SUBJECTIVE EXPERIENCED HEALTH AS A DRIVER OF HEALTH CARE BEHAVIOR

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Abstract
This paper describes the key role of the subjective experience of health as the driver of health related behavior. Individuals vary greatly in terms of behaviors related to health. Insights into these inter-individual differences are of great importance for all parties involved in health care, including patients and consumers themselves. Such insights allow for better tuning of health care offerings to patient and consumer needs. Subjective experienced health is identified as the key driver of health care behavior. Consequently, insights into the subjective health experience and its antecedents are essential to describe, explain, predict, and control health-related behaviors. Implications of these insights are discussed for a number of topical issues in health care: services-diversification, therapy non-adherence, patient self-management, and outcome measurement.

Keywords
Subjective experienced health; health related behavior; patient typology; health care services; therapy non-adherence; patient self-management; outcome measures

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§1 Theoretical basis

§1.1 Introduction
There are substantial differences between individuals in terms of the ways in which they behave in relation to their health. Where some people have low thresholds for seeking care, other people are principally inclined to try and solve their own problems, and only seek care if they are unsuccessful in managing their health. Individuals also show huge variation in the ways they adhere to therapy and the use of prescribed medicines, with some individuals following all therapeutical agreements, and others ignoring (at least partly) what was agreed upon. People also differ in the extent to which they actively use information to get insights into their own health condition. Where some individuals go to great lengths in collecting information in order to be fully informed, others show more evasive behavior and passively await the opinions and judgments of health care professionals. It is evident that insights into these interindividual differences in health related behavior are of great importance, not only for health care professionals and institutions, but also for policy makers, health care insurance companies, scientists, and – of course – for patients and their friends and relatives.

To understand individual differences in health related behavior, insights are needed into the mechanism that drives health related behavior. In line with basic psychological insights, the subjective experience of health can be identified as the driver of health related behavior. In this article, we explore subjectively experienced health and its relation to behavior, specifically in the domain of health. On the basis of a newly conceived model, we also discuss how insights into the subjective experience of health and its antecedents can help to describe, explain, predict, and (ultimately) control behaviors in the domain of health care. We illustrate how such insights can help to get a better understanding of important issues in health care. We will discuss the need for diversification of services to be offered to health care consumers or patients, issues around therapy non-adherence, patient self-management, and finally the integration of individual experience in outcome measures in addition to biomedical and costs-parameters.

1 In this article we will alternately use the terms ‘patients’ and ‘health care consumers’ to refer to individuals who are confronted with choices related to health
§1.2 Health related behavior

Before exploring the concept of subjective experienced health in detail, we must specify the domain within which we will explore health related behavior. Our perspective of the domain of health care behavior is based on an earlier framework describing medical care that has been developed by Pepermans, Groenland, Bloem & Stalpers (2001). Our perspective differs from the aforementioned framework. It is different in the sense that our focus is broader and not only encompasses health care as provided by medical professionals. From our perspective, health related behavior includes all behaviors undertaken by an individual in relation to his health. So, in addition to the seeking of professional (medical) care, health related behavior may also include self-care, the seeking of alternative care, etc. (see Figure 1).

The framework describes, on a generic and high level of abstraction, the processes involved of individuals seeking (medical) care. It describes individual choice behavior processes in the course of time. The focal point of the framework is the individual in his role as a health care consumer. It must be noted that the framework is non-normative; the individual choice processes are based on subjective evaluations of health by individuals.
The starting point of the process is the actual subjective experience of health, i.e., the experience by the individual of the quality of his health state. The framework describes the behaviors individuals engage in with the intention to maintain, improve, or optimize the level of experienced health.

Under the assumption that the actual state is always less preferable than the desired state, the framework postulates that an individual's experience of a gap between actual and desired state leads the individual to engage in behavior aimed at reducing that gap. These behaviors may be of multiple kinds; we will label these behaviors as 'seeking (medical) expertise'. Seeking expertise may range from visiting a medical professional, consulting a psychologist, a sports coach, seeking information from impersonal sources (e.g., the internet), to seeing a homeopathic physician. The seeking of expertise may be related to one source, but may also involve multiple sources. Care for diabetes, for example, may encompass the GP, diabetes nurse, dietician, ophthalmologist, vascular specialist, etc.

