



What is Value in Healthcare?

A Qualitative Study of the Patient Perspective on Value



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Abstract

The definition of value in healthcare has been subject to an extensive academic and medial debate over the last years. Although several frameworks for value in healthcare have been developed, most do not consider the patient perspective when defining value. This interpretive, qualitative interview study aims to explore how patient value is created in healthcare. We interviewed nine representatives from eight patient organisations in Sweden to understand patients' perspective of value. Using an abductive approach, a theoretical framework for analysis based in the literature on value-creation in the service industry was developed in parallel with the empirical material.

We find that patients interpret value subjectively by evaluating perceived outcomes from healthcare. Healthcare processes form value propositions that are translated into functional and emotional outcomes of healthcare for patients. Outcomes are evaluated using patients' individual filters such as needs, expectations and prior experiences of healthcare. Furthermore, individual and situational filters are not fixed. Healthcare providers may increase perceived value for patients by either improving processes and/or moderating patients' filters through dialogue.

Our results indicate that current healthcare value frameworks do not consider patients' subjective evaluation of outcomes when defining value. Current frameworks disregard emotional outcomes that patients may perceive as highly valuable. Patients' internal factors determining evaluation of outcomes need to be investigated further to fully understand patients' interpretation of value.

Keywords: patient value; value-creation; healthcare; patient organisations; value-based healthcare

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Introduction

Value-based healthcare (VBHC) recently awakened intensive media attention during its implementation at Nya Karolinska University Hospital in Stockholm.

Apart from controversies in the implementation process itself, the recent events have sparked a continued debate whether value-based healthcare and the new organisational model implemented has improved or reduced healthcare performance (Knoxborn & Derblom Jobe 2018). This recent debate about value-based healthcare as a management concept to measure and improve the outcomes and quality of healthcare has made us interested in understanding: what is value in healthcare?

Healthcare is a vital concern for any modern society. In Sweden, annual healthcare expenditure amounts to 11% of the GDP, ranking 12th globally (Statistics Sweden 2019; The World Bank 2019). The performance of healthcare systems worldwide has been a subject of in-depth scrutiny and national attention. There is an ongoing debate about the value produced by the Swedish healthcare system (Örstadius 2018). Although the Swedish healthcare system delivers high quality of care in international comparisons and has improved greatly over the last decades on a number of measurable outcomes, several surveys indicate increasing issues with accessibility, and increasing differences between geographical areas and socioeconomic groups (Swedish National Board of Health and Welfare, 2018; OECD/EU, 2019). Furthermore, hospitals struggle with overcrowding and lack of staff (Örstadius, 2018; Swedish National Board of Health and Welfare, 2018).

The problem

These issues have given rise to a discussion about how to organise the healthcare system to improve performance, as well as how to measure performance in healthcare (Berwick, James & Coye 2003; Nilsson, E., Orwelius & Kristenson 2016). Several frameworks, such as value-based healthcare (Porter 2010) and value assessment frameworks (Sorenson et al. 2017), have attempted to create ways of restructuring healthcare in order to increase value. Although value creation for patients is the central focus of these frameworks, they have also been repeatedly criticised for not considering patients' perspective when defining value (Gray 2011; Ebbevi 2016; Perfetto, Oehrlein, Boutin, Reid & Gascho 2017; Pendleton 2018).

Several studies have shown that patients value different things than other stakeholders. For example, Pendleton found that physicians generally value clinical results more than patients who may value more human aspects like the friendliness of healthcare staff (Pendleton 2018). Another example is Perfetto et al. (2017) who found that when patients assess perceived value they consider not only clinical outcomes or costs

but also whether the medical treatment can help them achieve their individual goals. Our literature search has shown that the provider, payer and clinician's perspectives have already been covered extensively in existing research while we found that the patient's perspective has not been extensively discussed in research. Based on this, we set out with an open mind in an explorative study, to understand how patient value is created from patients' perspective.

Delimitations

In the process of writing this thesis we have learnt about a number of important issues in the modern healthcare system. However, we cannot cover everything in just one thesis. For this reason, we have had to make a set of delimitations to be able to deliver a thesis that provides focused knowledge. First and foremost, we study the perspective of the patient.

The second delimitation is that our study has been in a Swedish public healthcare context. The Swedish healthcare is an example of a *Beveridge healthcare system*, meaning healthcare is controlled by the government and financed through taxation (Van Der Zee & Kroneman 2007). This is different from other healthcare models where healthcare is financed out of pocket or through private or group-based insurance. As such, our findings are limited to systems similar to the Swedish one. The small fraction of privatised healthcare in Sweden will be disregarded in this thesis (Socialstyrelsen 2018).

Purpose and research question

The purpose of this thesis is to bring the reader closer to understanding what value in healthcare is and how it is created. We want to explore the concept of value in healthcare, as seen by patients. Our aim is to build understanding of patient's perspective of value in healthcare that researchers can use in further research of value in healthcare. This thesis will hopefully be valuable to representatives of patient interest organisations in their work of pursuing their members' interests. We also believe that this thesis is useful for providers of healthcare who aim to provide high-value healthcare to patients and who wish to understand the patients' view of what value is and how it can be created.

Research question

How is patient value created in healthcare?

Method

We believe that the definition of value depends on what perspective is used. In that, we subscribe to a constructivist view of reality (Guba & Lincoln 1994; Bryman & Bell 2015). In the purpose of this thesis, we acknowledge the existence of different understandings of value, which can be seen a constructivist proposal. We also recognise that both our data and our analysis of the data are only one of many possible interpretations of value, and that we as researchers partake in the construction of the reality we observe.

The goal with our study is to understand how patient value is created. To do this, we adopt an interpretive approach and try to see the world from patients' perspective using a qualitative interview study with patient representatives (Kvale & Brinkmann 2009; Bryman & Bell 2015). We asked questions about why the interviewees thought or argued in a certain way. We also diverged from the manuscript to explore new issues that were created by the specific context and interaction between us and the interviewee. In the analysis, the aim was to understand why interviewees answered the way they did.

Using an abductive approach, the research question and scope of the study were successively refined based on theory and the analysis (Bryman & Bell 2015). Although the empirical material was collected inductively, it was influenced by the parallel development of theory, and vice versa. We initially believed we could define patient value in concrete terms, such as a list of clearly defined processes, factors or components of healthcare. We realised through the empirics this would be an over-simplified conclusion. This exemplifies the strength of an abductive approach in that we are not constrained by our original presumptions, but free to search for alternate and better theoretical explanations for our empirical findings (Bryman & Bell 2015).

Selection of respondents

In order to understand the patient perspective on value, we interviewed nine representatives from eight patient organisations.¹ Representatives were predominantly presidents of the organisations, but in some cases other representatives were interviewed. A list of interviewees and their organisations are listed in appendix I.

Patient organisations are generally regarded as representative of the patient perspective. Seen from a social constructivist perspective, representatives of patient organisations are part of a social context in these organisations, which will influence their ideas and interpretation of reality (Weick, Sutcliffe & Obstfeld 2005; Alvesson & Sköldberg 2007). As representatives, their social role is to consolidate different interpretations in the organisations (Bolden, Hawkins, Gosling & Taylor 2011). Based on this, we believe that representatives of patient organisations interpret value similarly to the patients they represent.

