’s view of his/her body.”
9. *Negative Feelings*: “how much a person experiences negative feelings, including despondency, guilt, sadness, tearfulness, despair, nervousness, anxiety and a lack of pleasure in life.”
10. *Positive Feelings*: “how much a person experiences positive feelings of contentment, balance, peace, happiness, hopefulness, joy and enjoyment of the good things in life.”
11. *Self-Esteem*: “how people feel about themselves.”
12. *Spirituality/Religion/Personal Beliefs*: “examines the person’s personal beliefs and how these affect quality of life.”
13. *Thinking, Learning, Memory, and Concentration*: “a person’s view of his/her thinking, learning, memory, concentration and ability to make decisions.”

Domain III: Social Relationships

14. *Personal Relationships*: “the extent to which people feel the companionship, love and support they desire from the intimate relationship(s) in their life.”
15. *Social Support*: “how much a person feels the commitment, approval, and availability of practical assistance from family and friends.”
16. *Sexual Activity*: “a person’s urge and desire for sex, and the extent to which the person is able to express and enjoy his/her sexual desire appropriately.”

Domain IV: Environment

17. *Financial Resources*: “the person’s view of how his/her financial resources (and other exchangeable resources) and the extent to which these resources meet the needs for a healthy and comfortable life style.”
18. *Freedom, Physical Safety, and Security*: “the person’s sense of safety and security from physical harm.”
19. *Health and Social Care: Availability and Quality*: “the person’s view of the health and social care in the near vicinity.”
20. *Home Environment*: the “principal place where a person lives, and the way that this impacts on the person’s life. The quality of the home would be assessed on the basis of being comfortable, as well as affording the person a safe place to reside.”
21. *Opportunities for Acquiring New Information and Skills*: “a person’s opportunity and desire to learn new skills, acquire new knowledge, and feel in touch with what is going on.”
22. *Participation in and Opportunities for Recreation/Leisure Activities*: “a person’s ability, opportunities and inclination to participate in leisure, pastimes and relaxation.”
23. *Physical Environment (Pollution/Noise/Traffic/Climate)*: “the person’s view of his/her environment. This includes the noise, pollution, climate and general aesthetic of the environment and whether this serves to improve or adversely affect quality of life.”

24. *Transport*: “the person’s view of how available or easy it is to find and use transport services to get around.” [23]

The WHOQOL instrument provides a way to categorize behaviors and QoL aspects. As defined earlier, the WHOQOL instrument presented here serves as the organizational method for this book.

Learning from the ‘Quantified-Self’ Community

In this section, we present and discuss a subset of currently available technologies for the assessment of behaviors, health state, and—as a result—QoL. The “quantified self” is a term coined in 2007 by Gary Wolf and Kevin Kelly to accommodate actions such as lifelogging and self-tracking, in which motivated individuals use various analogues (e.g., paper and pencil) or digital, technology-enabled tools (e.g., Excel spreadsheets) and devices (e.g., wearables) for tracking certain aspects of their lives—be they in relation to physical health, mental health, social relationships, or even the environment surrounding them. This section presents a nonexhaustive view on the community, surveying individuals who actively participate in the quantified-self movement, as well as what they self-track and how they do it. Specifically, this chapter presents a qualitative study that examined the quantified-self community based on a curated set of self-tracked projects presented in video talks from quantified-self conferences and meetings (organized in the form of meet-ups) between 2015 and 2019. In total, 71 quantified-self projects were analyzed with the purpose of finding out who self-tracks, what they track, and how they track it. A variety of variables are categorized and analyzed, including the self-tracker’s sex, domains of tracking (coded along the WHOQOL instrument dimensions and subdomains), and devices and tools used, among others. We then extrapolate upon the applicability of the tools, approaches, and lessons learned toward the larger public, for which we aim to quantify QoL.

This section is structured as follows: we first define the quantified-self movement and quantified-self community, then describe our research methods and results, and then analyze the outcomes, implications, and limitations. We end with a conclusive remarks section that summarizes the lessons learned within the section and links them to the chapter as a whole.