Seeking expertise may result in a (self)-diagnosis. This diagnosis may, in turn, lead to the use of (non)-medical remedies (prescribed or advised by a professional, non-professional, on own initiative, etc.), to behavioral initiatives (programs to lose weight, to stop smoking, meditation programs, etc.).

Diagnoses, remedies, and behavioral initiatives are all aimed at reducing the gap that was experienced between actual and desired state. When the individual is satisfied with his experienced health condition, the process of seeking care comes to a halt, to start again when a new gap is experienced. The existence of a gap between actual and desired state motivates the individual to reduce the gap. This line of thought is based on the idea of homeostasis. If the individual experiences arousal or discomfort, the individual will be motivated to reduce this state of arousal or discomfort to return to a state of equilibrium or homeostasis (Ryan, 2012).

The process described in the framework is circular. That is, an individual may move through this process repeatedly, using single or multiple sources of expertise in order to diminish the experienced gap.
We have described the process of seeking care, and signaled that individual experience is a key driver of the individual's health-related behavior. This relationship between experience and behavior will be further explored in the following paragraphs.

§1.3 The individual world of experience and its relation to behavior

An individual's world of experience can be thought of as the resultant of an individual's reflection on his inner world and outer world (Bloem, 2008). We refer to this world of experience as subjective experience. The inner world consists of an individual's views about himself as a being, as a human entity. The outer world encompasses the individual's views about himself in relation to his perceived environment and social others. An individual's world of experience can therefore be thought of as an idiosyncratic collection of representations of reality of which the individual is aware. A representation, in this sense, can thus be conceived of as an idiosyncratic image of - an aspect of - reality, as perceived by the individual.

Representations can be shaped by various factors. On the one hand, conscious processes based on elaboration and learning may add to the construction of representations; on the other hand, representations may be affected by unconscious factors such as modeling, instincts, fears, etc.

The set of representations in an individual's world of experience is crucial for the individual's existence in the sense that it serves as a blueprint of reality. It allows the individual to express himself, while others may get access to the individual's world of experience by getting to know and understand these representations. In this process of reciprocal cognizance two aspects are important, a communicative and an interpretative aspect. The communicative aspect refers to the willingness and the capacity of the individual to express a representation’s content. An individual may be hesitant or unwilling to share a representation with others. Otherwise, it may just not be possible for an individual to express the content of a representation to others in its idiosyncratic fullness. The interpretative aspect is important in the sense that reciprocal cognizance requires that others can understand the content of the representations that are expressed by the individual.

Given the above, it is evident that there is no objective reality that serves as a structuring force for an individual's behavior. Rather, it is reality as captured in his individual representations that is the foundation on which behaviors are based. In other words, it is the individual experience as laid down in the representations of reality that drives behavior (Figure 2).
1.4 The subjective experience of health

In the preceding paragraph, we have discussed the nature of experience and its relation to behavior. We will now direct our focus to the domain of health and health care. As follows from our line of reasoning, health, as experienced, parts from an individual idiosyncratic perspective. This implies that the experience of health may differ substantially between individuals, with obvious consequences for health related behavior; individuals with identical biomedical diagnoses may vary substantially in terms of health experience and consequently in health related behavior.

Based on research, a set of key characteristics can be distinguished that conceptualize experienced health. To start with, the experience of health is holistic in nature. Multiple representations may be involved in experiencing health, but the whole is experienced more directly than the composing parts. In a strict sense, the experience of health is not undivided in itself; the wholeness is a construction by the individual.

A second key characteristic of the concept of experienced health is its relation with individual functioning. Functioning must be understood as physical functioning, as well as mental functioning, to be further specified into cognitive and affective functioning. The experience of health is not a specific end-state of complete wellbeing, but the health experience is related to the quality of functioning itself. Functioning must be seen in relation to the innate striving of the human being for maintenance, improvement, or actualization of the self; functioning helps to fulfill this ambition.