The strength of our selection is that the representatives can provide us with a better understanding and contextualisation, that elevates our analysis (Kvale & Brinkmann 2009). The representatives have professional experience with the diagnoses and some of them are or have themselves been patients with the diagnosis in question. This means they provide us both with an aggregated perspective from representing others with the diagnose, but also with a personal patient perspective. We think that we get a more nuanced data by interviewing representatives instead of patients.

A concern with any selection is whether the selected respondents will represent the population you investigate (Bryman & Bell 2015). In our case, this could be whether representatives of patient organisations interpret value differently than patients in the organisations they represent. The question is not whether we find the true answer – we do not think there is one – but rather if the representatives differ so much in interpreting value that our conclusions will be different. Any interviewee will interpret value based on personal experiences and biases (Weick, Sutcliffe & Obstfeld 2005). For example, representatives may have certain collective attributes such as education or actionability that separate them from other patients. While having personal experience as a patient may lead representatives to understand the patient perspective better, it may also bias

¹According to Swedish National Board of Health and Welfare, a patient organisation is defined as any organisation with the purpose of advancing the interests of a patient group (often based on diagnosis). In order to receive government grants, the diagnosis must lead to persistent disability. There are no official statistics of how many patient organisations there are in Sweden.

interpretations based on these experiences. This will create a filter through which they interpret value differently than the average member. However, respondents have communicated the same ideas about value, regardless of personal experience as patients. This suggests there is a unified interpretation between patients and representatives of patient organisations.

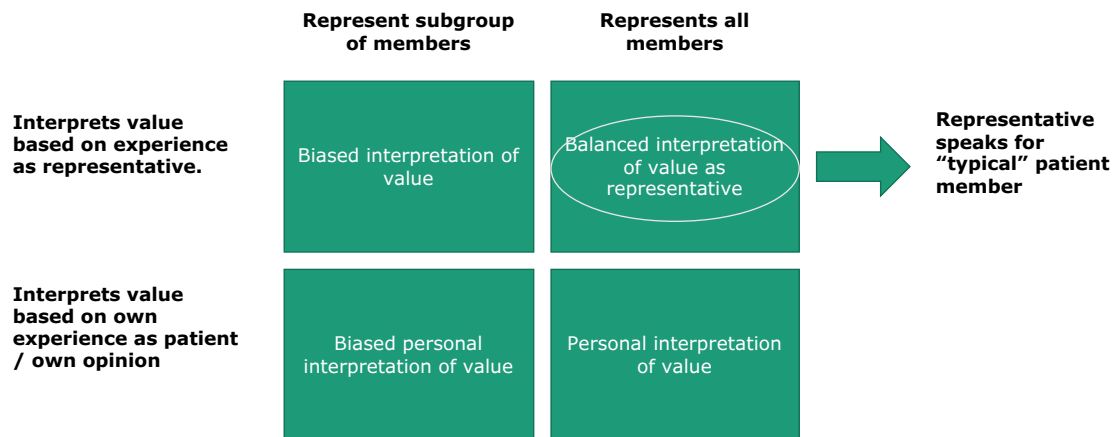


Figure 1: Conceptual matrix of respondent types. Respondents influenced by personal experiences or certain personal characteristics may differ in their interpretation of reality.

Patients in patient organisations may also interpret value differently than a general patient population. Patients who are members could share attributes such as having a chronic or serious illness, being more sociable or having had a bad experience as a patient that make them more likely to join a patient organisation. Patients with severe illnesses may also avoid engaging in patient organisations, as they are simply too sick to participate. However, we believe that the definition of value and how value is created is similar enough across patients for our selection of respondents to be representative of patients in general. As such, these results from this study should also be transferrable to other groups of patients (Bryman & Bell 2015). Furthermore, this type of issue is present no matter what selection is made.

In conclusion, representatives of patient interest organisations are a potential source of valuable and nuanced knowledge about value-creation in healthcare. Interpreting their answers, we must remember that their interpretations are in turn influenced by their sources of information, their ability to represent their members in an unbiased way as well as the organisation's representability of the patient group as a whole.

Sampling procedure

We used purposive sampling procedure to select organisations that maximised variation in terms of medical conditions. Sirona Health Solutions – a management consulting firm specialised in healthcare – put us in contact with the president of the umbrella patient organisation Funktionsrätt Sverige. We sent out a request for interviews to all 41 member organisations of Funktionsrätt Sverige. We selected representatives based on the diagnoses the organisations represent to get a spread of acute, chronic, physical and psychiatric illnesses, as well as representatives' ability to participate in the interview. The purposive sampling procedure, described by Bryman and Bell (2015), allowed us to get a spread of organisations representing a heterogeneous group of diagnoses. Since access to the organisations was mediated through a familiar contact, we believe that respondents were more open to discuss difficult topics.

The decision to select patient organisations based only on their type of diagnoses can be discussed. For example, we did not stratify to include diagnoses affecting both children and adults, although our sample ultimately did include both. Other issues that may skew the selection of organisations is their relative size, financial status and demographic spread of the diagnoses. All information pertaining to such issues can be found in the appendices. This information is included to provide the reader with relevant background information that is needed to understand the context of the study.

Data collection

The semi-structured interview method was chosen due its suitability to explore intangible and abstract concepts (Kvale & Brinkmann 2009; Bryman & Bell 2015). We covered a set of fundamental questions and topics in each interview. Follow-up questions were varied depending on diagnoses of the patient organisation and the answers provided by the interviewee. For example, representatives of rare illnesses were asked about benefits of clustering healthcare competence for a certain diagnosis in order to improve outcomes and survival rates, while representatives of organisations for patients with psychiatric illnesses were asked about differences in care between psychiatric and somatic diseases. This allowed us to gather information about core issues during all interviews but also allowed new issues to emerge.

The key advantage to semi-structured interviews is that it is possible to gain deeper insights by letting the interviewee speak freely about issues that matter to them (Bryman & Bell 2015). The flexibility means interviewees can freely structure their answers, which helps us understand their interpretation and what they think is important. Semi-structured interviews also allows us to capture information in body language, speech, tone and allows us to ask probing and clarifying questions (Kvale & Brinkmann 2009; Bryman & Bell 2015). This lets us develop unexpected issues during the interviews.

We would often exemplify and ask the interviewee to give their opinion of the examples. This allowed us to gauge the interviewees perception of a specific concept, but also served as a way to open new areas to discussion (Kvale & Brinkmann 2009). There is a risk that such questions become overly biased or leading the interviewee into giving a specific answer. We found that some of our questions did not provide valuable insights, because they were too leading. Answers to any questions deemed too leading have been excluded from analysis.

Other data collection methods were considered. It is however much more difficult to ask probing questions or clarifying questions based on the answers in a survey than in an interview. Therefore, a survey is unlikely to yield sufficient insights into individuals' interpretation of value. Quantitative methods would not bring sufficient clarity to what value in healthcare is because value may contain aspects that are difficult to quantify.

Literature search and theory development

As previously described, theory was developed abductively in parallel with data collection and analysis. In the interviews, we found unexpected patterns leading us to theory about value creation in service organisations. Based on both empirics and theory, we could construct a model for patient value in healthcare. This model was then anchored in and related to the literature about value in the service industry. Some of the literature was collected before the interviews (such as VBHC), but this was primarily to understand the context – not to be used to explain the empirics.