The Quantified-Self Movement

The quantified-self is a way of logging and measuring a variety of data about an individual and/or his/her surroundings, such as steps, calories eaten, or miles biked [24]. The quantified-self in its simplest form is a way of logging a variety of data for different reasons, be it for self-improvement, curiosity, or health benefits related to

a specific tracking category. It is a practice that has developed a particularly rich design space with the introduction of personal digital technologies enabling self-tracking, such as smartphones, smartwatches, and intelligent wristbands that, among other devices, are now a part of many individuals' lives. Yet, the actual practice, emergence, and use of self-tracking as a method have been discussed for millennia [24]. While most individuals may or may not be aware of technology such as step counters in smartphones, the population of quantified-selfers purposely tracks an array of different variables of their lives, both quantitatively and qualitatively, with various goals, thus contributing to an enhanced understanding of their own behaviors, state, and potentially their own QoL.

The Quantified-Self Community

The quantified-self community arranges conferences and meet-ups where quantified-selfers have the opportunity to present their individual projects. Their motto is “*self-knowledge through numbers*.” [25] This community provides a platform for individuals—in principle anyone—to present *what they did, how they did it, and what they learned*, from which other individuals can both learn and be inspired to shape their own projects [26]. Throughout the year, location-based group meet-ups are conducted within the quantified-self community. Furthermore, yearly (or bi-yearly) conferences are held in which individuals from all over the world participate [25]. The talks at the conferences are recorded, and the best of which (as selected by the community founders) are curated and published on the community website. These video recordings are the primary self-project materials leveraged for the analysis in this section.

Methods

This section provides insights into the methodological considerations of this study as well as a justification of methodological choices, as there will arguably be different ways to interpret and work with the self-tracking project material gathered by the quantified-self community in both current and future research.

The research in this section largely follows a qualitative research methodology that incorporates the basic principles of hermeneutics [27], which ensures that both the data and their interpretation are conducted cautiously. For this section, it is crucial to examine these results with a pre-understanding of self-tracking projects being both *inductive* and *deductive* in nature, and to acknowledge a potential confirmation bias in the self-tracking projects. As with most qualitative research, given this approach, it is difficult to generalize the results for the specified population, but the goal is not to develop a standing thesis about the quantified-self community;

rather, the goal is to identify current self-tracking trends and patterns within the sample [28].

The self-tracking projects analyzed in this section are in the form of video recordings of a talk related to the project, as presented by its author at a quantified-self conference. The employed video sampling method was *purposive sampling*. This represents several approaches within purposive sampling in qualitative research methods [28]. The video inclusion criteria included the following: the video material had to revolve around a quantified-self project and had to be selected by the community leaders to be uploaded to the quantified-self website, thus narrowing the analyzed examples to those presented within the curated content. Therefore, some of the examined cases are arguably extreme deviant cases, rather than typical self-tracking project cases.

This research was approached as a bottom-up gathering of data, from which 72 video presentations from quantified-self conferences (2015–2019) were examined and analyzed based on pre-existing themes and categorizations, as well as on themes growing from the material while trawling video presentations. Without adding search filters, the website was trawled from the top (the newest) to bottom, within the timeframe for the study (14 weeks in total). The website was updated twice (week 10 and week 14 of 2019) during the project, which means the order of the videos examined was disrupted at least these twice, and new video presentations were added during the study period. One video was deemed to be outside the scope of the project due to it having a vastly different goal to the others (i.e., educational), in which a use case of ‘quantified-self’ as an educational material was presented. This video was removed from the data set, thus making the actual data set consist of 71 videos. An overview of the 71 analyzed self-tracking projects (authors, titles, and years of publication) can be found in Appendix 1.

While it may be difficult to fully transform the words and personal experiences of self-trackers into quantitative evidence, we aimed to present here the qualitative approach that we employed; categorization and thematic analysis provided the opportunity to count self-tracking projects and partly quantify some of the material presented within each project [28]. The thematic analysis is based on examining project descriptions and identifying two kinds of codes to describe the projects: *descriptive* and *interpretive* codes [29]. The interpretive codes were defined beforehand (along the WHOQOL subdomains), and the descriptive codes were identified afterwards and noted within the dataset, as presented later in this section. The codes were agreed upon by two independent coders.