A related third characteristic of experienced health is the notion of freedom. Freedom implies not only that the individual perceives that possibilities exist to realize his strivings. It also means that the

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3 An extensive overview of approaches and conceptualizations of health is presented in Bloem (2008).

4 As stated, the concept of experienced health is holistic in nature. This does not preclude that - on an analytical level - separate elements related to modalities of functioning can be detected that together constitute the concept of experienced health. Bloem distinguishes six constituting elements (Bloem, 2008).
individual experiences no constraints on functioning while trying to realize his strivings in terms of maintenance, improvement, or actualization of the self. It must be noted that there may be idiosyncratic limitations on the possibilities that are available to the individuals. These limitations may be related to hereditary factors, age, nature of a disease, handicap etc.

The final key characteristic is the variable nature of the concept of experienced health. The concept can change due to different factors over time. One reason for change may be that the limitations on functioning as experienced by the individual may change. A second reason may be that the content of the concept of experienced health itself may change, due to the fact that new and other representations enter the experience of health. Finally, the relative contribution of the representations that make up the concept of experienced health may change.

Based on this conceptualization, the subjective experience of health can be defined as follows.

The subjective experience of health is an individual's experience of physical and mental functioning while living his life the way he wants to, within the actual constraints and limitations of individual existence.

We have conceptualized and defined the concept of subjective experienced health. For theoretical and practical use, it is highly relevant to get insights into the determinants of the concept. Such insights may help to understand why individuals experience health the way they do, and may provide insights into ways of influencing the subjective experience of health.

§1.5 Subjective experienced health and its psychological determinants

There is a relation between the subjective experience of health and the biological-physiological state of the organism. However, evidence abounds that other factors also may affect this subjective experience (Vingilis et al., 2000). Individuals identical in terms of biological-physiological parameters may differ in terms of experienced health, and vice-versa. These findings suggest that other factors, in addition to and besides biological-physiological factors, may have an effect on the subjective health experience. In a series of studies, several key psychological determinants of subjective health have been identified (Stalpers, 2009). Based on this research, Stalpers has developed a population model that describes the pattern of relationships between the subjective health experience and its main psychological determinants.
The model identifies two variants of experienced health, depending on the respective time frame: short-term experienced health (time frame: past week) and long-term experienced health (time frame: past year). The short-term experience of health is more volatile and reflects current variations in experience whereas the long-term health experience, in general, has a more stable character and reflects the level of experienced health over a prolonged time period.

Three determinants can be identified that have a impact on the experience of health. These determinants are: perceived control, acceptance, and adjustment. Perceived control can be seen as the belief of the individual that his health condition, in the individual’s perception, can be influenced or controlled by himself or by others. Acceptance can be defined as the feeling by the individual that his health condition and the possible constraints on functioning resulting from it, are acceptable and fitting for him as a person. In psychological terms, it represents an individual’s experience of his health condition as an integrated and inalienable part of his self. Finally, adjustment is defined as the extent to which the individual is willing and successful in tailoring or adapting behaviorally to the constraints that he perceives are imposed on him as a consequence of his health condition. Whereas perceived control and acceptance have a relatively major impact on experienced health, the impact of adjustment is less pronounced, at least in a general population. For a further elaboration of the key determinants see Stalpers (2009).

In addition to the population model, additional models have been developed and validated for a number of specific subpopulations, such as females and males, a young population and an elderly population, a healthy as well as chronically ill population. A more detailed description of the various models can be found in Stalpers (2009).

On the basis of the two main psychological determinants of subjective health, perceived control and acceptance, it is possible to develop a patient typology. The relevance of segmenting patients is that it allows optimal targeting of actions and initiatives toward patients, i.e., to personalized care.

§1.6 Patient typology

There are multiple ways of segmenting patients. In many cases, segmentation is strongly empirically-driven and usually not based on theory. We decided to use individuals’ positions on perceived control and acceptance as a basis for patient segmentation because these two factors have been demonstrated to be the main determinants of subjective health (Stalpers, 2009). Stalpers relates to the various combinations of positions individuals may have on the two determinants as ‘mental styles’.
He relates these mental styles to coping strategies and coping styles and concludes that the chosen approach offers a theoretical basis for the exploration of coping strategies and styles instead of the empirically driven approach that is common in coping research.