Areas of interest identified in the interviews were explored in the literature. We made broad searches based on keywords from our empirical material to find some articles that have high significance in the field by being well-cited and/or recent. These articles' reference lists yielded additional relevant articles and new areas of interest, which were then explored with the same strategy. By concentrating on a few strands of literature we get a high level of depth in some theories, as opposed to general knowledge of many theories. A deficit of this snowball method is that it can create biased selection in the

literature and risk excluding potentially relevant literature (Bryman & Bell 2015). For example, strands of literature about patient value that is poorly cited or use different key words but discuss the same topic, might not be included in our literature search.

Analysis procedure

The analysis was an iterative process, continuously comparing theory and empirics based on our coding. Coding was a dual process using both inductively created thematic codes from a holistic interpretation of the interviews and a detailed open coding of the transcripts using computer-assisted qualitative data analysis software. Final codes in from the interviews were created from combining both these methods. The analysis was then guided by the theoretical concepts we had developed, which helped us explain empirical phenomena through a theoretical lens.

Ethical considerations

Patients with serious illnesses are a vulnerable group, which must be considered during research. As we interviewed representatives of patient organisations, the interviewees had already chosen to be a public figure of their organisations. Nevertheless, information about the respondents' medical conditions has been treated carefully in this essay. No information that can be tracked back to specific representatives has been published without their approval. A larger issue is the impact this study might have on how the patient perspective may be adopted in healthcare. As the study aims to understand patient value, which may improve healthcare for patients, we do not believe the study will have a negative impact on patient health.

Some reflexive and critical remarks

During this process, we have identified multiple routes this thesis could go. One concern is how biased we have been in our decisions about empirics, analysis and development of theoretical framework. We spent a lot of time discussing the empirical data, reviewing the interviews and coding the material, which gave us a good understanding of its content. We also wrote several different analyses to evaluate what would be the most interesting and just representation of what we learnt in the interviews. This approach made sure that we were not creating something in our minds that did not exist in the empirical material. However, we realise that ultimately our interpretations have inevitably influenced the selection of empirics and the way we have chosen to analyse the data. We would argue that our awareness about this issue and our attempt to minimise its impact speaks to the trustworthiness of our study (Lincoln & Guba 1985; Bryman & Bell 2015).

In order to improve credibility of our study, we conducted three interviews for respondent validation (Lincoln & Guba 1985; Bryman & Bell 2015). During these, the results and our interpretations were explained to the interviewee, who then gave their opinion of our study. Interviewees felt that we had correctly interpreted them, and that the conclusions were reasonable based on their perception of reality. We also conducted reference interviews with one ex-nurse and one rehabilitation physician. Reference interviews were done to gain deeper insights into the subject and ensure our conclusions would be relevant in the healthcare context.

Theory

The term value is commonly used in business, management and health literature alike, but its definition is not clear. Some even regard value as “the most ill-defined and elusive concept in service marketing and management” (Grönroos & Voima 2013). In this section we will first provide an overview of existing research about value in healthcare and discuss their applicability to our research question and the Swedish healthcare system. We then use business and service management theory to build a model for analysing our empirical material. We see healthcare as a service where the customer is the patient, similar to many other authors in the field (Berry, Carbone & Haeckel 2002).

Previous research on value in healthcare

Over the last decades, literature value in healthcare have become extensive. A milestone in the healthcare literature was the report *Crossing the Quality Chasm* (Institute of Medicine 2001), which is largely credited for bringing the problems with the short-sighted healthcare system that existed in the U.S. into light. Berwick, Nolan and Whittington (2008) developed the concept into *The Triple Aim*, adding the two dimensions improved population health and reduced cost of healthcare to the improvement of individual patient care defined in the IMI report. Focusing on healthcare improvement on a societal level, neither of these reports discuss value-creation from the individual patient’s perspective.

Value-based Healthcare

Value-based healthcare (VBHC) is a concept that aims to increase healthcare value (Porter & Olmsted Teisberg 2006). In VBHC, value is defined as patient outcomes from healthcare relative to the cost of providing them. Outcomes are categorised into three groups (Porter 2010):

- health status achieved (e.g. survival or degree of recovery)
- process of recovery (e.g. time to recovery or complications during treatment)
- sustainability of health (e.g. long-term consequences of treatment received)

In addition to specifying value in healthcare, Porter and Lee describe six key changes to healthcare providers’ organisation that are required to maximise value creation, including organising healthcare into integrated practice units where all of a patient’s needs can be attended and measuring outcomes and costs for each patient (Porter & Lee 2013).

VBHC has been criticised for being provider-centric and not taking the patient perspective into account (Ebbevi 2016; Pendleton 2018). VBHC's focus on organisational aspects of value creation in healthcare also makes it difficult to translate into the Swedish context (Statens beredning för medicinsk och social utvärdering (SBU) 2018). Despite this, studies have shown that on implementation, professionals mostly perceive VBHC as taking the patient perspective on value in healthcare (Erichsen Andersson, Bååthe, Wikström & Nilsson 2015; Nilsson, K., Bååthe, Andersson, Wikström & Sandoff 2017). Although it has been debated whether the outcomes specified in VBHC are the most relevant for the patient perspective (Ebbevi 2016), we find that the definition of value in VBHC is rarely questioned in the literature.

Muir Gray and NHS framework for value in healthcare

Gray sees value in healthcare as subjective, and that the definition of value depends on what perspective is taken. For example, patient value depends on the outcomes of care and how these are delivered, while manager value is derived from productivity (Gray 2011). Gray does not quantify value; the definition of value in VBHC is by Gray considered as closer to efficiency. Gray – like Porter – mostly focuses on organisational aspects of value-creation, such as healthcare integration, resource allocation and IT, and does not provide a model for creation of patient value.

Value assessment in healthcare

Different value assessment frameworks have been created in multiple countries over the last decades to evaluate treatment effectiveness and cost (Perfetto, Harris, Mullins & dosReis 2018). There is great variation within these frameworks, but the definition of value is generally centred around optimising pre-defined outcomes for patients with specific diagnoses. The frameworks have been criticised for their inability to incorporate patient perspective and focus on specific decisions rather than holistic view of patients' perspective of value (Armstrong & Mullins 2017; Perfetto et al. 2017; Sorenson et al. 2017). Our conclusion is that value assessment frameworks do not provide a model for individual value creation nor a definition of value from a patient perspective.

Summary of previous research

The described theories offer several definitions of value in healthcare. However, these make generalised assumptions about what all patients value and produce limited explanations for how value is created for patients on an individual level. This is where we see a clear gap in healthcare theory. To explain what patient value is and how it's created,

we need to look beyond the existing healthcare value literature. In the next section we will examine theories about value from business and service marketing literature to find a theoretical framework to answer our research question.

What is patient value in healthcare?

A fundamental distinction of value in the business literature is that of “value in use” versus “value in exchange”. Value in use is the value gained by the customer from use of a product or service (Bowman & Ambrosini 2000). Value in use can also be seen as the aggregated value of the customer’s *entire experience from use of a service* (Sandström, Edvardsson, Kristensson & Magnusson 2008). Value in use is defined by the customer or end-user, which in the Swedish healthcare context equals the patient. As such, value in use is a good concept for patient value. Value in exchange is defined as the monetary value that is paid for the service or product at the time of exchange (Bowman & Ambrosini 2000; Vargo, Maglio & Akaka 2008). As opposed to value in use, value in exchange is a measure of value that only works from the payer and provider perspective. In Sweden, patients do not pay the full cost for healthcare directly, but instead pay indirectly via taxes. Hence, value in exchange is not a relevant measure of patient value in the Swedish healthcare context (Garrison, Pauly, Willke & Neumann 2018).