Results

First, the overall findings are presented per a WHOQOL variable (Sect. 3.4.1), and afterwards a deeper examination is presented of what is tracked and how it is done, starting at a macro level and then proceeding into a micro level analysis of different variables included in each of the projects (Sect. 3.4.2).

One-Dimensional Presentation of Data and Findings

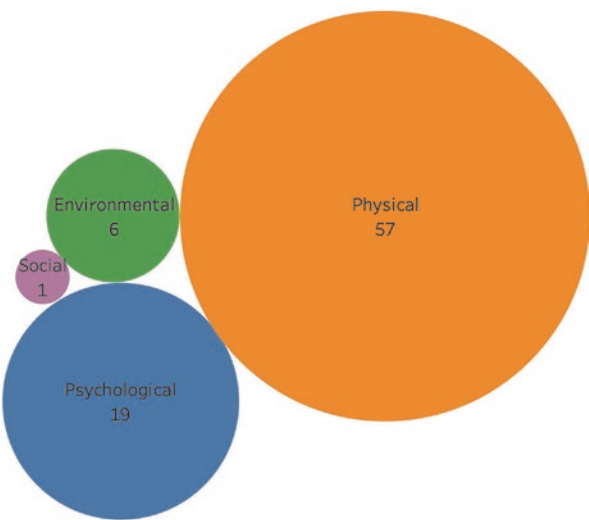
Sex Self-tracker sample comprised $n = 26$ females (36%) and $n = 45$ males (64%).

QoL Domains Figure 1.2 presents the coded self-tracking project along the WHOQOL-BREF domains. Each project was assigned one main QoL domain, even if, as presented below, some projects in fact analyzed two or more different subdomains. As seen in Fig. 1.2, the largest domain that was tracked is the physical domain, embracing variables such as “exercise” and “sleep,” as detailed later. The distribution of the tracked QoL domains is as follows: physical ($n = 41$), psychological ($n = 26$), social ($n = 1$), and environmental ($n = 3$).

QoL Subdomains Figure 1.3 presents the domain distribution with the subdomains. It is important to keep in mind that several projects are marked with more than one code, due to the projects sometime being cross-field examinations of parts of the self-tracker’s life, or even holding variables from different domains against each-other, such as “location tracking” as a facilitation of “memory tracking of daily life activities,” which in WHOQOL codes corresponds to “env-enviro” (location) being tracked to keep track of “phy-adl” (activities) (appendix 2) [30]. A total of 84 codes were applied across 71 videos and are presented in Fig. 1.3 below.

Quantitative Vs. Qualitative Project Each project was assigned to one category (quantitative or qualitative) depending on its main goal. While the community is named after the term ‘quantified self’, qualitative studies are also present in the sample. Studies that have been defined as quantitative rely on datasets derived from smartphone apps (e.g., location) or wearables (e.g., steps). Studies that were defined

Fig. 1.2 Distribution of the WHOQOL Domains Tracked (N)