Based on a combination of individuals' positions on the two determinants (i.e., different levels on perceived control or on acceptance), four mental styles have been identified\(^5\). Figure 3 illustrates these different styles. Individuals can be allocated to quadrants on the basis of a concise set of questions (Stalpers, 2009). The preliminary profiles of individuals in the different quadrants are based on secondary analyses of the data bases collected as part of PhD research by Bloem (2008), and Stalpers (2009).

- Quadrant I. Individuals with high levels of perceived control and acceptance. Individuals in this quadrant have a high level of self-reliance. The basic need to be fulfilled in this quadrant is the need for information, in order to strengthen a feeling of proudness.

- Quadrant II. Individuals with high levels of acceptance in combination with low levels of perceived control. Individuals in this quadrant are seekers; they have, in principle, the willingness to change but lack the capacity and overview to realize changes. The basic need to be addressed is the need for planning and structure; this can be realized by providing practical help.

- Quadrant III. Individuals with high levels of perceived control and low levels of acceptance. For individuals in this quadrant, disease is an enemy. They waste energy and are resistant. The basic need for this group is the need for emotive support. By offering peace and comfort tension and resistance may be reduced.

- Quadrant IV. Individuals with low levels of perceived control and acceptance. Individuals in this quadrant are passive and inert, down and out, and display low aspiration levels. The basic need to be fulfilled is the need for personal guidance. This need can be addressed by leading these individuals by the hand, in order to provide hope.

As stated, the determinants perceived control and acceptance are dynamic constructs, i.e., constructs that may change over time and circumstances. This implies that individuals do not per se have fixed positions in terms of the quadrants over time.

\(^5\) The third determinant, adjustment, will initially not be used for patient segmentation purposes. Though relevant in subpopulations of severe chronic illness, over all subpopulations the two determinants perceived control and acceptance stand out as the most important influencing psychological factors of subjective health.
More research is needed to provide more comprehensive and more detailed information about consumers and patients in the different quadrants.

In the preceding paragraphs, we have made clear that the subjective health experience drives health related behavior. In addition, we have identified the key concepts, experienced health and its psychological determinants. Besides, we have built a patient typology, based on the two main psychological determinants. We will now discuss the relevance of these insights for a number of issues in health care: services offered to consumers, therapy non-adherence, patient self-management, and outcome measures. For the first three issues, the patient typology serves as a frame of reference for optimizing treatment options. In the paragraph on outcome measures the line of thought that has been developed in paragraphs 1.4 and 1.5 is extended to the domain of the assessment of therapeutic actions and interventions.
§2 Issues in health care

§2.1 Services offered in health care
In health related care, numerous programs and services have been developed as part of therapeutic offerings to patients. For many of those programs and services, it is not clear why they are offered to what groups of consumers and patients. It may be clear that for programs to be effective, it is a prerequisite that they connect to the wishes and needs of different consumer and patient groups. We decided to use the main psychological determinants of subjective health, perceived control and acceptance, as dimensions for segmentation of patient and consumer groups. The rationale is that it may be expected that different positions on these dimensions may reflect different needs and wishes of patients. This, in turn, means that different offerings should be available for these groups. The more the offerings are in line with needs and wishes of target groups, the more effective they are.

Given the different profiles of individuals in the different quadrants of the patient typology, existing services can be allocated more precisely to quadrants, and new and innovative services can be developed, based on the characteristics of the quadrants. With the current state of knowledge, it is possible to allocate programs and services to individuals on a qualitative basis. Knowledge of available services and insights provided by the typology may help the health care professional (HCP) to intuitively allocate services to specific patients. However the long-term objective is to match services and programs with the quadrants in a more elaborated way. In order to be able to do so, taxonomies of characteristics of programs and services must be developed, and related to the wishes and needs of individuals in the different quadrants.

§2.2 Therapy non-adherence
We have extended our line of thought around mental styles to the issue of non-adherence. A concise definition of non-adherence is: the refusal or failure to comply with a therapeutic regime that should be adhered to. Non-adherence is a major issue in the domain of health related care. Despite this body of research, non-adherence remains an unresolved healthcare issue (Lehane & McCarthy, 2007). Non-adherence or limited adherence has many negative consequences, such as lack of treatment efficacy, increased healthcare costs, and increased patient morbidity and mortality.