Value is perceived by the customer

Value in use is closely connected to service-dominant logic as discussed by Vargo and Lusch (2004). The service-dominant logic claims that companies can only create value propositions of products or services for customers that create value when used by the customer. It is the customer’s subjective evaluation of the service or product that determines its value (Vargo & Lusch 2004).

Many authors consider value from a service to be based on the customer’s subjective evaluation of the gains from using it. For example, Zeithaml (1988) views the customer’s perceived value as “the customer’s overall assessment of the utility of a product”. Boksberger and Melsen (2011) state in a comprehensive review of the literature that a customer’s perceived value of a service is “a combined assessment of consumers’ perception of benefits and sacrifices [...] for a variety of perceived value dimensions.” Other authors see use of a service as a way of reaching different end-states or outcomes, such as happiness, security or improved physical health (Gutman 1982; Vargo & Lusch 2004; Sandström et al. 2008). The sum of the customer’s evaluation of these outcomes make up the customer’s total perceived value from using the service. Sandström et al. (2008), discussing Vargo and Lusch (2004) explains the difference between outcomes and value in the following way:

“Note that value is not the same thing as the sum total of all [...] outcome dimensions, but the evaluation of these. For example, even if the experience of playing a game on their mobile phones is much the same for two different customers, one of these may consider it important to have the possibility to play while the other does not.”

The conclusion is that customer value is subjectively determined by customers through the use of services. A consequence of this reasoning is that customer value cannot be universally defined. This is fundamentally different from value theory in healthcare, in which patient value is often defined as objective outcomes that hold the same value for all patients.

To summarise this section: *There is no universal way to define what is valuable to patients, because all patients are different and value different things. Patient value can be seen as a patient’s individual, subjective evaluation of outcomes from healthcare services, which we label “patient-perceived value” (PPV).*

What is an outcome in healthcare?

Outcomes can be thought of as any change of state experienced by the customer due to use of a service. The evaluation of reaching outcomes is what defines customers’ value from use of a service (Sandström et al., 2008). The distinction between value and outcomes has however not been clearly articulated in the business literature. We think that the “utility of a product” (Zeithaml 1988) or the “perceived value dimensions” (Boksberger & Melsen 2011) that are evaluated by the customer according to the literature above can be seen as what Sandström et. al. refer to as outcomes. This distinction also makes sense according to the service-dominant logic, because reaching a certain outcome through use of a product or service does not determine whether or not you actually care about or value that outcome (Vargo & Lusch 2004).

Creation of outcomes – value-creating processes

Outcomes do not just spontaneously arise when customers use a service. They are instead a consequence of the service’s value proposition, made up by different value-creating processes of the service² (Vargo & Lusch 2004). The distinction between a process and an outcome can be explained using Grönroos and Voimas’ (2013) distinction between

² We use the term “value-creating” to label processes that contribute to patient value, although according to the service-dominant logic these processes do not by themselves create value. Value-creation is used because it is widely accepted in value theory.

customer and provider spheres. Applied to healthcare, the processes are within the sphere of the provider. It is the provider who delivers the processes and certain processes are provided without the patient being involved. Some processes can be in the joint sphere in which patient and provider co-create value. Outcomes are in the patient-sphere. While providers can influence the outcomes through processes, outcomes are ultimately perceived by the patient; they are “closed to the provider” (Grönroos & Voima 2013).

The influence of the spheres can vary between situations. In some situations, the patient-sphere is rather small (such as for surgery where the patient is mostly passive recipient of care) whereas in another situation (such as rehabilitation which requires active involvement of the patient) the patient and/or joint sphere may be much larger. According to Grönroos and Voima (2013), the joint sphere can differ in size between different situations or not exist at all depending on the level of interaction that is required. We acknowledge that the line between outcomes and processes is not crystal clear. We make a distinction between outcomes and processes based on the relative influence of the spheres. If an activity is mostly in the patient sphere – then it is a patient outcome. If it is mostly in the provider sphere – then it is a value-creating process.

In the healthcare context, the patient is often considered a co-creator of their care (McColl-Kennedy, Vargo, Dagger, Sweeney & van Kasteren 2012; Osei-Frimpong, Wilson & Lemke 2018). The patient engages in value co-creation by participating in medical treatments, by complying with doctor recommendations and by searching for information on their own before encounters with healthcare (Osei-Frimpong, Wilson & Lemke 2018). Co-creation has recently been given considerable attention in the patient-centered healthcare where some researchers consider shared decision-making between patient and clinicians to be very important for high value care (Armstrong & Mullins 2017). According to Vargo and Lusch’s (2004) reasoning, patients are always co-creators of their care. Grönroos (2011) is a bit more cautious and makes the distinction that co-creation may be less relevant in some situations than others (e.g. rehabilitation where patient is highly involved vs. surgery where patient is barely involved in co-creation).

Different categories of outcomes

Sandström et. al. (2008) distinguish between functional and emotional outcomes from use of services. This indicates a service process can lead to both functional and emotional outcomes for the customer. In a healthcare setting, feeling like you received information from healthcare staff is one example of a potential emotional outcome in healthcare. Becoming healthy from an illness is an example of a functional outcome. We

define these as Patient Perceived Outcomes (PPOs) – the individual patient’s experience of outcomes from healthcare.

Several other business researchers have suggested that value consists of multiple components. Smith and Colgate (2007) define four different types of value: functional, hedonic, symbolic and cost value. Berry et. al. (2002) created an alternative framework for customer value that consists of functional and emotional benefits minus the financial and non-financial burdens (cost) that customers get from a product or service. Neither of these frameworks do however distinguish between outcomes and value. However, we reason that if cost value exists, that cost value must be preceded by a cost outcome (such as monetary cost, reduced time by using the service instead of an alternative). Based on above definitions, the different aspects of value suggested in the literature can be understood as different *outcomes* rather than different aspects of value.

Any attempt to categorise the components of value in use can be criticised for being too general and not specific enough for a given customer. In order for the concept to be useful in our analysis, it needs to be dissected into some kind of components. We do however recognise that all such categorisations are ultimately approximations; at least, or maybe especially, for the individual customer or patient. Acknowledging different categories of outcomes does however allow us to see that healthcare value theorists like Porter (2010) or Gray (2011) really mostly consider functional outcomes from healthcare.

To summarise this section: *Theory suggests that patients experience outcomes of healthcare processes as either emotional or functional. We refer to these as patient-perceived outcomes (PPOs). Healthcare providers co-create these outcomes with patients through healthcare services.*

How do patients evaluate outcomes?

Customers’ definition of value is according to some authors determined by their beliefs, needs, prior experiences and their expectations of the service according to (Bowman & Ambrosini 2000). Related to healthcare this would imply that the value patients perceive from healthcare is determined by their needs of the healthcare system (based on for instance medical diagnosis, personality, life situation), prior experiences with healthcare and their expectations of healthcare. We call these personal attributes “individual filters” using terminology from Sandström et. al. (2008).