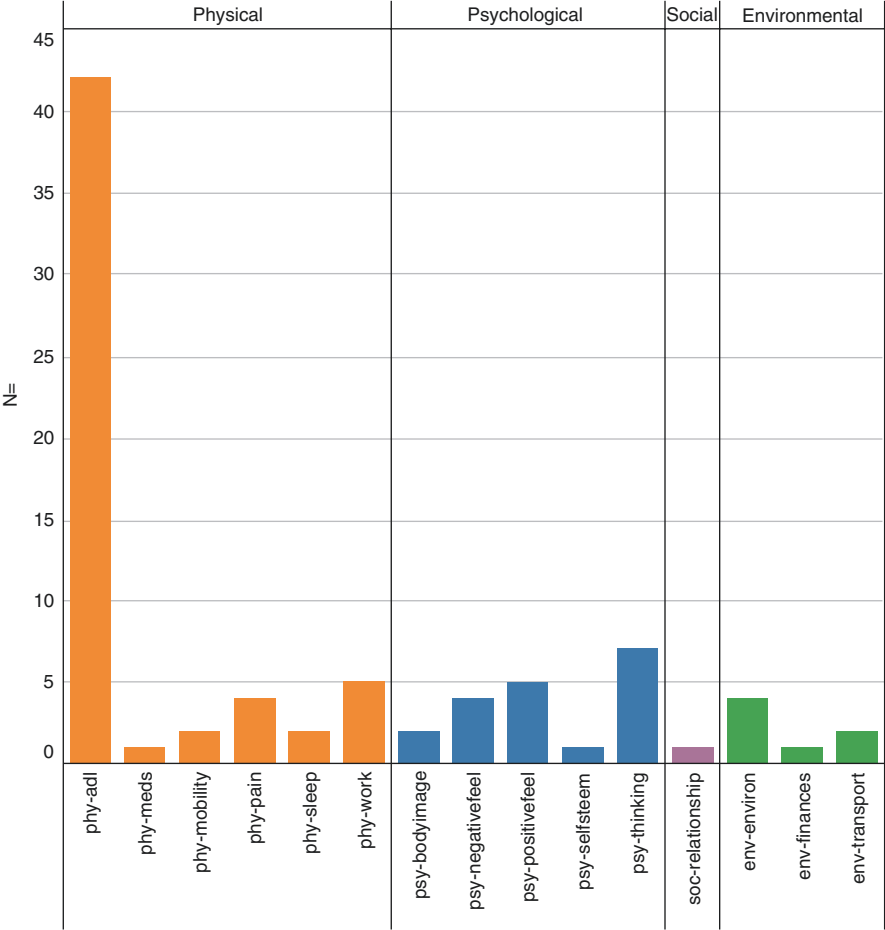


Fig. 1.3 Distribution of the WHOQOL Subdomains Tracked

as qualitative relied on journals/diaries or other kinds of self-reporting tools to describe feelings/emotions or other internal, difficult-to-observe states of individuals. Overall, within the sample projects, quantitative projects ($n = 59$) were more popular than qualitative projects ($n = 12$).

Manual Vs. Automatic Tracking Each self-tracking project has an element of tracking quantitative and/or qualitative data, and this tracking can be realized through manual (e.g., paper and pencil) or automatic means (e.g., smartphone phone loggers). Each project was assigned to one category (manual or automatic) depending on its main goal. The results reveal that the majority of projects include automatic logging ($n = 42$), whereas the projects with manual logging (via e.g., a spreadsheet) are less represented ($n = 29$).

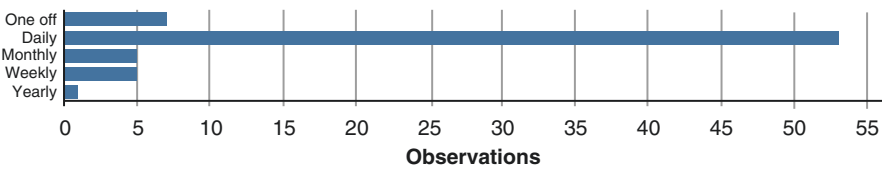


Fig. 1.4 Projects’ Self-Tracking Frequency

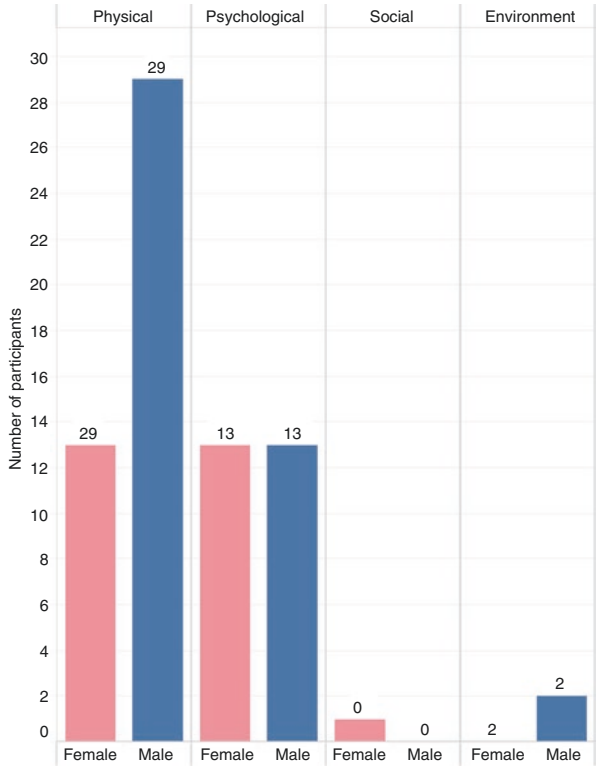
Tracking Frequency Each self-tracking project has an element of tracking of some data at a specific frequency (from ‘one-off’, i.e., one observation, not repeated, to repeated ‘daily’ to less frequent), and it was assigned to a category depending on its main goal. Figure 1.4 presents the tracking frequency, whether it is daily (n = 53), weekly (n = 5), monthly (n = 5), yearly (n = 1) or one-off (n = 7). The daily group is the largest group, followed by one-off projects, weekly, monthly, and finally ‘yearly’ tracking.