Agreement exists that the concept of adherence needs differentiation. Two types of adherence can be distinguished: intentional non-adherence and unintentional non-adherence. Intentional non-
adherence can be conceived of as the deliberate choice by the individual not to comply with the therapeutic regime that was decided upon. Unintentional non-adherence can be conceived of as unintended non-observance of the therapeutic regime resulting from patient factors (age, gender, habits), treatment factors (dosage, frequency), and patient-provider factors (interactions with HCP).

In our line of thought, non-adherence is related to an individual’s position in the constellation of acceptance and perceived control. As a consequence, non-adherence can be affected by influencing an individual’s level on these two determinants. Based on insights from various studies on non-adherence, we postulate that the two types of non-adherence can be related to the mental styles quadrants in the following way. There is a relationship between intentional non-adherence and the level of acceptance. Individuals with high levels of acceptance are individuals who have internalized the disease they are suffering from. Disease is part of their daily live, and intentional adherence to the therapeutic regime is instrumental in adequate dealing with the disease. These individuals have low levels of intentional non-adherence. Individuals with low levels of acceptance deny their disease. This being so, for these individuals there is no reason to actively comply with a therapeutic regime for a disease that is not present in their self-image (their perception of reality including the self). These individuals are high in intentional non-adherence.

There is a relationship between unintentional non-adherence and the level of perceived control. Individuals with high levels of perceived control are individuals who believe that their health condition can be influenced or controlled by actions by themselves or by others. Since actions matter, actions are worth undertaking. Individuals with low levels of perceived control do not attribute importance or effects to their behavior in relation to their disease. As a consequence, the drive to modify or adapt behavior is limited; individuals are inclined to stick to well-known and trusted habits and to routinized behavior.

As was the case with the programs and services in relation to various groups of consumers and patients, this approach may lead to a better match of supply and demand. The chosen conceptualization of non-adherence may lead to a more optimal allocation of non-adherence programs and tools to individuals with different mental styles. Here also, it is of importance that taxonomies of characteristics of non-adherence programs and services are developed, in order to realize an optimal match between program and individual.
§2.3 Patient self-management

In health care, there is a growing tendency to focus on patient self-management (Lorig, 2007). The main reasons for this increased interest are twofold. One reason is the understanding that patients benefit when they are able to take their own responsibility in relation to their health. The other, obvious, reason is that by giving more responsibility to patients themselves for their own fate, health care expenditures may be reduced (Gordon & Galloway, 2008; Lorig et al., 1999).

There is no single clear-cut definition of the concept of self-management. Definitions are either concise and broad, or are extended and specified. A broad definition of self-management is “the active participation of people in their own health care.” (Department of Health, Western Australia, 2011). We will use this broad definition as a guideline.

On a meta level, several characteristics can be distinguished (McGowan, 2005). These include the participation of individuals in education and treatment programs to encourage specific health outcomes, to educate and prepare people to monitor and manage chronic health conditions on a daily basis, to practice specific behaviors and skills, and to develop abilities to reduce the physical and emotional impacts of chronic illness. These objectives may be realized by the patient himself. However, other parties may be directly involved. These other parties not only include health care providers, but the social environment may also play a role, as well as health care insurance companies and authorities.

Actions and initiatives by other parties aimed at assisting a patient in his self-management can be referred to as self-management support. Self-management support describes the techniques and strategies that health care providers, organizations, and systems do to assist those living with chronic conditions to practice self-management (Department of Health, Western Australia, 2011).

Techniques or strategies may differ in terms of the role of the patient. Tools may be such that they can be used by the person himself at his own initiative without direct support from other parties. Examples are websites, apps, but also tools for self-diagnosis. Other tools involve the cooperation with other parties. Examples are online interventions, and e-therapy. Tools may have the function of providing signals for patients to organize and structure daily life. Examples are sound and text reminders to initiate desired behavior, such as taking medication, and initiate exercise. Finally, tools may be invasive in the sense that they infringe upon a patient’s privacy. Examples are video monitoring systems and sensor systems. In this case, the patient has a passive role. In addition to the
patient’s role, tools may also differ in terms of (technical) complexity. As far as complexity is concerned, tools may range from printed brochures to sophisticated apps, and telemonitoring programs.