Other types of frameworks have been developed to understand how patients’ personal attributes can influence their evaluation of outcomes. McColl-Kennedy et. al. (2012) have developed a taxonomy with five different types of patient co-creators. McColl-Kennedy et. al. (2012) found that the type of category a patient belongs to has

implications on their perceived quality of life. Armstrong and Mullins (2017) have developed another taxonomy that distinguishes patients' personal values into four different categories; global values, decision-specific values, situational values and external values. These are alternative ways to understand patients' individual filters.

To summarise this section: *Theory suggests that patients have individual filters that influence how they value outcomes from healthcare.*

Model for creation of patient value in healthcare

This theory review has enabled us to construct the following theoretical model that we will use to analyse our empirics and understand patient value in healthcare:

Model component 1: Value-creating providers cannot create value for patients, only deliver value-creating processes. These healthcare processes lead to value propositions that patients and provider use to co-create outcomes.

Model component 2: Healthcare process lead to outcomes for patients. We call them "Patient Perceived Outcomes" (PPOs). PPOs can be divided into different categories, for example functional or emotional.

Model component 3: Patients evaluate PPOs through their individual filters, the result of which is the "Patient Perceived Value" (PPV). Individual filters consist of patients' personal attributes such as expectations, needs, beliefs and personal values that make them value outcomes differently from each other.

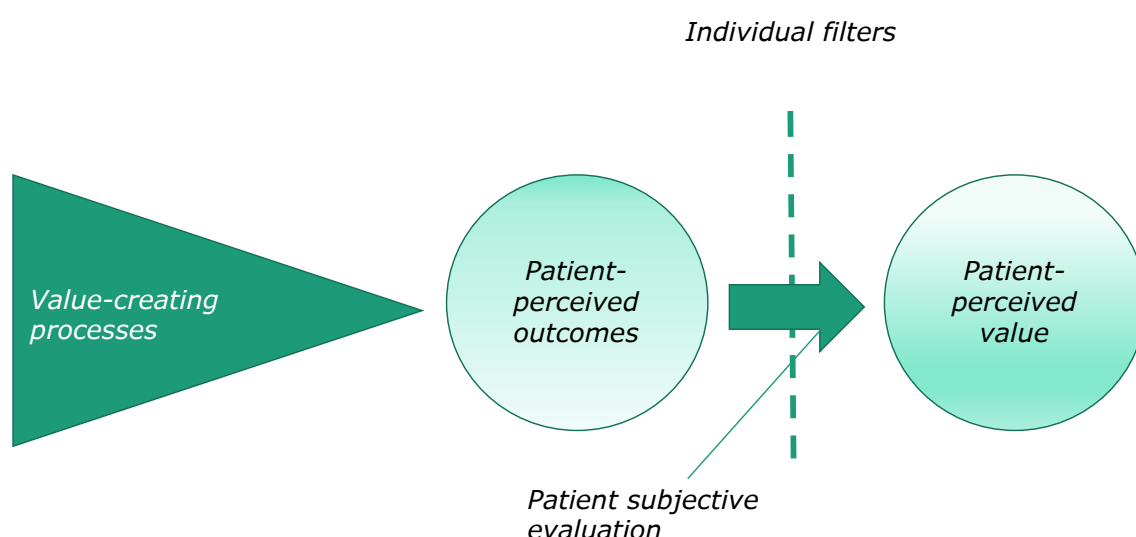


Figure 2: Theoretical model for value creation in healthcare

Empirical analysis

In the empirical material of our study, two distinct themes about value dominated: value as made up of concrete, defined components and value as subjective and individually defined. In the presentation below, the concrete components of value have been divided into *value-creating processes* and *outcomes* in accordance with the definitions presented in the theoretical section above (Grönroos & Voima 2013).

A third recurring theme was that the term value was ambiguous and unfamiliar. Some interviewees also regarded it as overlapping with the terms quality and utility, or defined value as a combination of the two. It was easier for interviewees to discuss changes or processes that could create value than it was for them to define what value is. While some interviewees felt value was ambiguous or difficult to define, all interviewees also discussed value as a subjective and concrete concept. For this reason, value being ambiguous is not discussed further in the empirical section.

Value-creating processes

All respondents talked about different value-creating processes during the interviews. Most respondents used value-creating processes to describe or explain value-creation, or exemplify which processes create value in healthcare. Some respondents instead used processes as a definition of what value is. The value-creating processes can be grouped into four categories, which will be presented below.

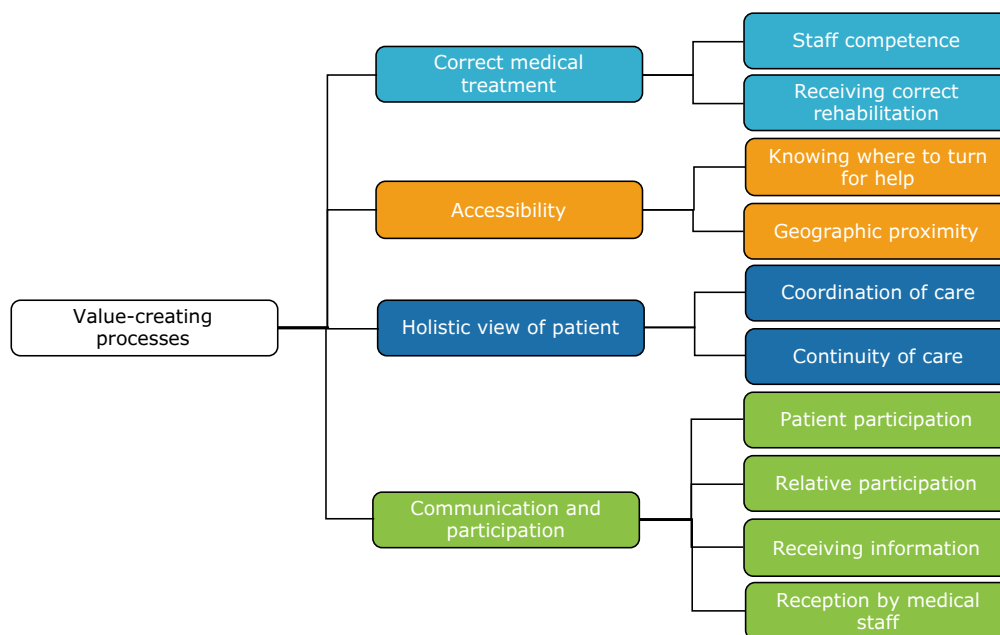


Figure 3: Overview of value-creating processes discussed by interviewees and described by interviewees as value-creating.

Correct medical treatment

All the respondents stated that correct medical treatment is value-creating for patients. This includes receiving correct treatment from healthcare staff with the right competence, as well as receiving correct rehabilitation when needed. Another aspect that was discussed by some interviewees was avoidance of complications from healthcare, such as healthcare-induced infections or injuries.

"I think the classic – cure and ease suffering – that's healthcare's... that's what healthcare should be doing."

Accessibility

Aspects of accessibility to healthcare were discussed by all interviewees as important to value. This included both knowing where to turn in order to receive care and geographical distance to care. Representatives of certain patient groups were especially concerned with the need for accessibility. For example, patients with psychiatric illnesses find the healthcare system difficult to navigate, especially for young people. Patients with rare illnesses also find the healthcare system difficult to navigate. The general view by respondents was that it is far easier for patients with a single, clearly defined somatic condition to navigate the healthcare system.