Self-Tracking Project Duration It was difficult to analyze project duration because many projects contained no clear indication of their length and were thus coded as ‘N/A’ (n = 54). This is due to a variety of reasons, but most commonly it seemed that some projects did not focus on events in a given time duration, but rather on a number of certain events to be tracked in some (unspecified) observational period, selected as convenient, or even defined only post-experimentally by the individual. However, it can be noted that the most common durations range from 1 month (n = 3), 1 year (n = 7), and 3 years (n = 4) to 10 years (n = 3).

Observational Vs. Interventional Projects With regard to whether the project was an observation of an individual state or behavior, or explicit intervention (implying an implicit intention of change of an individual state or behavior), it was found that observations were the most common aim of individual self-tracking (n = 47). Interventions were documented within 22 projects. The last two projects led from observation to intervention on the state or behavior observed at first.

Self-Tracking Tools Used A total of 71 unique commercial and noncommercial devices and digital tools were identified through the course of this study. For the sake of simplicity, both actual devices such as wearables and smartphones (and their apps) were defined as a “self-tracking tool.” Additionally, these seem to have increasing importance in the quantified-self community as well as in everyday life [24, 31]. Furthermore, several projects relied on data provided from companies such as 23andme and uBiome, which were also defined as a *tool* for self-tracking in this project. Several projects used multiple tools to gather their desired data. Figure 1.5 illustrates the distribution of the various tools across all 71 projects in a diagram, where the tools written in larger fonts correspond to the more common tools and those in smaller ones correspond to less common tools. The color coding is arbitrary.

Fig. 1.6 QoL Main Domain Vs. Self-Trackers' Sex



self-tracking project and categorized under the four main WHOQOL domains. There were relatively few repeated variables, but “productivity” (n = 5) was the most observed variable for female trackers, whereas “sleep” (n = 4) was the most observed variable for male trackers. Furthermore, “menstrual cycle” (n = 3) was the second most tracked independent variable for female trackers, whereas “daily activities” (n = 3), “running” (n = 3), and “stress” (n = 3) shared this position for male trackers. The rest of the variables were unique for one or two projects (n = 40 projects).

Discussion

While the results are not generalizable, they do prove one point: the field and interest of the quantified-self projects and inputs to the community are highly diverse and represent a broad spectrum of self-tracking projects.

The distribution of self-trackers’ sex is interesting to reflect upon. It suggests that female self-trackers would perhaps be more inclined to conduct a self-tracking study with an emphasis on psychological means of life, whereas male trackers seem

psychological health domain and more specifically the “thinking, learning, memory, and concentration” variable, which has high interest and includes self-tracking of, for example, mindfulness and willpower. Again, to date, these are almost impossible to track autonomously and pervasively in the daily life of individuals. Our results indicate that the projects are not necessarily dictated by which self-tracking tools exist, but rather by curiosity and personal interest in self-tracking.

The results acquired here also provide an interesting perspective on the quantified-self as a trend itself, since on the one hand we are living in an age where we are “datafying” ourselves at an increasing rate, while on the other hand data protection and privacy questions are arising with the digitalization of everyday means [24]. These questions will become even more urgent to tackle with the emergence of tools tracking psychological health [34, 35].