For techniques and strategies to be maximally effective, it is imperative that they match with relevant consumer and patient characteristics. By analogy with what has been said in earlier paragraphs, here also the patient typology must be leading in matching techniques and strategies with patients’ relevant characteristics. Refining the attribution of techniques and strategies to patients may be further optimized when taxonomies of these interventions are available.

§2.4 Subjective experience and outcome measures
In health care, outcome measures have become more relevant over the years. Given the financial means invested in health care, it has become more and more important to assess the effects of treatment in relation to the costs. The exploration of long-term effectiveness of therapies in relation to costs is one of the central themes in health economics studies. Also, outcome measures may serve to assess the efficacy of treatment in improving the biomedical status of the individual as well as the quality of life.

In general, outcome measures have a post-hoc character and often are on an aggregate level. This makes it difficult to use the information provided by these measures, to adjust or optimize treatment programs for individual patients. In addition, not surprisingly, outcome measures have traditionally focused solely on biomedical parameters.

Many studies have demonstrated the importance of subjective patients’ experience. Insights into the subjective health experience of individuals, in addition to and complementary to insights into biomedical parameters, will contribute to better diagnoses, better treatment plans, better adherence, and higher levels of reported patients’ satisfaction (Bloem, 2008; Stalpers, 2009).

Several scales are available that are used to assess subjective patient data. Some of these scales are general in nature, while others are disease-specific. Many of these scales share the problem that they lack an adequate theoretical and conceptual basis. In addition, their primary use is in clinical research and in social-science; they are not well-equipped to serve as a basis for evaluation and fine-tuning of
individual therapy. Finally, many of the scales are too long to be used in daily practice of health care (McDowell, 2006).

We suggest that the assessment of patients’ subjective experience should cover at least three aspects. The first is an overall measure of subjective experienced health. Bloem (2008) has developed a concise ladder-type scale that can easily be used in daily practice. In addition to this overall measure, we suggest an assessment of the patient’s status in terms of the main psychological determinants, perceived control and acceptance (Stalpers, 2009). This approach allows for tracking a patient’s subjective health experience over time, as well as his dynamic position in terms of the quadrants (see paragraph 1.6). In case, a specific effect is part of the therapeutic program, an additional measure is advised to monitor the effectiveness of the therapy in this respect. A concise set of scales to assess patients’ subjective experience in the above format is available (Bloem, 2008; Stalpers, 2009). The frequency of assessment of subjective measures should be dependent upon the intensity of therapeutic interventions. The more often therapeutic interventions are initiated, the more often an assessment is indicated. It is imperative to obtain a baseline measurement of subjective experienced health (ladder scale and determinants), i.e., before therapeutic intervention. A minimal assessment will consist of a baseline measurement (t=0) and one measurement after therapeutic intervention (t=1).

§3 Summary

As stated in paragraph one, subjective experienced health is the main driver of health related behavior. This means that, in order to understand health related behavior, insights are needed into the subjective health experience of the individual care consumer. This health experience in turn is dependent upon two main factors. The subjective experience of health is to an extent a reflection of the biological-physiological state of the organism. However, psychological factors may also influence the subjective experience of health. Research has identified key psychological determinants of subjective health, the two most important of which are: perceived control and acceptance. We have used these two determinants as a basis for patient typology. The importance of this typology is that actions and initiatives aimed at improving an individual’s status may be aligned optimally with the individual characteristics of target patient or patient group.
We have identified a number of issues in health care and indicated the relevance of the line of thought we have developed for these specific issues. Insights into an individual's health experience, as well as his position in terms of the main determinants of this experience, perceived control and acceptance, may help to substantiate the choice of tools and networks aimed at supporting the therapeutic approach of the individual. Critical monitoring of the implementation of tools and networks may help to further optimize the alignment of therapeutic offerings and consumer and patient groups.
References