With regards to geographical distance to care, interviewees thought that differences in accessibility of acute care was a big problem for patients. One example mentioned is that patients with acute stroke living in Norrland have much lower chances of recovery, partially due to long distances to care providers. However, for specialist care, the value from increased competence from meeting experts outweighed the negative impact of travelling. Interviewees said their patients would gladly make long trips if they knew their chances of survival and quality of care was far better at an expert centre than at their home hospital.

"If I know the survival rate is 100% instead of 50% or whatever it is, I would gladly go 50 miles. Absolutely. And you can see that in comparable metrics, how the survival rate is. And I don't think any patient has anything... because it's just about the procedure you go to do. You won't need to be cared for afterwards at that hospital. Maybe 4-5 days and then you go back to your home hospital again."

Holistic view of patient by healthcare provider

Most interviewees expressed the view that healthcare needs to take a holistic responsibility to coordinate patients' care. This includes processes like continuity, coordination and scheduled follow-ups. These processes were deemed especially important by patients with rare and complex illnesses, since they require integrated care effort to perceive high value. Increased continuity, such as meeting the same staff at each visit, would create a lot of value because patients do not have to spend time explaining their complex illness each time they are in contact with healthcare. Holistic view of the patient was also perceived to be important for high-value rehabilitation.

"That is the problem. Who takes over responsibility? We think that there should be... when you leave the hospital you should have a person of contact for your rehabilitation in the next phase. There are systems for such things with coordinated rehabilitation. There are statutes about it. But it doesn't work. But we think that there should be a plan and there should be someone responsible for the plan, for me and for my rehabilitation that I can talk to, as a patient."

Participation and communication

Participation and communication were seen as processes that could increase value by themselves and in combination with other processes. Most interviewees said it was value-creating for patients be able to participate actively in their care. Patients have experience from living with the illness that should be taken into consideration by healthcare staff when deciding on medical treatments and rehabilitation efforts. One area where patient participation was deemed especially important was with rehabilitation.

"The competence of the patient should weigh in just as much as the competence of the profession. To provide the best possible care, healthcare should preferably listen, make suggestions and let the patient make choices."

Interviewees perceived two-way communication between caregiver and patient as a value-creating process. One interviewee said that their members had in some cases not received information prior to surgery that severely altered their faces. Receiving such information before surgery would have meant that patients could have made an informed choice about whether to undergo surgery.

Patient Perceived Outcomes

Interviewees described a number of outcomes as important to patient value. This is not a collectively exhaustive list for all possible outcomes from healthcare. The outcomes exemplified by interviewees have been categorised as either functional or emotional in accordance with our theoretical framework.

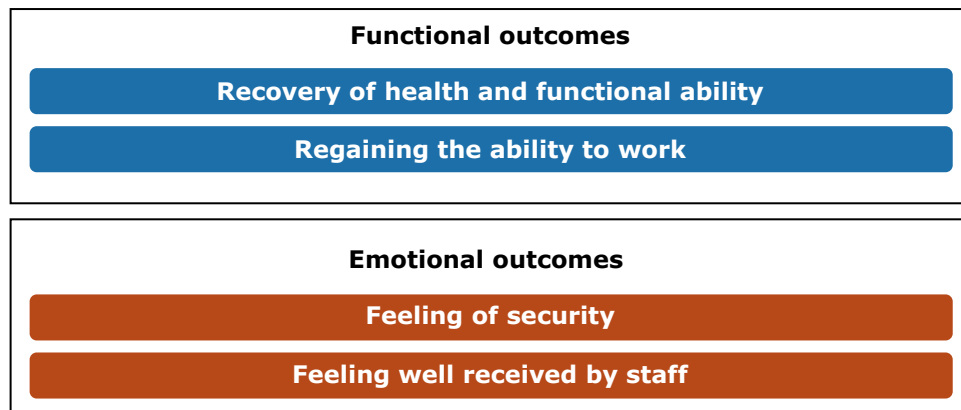


Figure 4: Functional and emotional outcomes from healthcare, non-exhaustive list to illustrate examples of outcomes discussed in the empirics.

Functional outcomes:

Interviewees agreed that becoming healthy was a key outcome that could add to value. Some of the interviewees that represent patients with conditions that severely reduce functional capabilities stressed that restoration of functional ability was an outcome that was valuable to these patients.

Interviewees also said that many patients who have become ill want to return to work. Interviewees said that not being able to work had a very negative impact on patients' quality of life. Interviewees saw work as a very important part of many patients' social lives and as such a big determinant for their quality of life. Being able to return to work was regarded as an outcome of high value to many patients. An interviewee said:

"We have younger patients who become ill in thirty-forty years old age. [...] Then you have different needs. You have family and kids you need to get to preschool in the morning and who you need to pick up and so forth. It's a completely different life and many absolutely want to get back to work and maybe only work part-time. There's a lot going on around that life situation and the life phase you are in."

Emotional outcomes:

Feeling secure was deemed by interviewees to be an emotional outcome that many patients perceive as valuable. Interviewees said that many patients feel insecure during the healthcare process. A key reason that patients feel insecure is being treated by staff who lack competence. Another example is that healthcare staff unknowingly do things that make patients feel insecure. One representative said:

“There are many people who contact me and say that when you have home care services and the caregiver has just been smoking, and is supposed to help you prepare for the night, maybe help you brush your teeth, being very close to you and smelling like smoke and tobacco from skin, clothes or hair. [...] the things I said, they spill over on the feeling of security because if you have been through that a few times that you have become sick after an encounter with a care provider, then it is likely that you begin to avoid seeking care.”

Another representative made the following statement:

“Value is meeting someone who makes me feel a bit more secure when I leave. To meet some staff who help me feel a bit more secure.”

Interviewees said that the reception patients get from healthcare staff was very important to increase or reduce the value patients perceive. Being listened to and feeling like healthcare staff care about your needs as a patient was identified by interviewees as important to a good reception and increased patient value.

“I believe that patients should feel well received and that they are treated well by staff and that they think: ‘They listen to me here, they know what my needs are and they hear what I say and keep that in consideration. They get to know what I need, and they will help me.’”

Analysis: Value-creating processes in healthcare

As demonstrated above, concrete components of value described by interviewees can be separated into processes and outcomes. Furthermore, processes can inductively be grouped into four different categories, while outcomes discussed by interviewees can be seen as predominantly functional and emotional (Sandström et al. 2008).