In addition, the acquired results bring into question the ultimate goal of self-tracking. The idea of the quantified-self stems from the idea of converting aspects of life into numbers and statistics, rather than (qualitative) writing in a daily journal to keep up with life. This can be described as the aspect of self-betterment, in which individuals seek to better understand themselves through numbers and analyses of everyday actions [24]. With roughly two out of three projects being observational in nature, this does not mean that the individuals involved do not seek behavior change, but it may be a distant goal rather than an immediate need. The immediate need focuses on understanding factors influencing one’s own behavior and state. Few cases have provided evidence that the results of an observation could be transformed into an intervention, specifically when the results have been too crucial to ignore for the individual self-tracker. One such case was a male individual who felt upset with drivers looking at their personal devices while driving. He decided to investigate his own behavior while driving and set up a quantified-self project to help him reach his goal of spending even less time looking at his phone while driving. He hypothesized that the results would indicate that he was much better than other drivers; however, that was not the case, as he realized he spent up to 25% of his time while driving on his phone (up to around 25 minutes per a day along a 100-minute commute). This observation called for an immediate intervention, and this self-tracker ultimately bought a bike for smaller trips—which also implied he was getting some physical activity while commuting (and not using his phone) [36]. This is just one example of a self-tracking project—including meticulous observation and self-reflection—turning into an intervention.

Limitations

An array of limitations arose in this study, which stemmed from the methodological approach as well as the approach to data analysis. This section presents some of these limitations.

At first, the coding and categories examined in the study were predefined, partially based on the WHOQOL and only loosely based on existing literature. The

other categorizations (the study duration and tools used) were agreed upon between two independent coders (having 90% agreement) as to what could prove to be interesting for the domain of QoLT, rather than what was found interesting in previous studies informing the QoL domain. This led to several categories yielding insufficient results or not covering relevant aspects of the research. Two examples are additional coding dimensions discussed along the “work/leisure” category (i.e., the professional or personal domain aim of the project) and the “chronic illness” category (i.e., if the self-tracker was a patient). It was proposed that, when identifying relevant categories, projects related to either work or leisure could yield interesting results; instead, it was almost impossible to define whether a project was solely based on or related to individuals’ work or leisure activities, and most categorizations ended up being a mixture of the two, which were then omitted. The self-trackers approached their self-tracking projects—as well as their own lives—holistically, and the projects encompassed these two domains. It was also proposed that chronic illness of the self-tracker, if applicable to his or her condition, could prove interesting to examine, especially if it was explicitly stated to be a major part (and potentially part of the aim) of the project. It turned out that just five out of 71 projects were based on chronic conditions, thus making it difficult to examine this dimension thoroughly.

We only analyzed a small percentage of the whole set of self-tracked projects (using the video database of quantified-self talks) that could have been examined. Our material only provides a narrow view of the overall population and its recent projects and cannot be generalized. Overall, the nature of qualitative studies makes it difficult to replicate their results, as the qualitative understanding and perception of material may differ in the “eyes of the analyzer.” [28]

This research does not derive or even suggest correlations between multiple variables, which could have proved to be an interesting aim on its own and should be considered in future work in the field, especially when larger datasets are acquired. Another limitation with regards to multivariate analysis is a lack of acquisition of basic information about the individuals studied. The only personal information collected is sex, which does not distinguish level of education, age, country of origin, cultural background, attitudes, or motivations for specific self-tracked variable(s), nor does it distinguish the level of digital literacy, which may be of importance when discussing the tools employed and use of data. These variables would have been paramount to include in an actual multivariate analysis, but it has not been possible to include them due to the structure of the datasets (i.e., the data were derived from videos).

Concluding Remarks on Self-Tracking and Quality of Life

While it is still too early to conclude anything that could be generalized to the population of the quantified-self community, which could then be applied to quantifying QoL, several valuable observations should be noted. Male

individuals were still dominant in the sample of self-trackers, which was also presupposed [24]. The projects have mostly focused on the physical domain of QoL, whereas the social domain has been focused on the least. Tools enabling automatic tracking of variables have been more commonly used as a method for collecting data within the projects. At a more specific level, physical health—“activities of daily life” is the most tracked subdomain across all QoL domains, with the next most common being psychological health—“thinking, learning, memory, and concentration.” Overall, individuals track many different categories of their lives and only a few variables are more dominant than others, namely “sleep,” “stress,” and “running” are the dominant variables for males, whereas “productivity” and “menstrual cycle” are for females. In total, 47 projects were observational, and thus had no inherent goal of changing the behavior of the individual, and 22 projects were designed to be behavioral interventions from the beginning. Two observational projects led to interventions. These behavioral interventions were self-designed and self-tracked and led to sustainable behavior change in most cases.

What we are able to derive from self-trackers is that their attitude, motivation, and overall curiosity-driven and personalized approach are likely to lead to effective change and improvement in the understanding of factors influencing the behavior or state, or to sustainable change in this behavior.

Future Outlook: Importance of Improving Quality of Life Quantification

Quality of life is a critical outcome in daily life and in medicine. Long-term QoL stems from behaviors and states that are repeated frequently; therefore, long-term QoL may be extrapolated through the quantification of these (short-term) behaviors/states. The quantified-self community’s efforts illustrate that we can leverage various existing and emerging tools to observe and understand our own behaviors and states, and improve them through self-management as well as meticulously designed, highly personalized interventions. An integral part of future research on QoL technologies and their use in medicine is an interdisciplinary effort for achieving a user-centric and holistic approach, including physical, psychological, social, and environmental viewpoints. An interdisciplinary approach is required because assessment and management of behavior in medicine cannot be readily completed using solely one of the dimensions (e.g., physical) or by one systematic methodological approach (e.g., qualitative or quantitative). Holistic individual assessment and improvement research will bring new approaches to theory, design, methods, measurement, and data analysis specific to each dimension, thus deepening it while enabling breadth. Because of the technological and methodological advances required, such research is a long-term process rather than a short-term self-contained activity.

The QoLT field is in its nascent stage. This book presents an overview of the state-of-the-art methods and tools for quantifying daily life, health, and QoL state through QoLT across all the QoL domains and subdomains. An enhanced understanding of technology-enabled or -supported continuous assessment methods of behaviors and states will allow for an improved understanding and modeling of the short- as well as long-term health and QoL of individuals.

Appendices

Appendix 1

Quantified-Self Talks (Author Name: Title, Year)	Year
Steven Jonas: <i>Stressing out loud</i>	2013
Kendra Albert: <i>The great book project of 2013</i>	2014
Valerie Lanard: <i>Breaking the TV habit</i>	2015
Jim McCarter: <i>Effects of a year in ketosis</i>	2015
Ilyse Magy: <i>Know thy cycle, know thy self</i>	2016
Ellis Bartholomeus: <i>Draw a face a day</i>	2016
Robert Macdonell: <i>The data is in, I am a distracted driver</i>	2016
Ahnjili Zhuparris: <i>Menstrual cycles, 50 cents and right swipes</i>	2016
Randy Sargent: <i>Unlocking patterns with spectrograms</i>	2016
Richard sprague: <i>Microbiome gut cleanse</i>	2016
Peter Torelli: <i>Narratives hidden in 20 years of personal financial data</i>	2016
Abe gong: <i>Changing sleep habits with unforgettable reminders</i>	2016
Mark Leavitt: <i>Daily HRV as a measure of health and willpower</i>	2016
Akhsar Kharebov: <i>A smart scale for healthy weight loss</i>	2016
Shelly Jang: <i>Can you see that I was falling in love?</i>	2016
Steven cartwright: <i>17 years of location tracking</i>	2016
Paul Lafontaine: <i>Using heart rate variability to analyze stress in conversation</i>	2016
Jon cousins: <i>Why I weighed my whiskers</i>	2016
Mark Wilson: <i>Three years of logging my inbox</i>	2016
Bethany Soule: <i>Extreme productivity</i>	2016
Jacek Smolicki: <i>Self-tracking as an artistic practice</i>	2016
Robby Macdonell: <i>The data is in, I am a distracted driver</i>	2016
Randy Sargent: <i>Unlocking patterns with spectrograms</i>	2016
Thomas Christiansen: <i>Over-instrumented running: What I learned from doing too much</i>	2017
Ahnjili ZhuParris: <i>Finding my psychedelic sweet spot using R</i>	2017
Stephen cartwright: <i>Seeing my data in 3d</i>	2017