According to the service-dominant logic, value cannot be created by service providers, in this case healthcare. Instead, services must be internalised into the customer's – patient's – sphere for value to arise (Grönroos 2011). Based on this reasoning, we see the value-creating processes as a way for healthcare providers to create value propositions (Vargo & Lusch 2004). As an example: receiving correct treatment was described as a value-creating process for many patients as it would enable them to become healthy (functional outcome). The following picture illustrates this relationship between value-creating processes and outcomes:

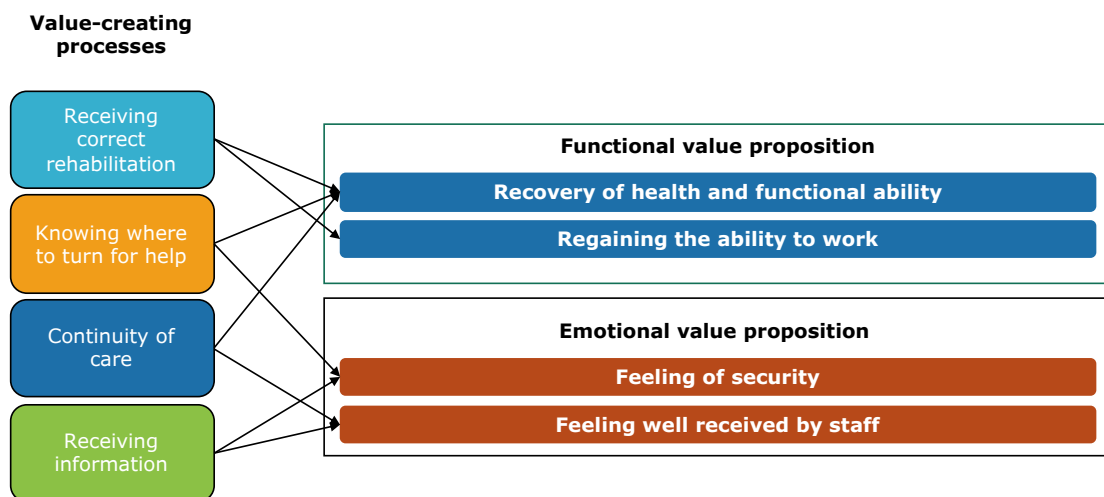


Figure 5: Illustration of how processes become value propositions of outcomes

The distinction between outcomes and processes was not clearly articulated by respondents. Many respondents discussed processes and outcomes interchangeably with regards to value-creation. However, when followed up with questions about why or how processes created value, respondents described the relationship between them; processes lead to outcomes. As exemplified by the following quote, follow-ups are seen by interviewees as a value-creating process that leads to the outcome of the patient feeling secure:

*“Then I think that there are also follow-ups, that it’s not just this healthcare encounter. They keep track of my condition. I get follow-ups and so on.
Then I feel secure as a patient.”*

Analysis: emotional and functional outcomes

Interviewees described outcomes from healthcare that we have classified as emotional or functional. This distinction was derived from theory and we can see that this pattern was present in the interviews as well (Gutman 1982; Sandström et al. 2008). It is clear from our empirical material that patients are not just valuing functional aspects of their care; they also care about emotional outcomes.

There were some examples that deviated from these two categories. One example being for patients who have teeth removed from cancer surgery. They have to pay for putting the teeth back. You could reason in accordance with Smith and Colgate (2007) or Berry (2002) that this is a cost value. Another example is one interviewee who reasoned that care in some hospitals is better than others. The interviewee’s reasoning hints towards differences in status between caregivers which could be seen as a symbolic value for patients who get to visit these hospitals (Smith & Colgate 2007). These deviations occur but are rare in the empirical material. In general, the outcomes described belong primarily to emotional or functional outcomes.

Preliminary conclusions

The analysis indicates that processes performed by healthcare providers create value propositions that lead to outcomes for patients. Using value propositions delivered by healthcare providers, patients and healthcare providers co-create outcomes for the patient. Based on our analysis so far, a reasonable conclusion would be to determine that patient value can be *defined* as a set of concrete outcomes, which are *created* from value propositions when healthcare providers perform certain processes. Such a conclusion would also be well in line with existing theory on value-creation in healthcare, defining value as outcomes which are often measurable (Porter 2010; Perfetto et al. 2018).

However, we believe such a conclusion would be a simplification. Partly, our empirical material included both discussions of value in concrete terms like above, and discussions about value as a subjective, individual concept. Furthermore, according to our model, value is the subjective evaluation of outcomes. This implies that certain processes and outcomes is not in itself value for patients. To explain how patient value is created, we must provide an answer to the question: How do patients evaluate outcomes?

Patient-perceived value

Regarding the subjectivity of value, three categories of reasoning were identified:

(1) value is a result of individual evaluation; (2) value is measured individually; (3) evaluation depends on patients' expectations.

Value is a result of individual evaluation

Many of the interviewees described patient value as highly subjectively.

Interviewees described that different patients value different things. For example, interviewees thought that quality of life was not possible to determine by anyone but the patient. One interviewee said:

"I can't tell someone that he or she has a good quality of life. That's something you perceive subjectively. And it doesn't really matter all the time what side effects you have. You can probably have a high quality of life despite very bad side effects."

Another example that suggests that value is subjective is that interviewees said that patients have individual goals that they want to achieve. Some patients want to be able to perform processes that they enjoyed before becoming sick, e.g. being politically active and holding speeches which may be impaired by a surgery for tongue cancer, or the ability to paint which may be rendered difficult because the patient had a stroke. An interviewee gave the following example:

"We think that [healthcare providers] should talk to the patient and make a plan. Because if someone wants to paint, that goal should be in their rehab plan. And that's where we think each individual should have their own plan."

Another interviewee said:

"You [healthcare providers] should listen to the patient. You [healthcare providers] should provide care based on the person's needs, not general care. That requires more listening and more understanding. I know that the doctor doesn't always have a lot of time and then maybe it's not the doctor but the nurse you should meet."

According to representatives, rehabilitation should be individualised for each patient so that they can reach their goals as best as possible. This is yet another example that suggests value is a subjective concept. Individualised care plans/rehabilitation plans were mentioned as a method to enable patients to formulate

which outcomes they value. An individualised care plan is a tool that is used by patients and healthcare professionals to co-produce and formulate goals and needs of the patient. These goals are then used as a basis in the care process for patients. Interviewees said that the individualised care plan needed to be a dynamic document that changes over time as patients make progress. One interviewee said:

"This rehabilitation plan should be alive and dynamic and should be changed during the process. My goal today might not be my goal tomorrow. Then I have moved my positions forward. So it's not static. You say: 'Yeah, when you get out of here you're supposed to be able to eat. Period.' But maybe I should be much better at that point. So this rehab plan must be a dynamic document."

Value is measured individually

To know if value has been created, it should also be possible to measure it.

Interviewees described in-depth interviews as a good way to measure patient value within a diagnosis group. Representatives for patients with psychiatric conditions thought of this as the predominant way to measure patient value, but interviewees from organisations who represent somatic or acute conditions also said that the healthcare provider needed to ask patients how they perceived value from healthcare. On the question of how to measure patient value, one interviewee said:

"Then you probably should do interviews with patients. Select a few interviews in some areas to get better answers. I think that's a good idea."

In somatic conditions however, quantitative measures such as measuring patients' functional improvement was also thought of as an appropriate measure of value in healthcare. This would however only be relevant if they had been individually adapted. Another interviewee said:

"...There is a subjective dimension of course. But there are also these functional tests that you can do. One could imagine that an in-depth test of the patient's functionality is made where you say: 'This is where we are today, and the goal could be for you to be at this higher level in six months.' And then you do another functional test to check the improvement. But then patient, physiotherapist and occupational therapist should be in agreement that this goal is attainable."