Quantified-Self Talks (Author Name: Title, Year)	Year
Whitney Erin Boesel: <i>My numbers sucked but I made this baby anyway</i>	2017
Kyril Potapov: <i>Tracking productivity for personal growth</i>	2017
Lillian Karabaic: <i>What if my life was the economy of A small country?</i>	2017
Sara Riggare: <i>Balancing neurotransmitters in neurological illness</i>	2017
Ellis Bartholomeus: <i>My health scars</i>	2017
Robin Weis: <i>Crying</i>	2017
Azure Grant: <i>Hot stuff: Body temperature and ovulatory cycles</i>	2017
Justin Lawler: <i>Taking on my osteoporosis</i>	2017
Azure Grant: <i>My biological rhythms in sickness and in health</i>	2018
Thomas Blomseth Christiansen: <i>Which grasses aggravate my allergies?</i>	2018
Mikey Sklar: <i>Three marathons on zero calories</i>	2018
Justin Lawler: <i>Tracking glucose as A person without diabetes</i>	2018
Madison Lukaczky: <i>How work distractions affect my focus</i>	2018
Whitney Erin Boesel: <i>Cholesterol levels while nursing</i>	2018
Benjamin best: <i>My blood values from diet and other activities</i>	2018
Albara Alohal: <i>Running storytelling</i>	2018
Lydia Lutsyshyna: <i>Separating work and home</i>	2018
Benjamin Smarr: <i>Does my stomach anticipate my meals?</i>	2018
Shamay Agaron: <i>Tracking breathing to control my focus</i>	2018
Maggie Delano: <i>Quantifying my Phd: Pomodoros and productivity</i>	2018
Jessica Ching: <i>Learning an impossible form of exercise</i>	2018
Kyrill Potapov: <i>What Insidetracker taught me about my five-day fast</i>	2018
Daniel reeves: <i>Tracking my personal reliability</i>	2018
Fah Sathirapongsasuti: <i>Blood oxygen on Mt. Everest</i>	2018
Mad ball: <i>A self-study of my Child's genetic risk</i>	2018
Aaron Parecki: <i>Ten years of tracking my location</i>	2018
Aaron Yih: <i>Tracking across generations</i>	2018
Alec Rogers: <i>What I'm learning from my meditation app</i>	2018
Jordan Clark: <i>Quantifying the effects of microaggressions</i>	2018
Jakob Eg Larsen: <i>My headaches from tracking headaches</i>	2018
Todd Greco: <i>Building my external brain</i>	2018
Lillian Karabaic: <i>#100daysofqs: Daily art from data</i>	2018
Ralph Pethica: <i>Finding the optimal training zone</i>	2018
Anna Franziska Michel: <i>Using running and cycling data to inform my fashion</i>	2018
Eli Ricker: <i>Tracking what I do versus what I say I'll do</i>	2018
Shara Raqs: <i>Estrogen and invention</i>	2018
Stephen Maher: <i>A decade of tracking headaches</i>	2018
Valerie Lanard: <i>Learning from excuses</i>	2018
Eric Jain: <i>Four weeks of blood sugar tracking</i>	2019

Quantified-Self Talks (Author Name: Title, Year)	Year
Kyrill Potapov: <i>Finding my optimum Reading speed</i>	N/A
Rocio Chongtay: <i>Quantified brain and music for self-tuning</i>	N/A
Mark Drangsholt: <i>What causes my heart rhythm disorder</i>	N/A
Steven Jonas: <i>Memorizing my daybook</i>	N/A
Steven Jonas: <i>Spaced listening</i>	N/A
Ari Meisel: <i>Experiments in treating my Crohn's disease</i>	N/A

Appendix 2

WHOQOL Codes used for categorizing projects from the quantified-self community, following past work of Wac [37].

QoL Domain	Subdomains
‘Phy’: Physical health	Phy-adl, phy-meds, phy-energy, phy-mobility, phy-pain, phy-sleep, phy-work
‘Psy’: Psychological health	Psy-bodyimage, psy-negativefeel, psy-positivefeel, psy-selfesteem, psy-beliefs, psy-thinking
‘Soc’: Social relations	Soc-relationships, soc-support, soc-sex
‘Env’: Environment	Env-finances, env-freedom, env-healthcare, env-home, env-info, env-leisure, env-environ, env-transport

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