Evaluation depends on patients' expectations

Interviewees said that patients' expectations were important for their evaluation of outcomes. Patients sometimes had unrealistic expectations of their care and rehabilitation. When those outcomes were not met, they often perceived low value from healthcare. Interviewees said that it was valuable for many patients that healthcare provider and patient established realistic expectations based on patient's needs and condition that enabled them to reach the patient's personal goals. One interviewee said:

"If the expectations are unrealistic in the beginning, you can actually communicate about it and say 'No, but in this facility we can't do this. What we can do is this.' And then I think that you reevaluate that value together. Maybe you can transform it a little bit. I don't want to say lower the expectations, but maybe create a more realistic picture of what is possible to achieve in care. [...] Together you have a common starting point if you talk to each other. What are the expectations from each party? What are the resources of each party?"

Another interviewee agreed:

"Some have the expectation of full recovery and they won't be able to achieve that. And then if you're not satisfied ... it's sometimes because you have an unrealistic expectation on your own ability to recover after [becoming ill]."

Analysis: patient-perceived value and individual filters

According to our empirical findings, value is seen as a subjective evaluation of patient outcomes from healthcare. As exemplified in the interviews, outcomes are evaluated differently by different patients. Whereas one patient may perceive feeling secure as very valuable, another patient might not. So regardless of whether both patients perceive the outcome of feeling secure in healthcare process, the value they attribute to that feeling can differ. According to our model, what interviewees refer to as measuring patient value with functional tests, they're really speaking of functional outcomes (Sandström et al. 2008). This is consistent with theory of value as a subjective concept, like how value is created in the service-dominant logic (Vargo & Lusch 2004).

Our interviews show that patients' individual filters likely have the ability to greatly influence perceived value both positively and negatively. Interviewees describe that patients require individualised healthcare because all patients have different needs, goals and expectations. According to theory, needs, goals and expectations are

important determinants of how patients value outcomes (Bowman & Ambrosini 2000), what we refer to as “individual filters”, (Sandström et al. 2008).

While not apparent from the empirical material, we theorise that low expectations might not affect patients’ evaluation of value positively. As PPVs are perceived by the patient, low expectations may also “bias” their evaluation of the outcomes they perceive from healthcare and as a result a negative expectation or prior experience may make them perceive value as more negative in relation to an observer’s opinion of the outcomes they perceive. For instance, they may have been treated well by staff in the eyes of an observer, but poor reception during previous visits may have spilled over on their evaluation of this visit.

Creating realistic expectations was described in interviews as a way to increase value for patients. Based on the empirical material, the best way of managing patient expectations is through dialogue with patients. This is especially interesting, as it has not been described in the literature. It is perhaps possible to view this as an aspect of co-creation, where the patient’s management of their expectations is a part of their contribution to a joint creation process. This is however a new path of co-creation.

Discussion

Critical considerations

Relationships can also exist between outcomes, for instance that increased functional ability may be a requirement to regain the ability to work. To make sure that the model is comprehensive we have not illustrated this relationship in any of the pictures.

An interesting question to discuss is why the interviewees said certain healthcare processes are value-creating? We theorise that there may be other processes not mentioned in interviews that are value-creating for patients but are taken for granted or already work very well. Why would there be a reason to bring up something that is not a problem? So, while interviewees have identified these processes as value-creating, we think it is highly likely that there are other processes that they are not mentioning that might be value-creating. For instance, what would happen if healthcare providers would spend a lot of resources focusing on the processes we found in interviews? That could potentially lead to a reduction in performance of other value-creating processes that interviewees did not mention in interviews.

Contributions to theory

Patient's value is different from concept of value described in much of the existing healthcare theory. The definition of value in healthcare that we have derived in our analysis provides an alternative to the value equation used in value-based health care (Porter 2010) and in value assessment frameworks. Our value definition is based on the patient's perceived outcomes and the value they attribute to those outcomes. Whereas value-based healthcare might be useful to improve value in healthcare from a provider's perspective, this does not necessarily mean that patient value increases. That is an important distinction to make.

Healthcare providers can influence patient's evaluation and preconceptions of their care by tweaking the patient's individual filters. We learned from interviewees that healthcare organisations can actually increase perceived value of patients by helping them set realistic expectations of their outcomes from healthcare. Although expectations are an individual filter within the patient's control, patients can be helped by healthcare professionals to set realistic expectations. If the expectations patients have of their rehabilitation after a stroke are too high, they become very disappointed when they realise that they are not going to reach those levels. One method of setting realistic expectations that was discussed in the interviews is to use individualised health plans that are co-created

by healthcare professionals and the patient. This would create an opportunity for patients and healthcare to agree on realistic goals that can guide treatment and rehabilitation efforts. Therefore, patient participation in healthcare is crucial to match patient individual filters with the strength of healthcare's value proposition (value-creating processes) given to patients.

We have shown that business value theory can be applied to understand value in healthcare.

The pool of literature we have found on value in healthcare was surprisingly shallow in regard to the patient's own perception of value. We have instead used service value theory and have built a framework for analysing patient value from business theories such as service-dominant logic (Vargo & Lusch 2004) and service experience theory (Bowman & Ambrosini 2000; Berry, Carbone & Haeckel 2002; Sandström et al. 2008). Given the different circumstances that makes Swedish healthcare unique (e.g. being a tax financed system where regional authorities are payers), we find that business literature is still highly applicable to understanding the patient's perspective. Ultimately, patients are customers of healthcare. In the future, it is not unlikely that we will see a healthcare system where the patient has more freedom of choice. This could potentially bring the healthcare system towards being more similar to a free market. These types of changes would make business value theory even more relevant as the difference is blurred between the patient and the prototypical customer of non-healthcare service organisations.

Suggestions for further research

It would be interesting to conduct a future study exploring individual filters in more depth from a sensemaking perspective.

Our initial plan was to do a study on patient value through sensemaking theory. We believe that sensemaking is an interesting field of research that can likely be applied to patient value in healthcare. While our analysis drifted more towards value theory in service experiences, we have been able to identify something that we have called individual filters that we have defined as patient expectations, needs, beliefs and prior experiences of healthcare. We have theorised that these individual filters influence patient's perceived outcomes from care as well as how much they value these outcomes.

Our empirical material shows that chronic patients and multi-ill patients are currently perceiving low value from healthcare.

This appears to be due to the fact that the healthcare system is organised for short periods of time, and for patients with specific illnesses. Patients with multiple rare illnesses suffer in the new system at Nya Karolinska Sjukhuset (Röstlund 2019; Röstlund & Gustafsson 2019) because it is structured according to clearly defined care flows (e.g. prostate cancer). Low coordination

and low continuity mean that these patients often perceive low value from healthcare system. It would be an interesting future research study to go in depth into how to organise the healthcare system to provide higher value for multi-ill and chronic patients specifically (beyond the methods described in our thesis) and weigh the strengths and drawbacks of different methods to do this.

It would be interesting to do a game theory study of value with patients to understand how processes and outcomes correlate. This could be done by giving patients 100 points and asking them to distribute these among different healthcare processes according to their perceived importance. The next step is to give 100 points and ask patients to distribute these according to how much they value certain outcomes. By using statistical methods and regression we could examine patients implicit assumptions of which healthcare processes generate certain outcomes. It would also provide insight into how patients prioritise. Perhaps there are clear statistical correlations that show patterns in how different personalities prioritise processes and outcomes.

Practical implications

Patient value - as defined in our study - is described well by the person-centered healthcare approach. Person-centered healthcare (PCHC) is about organising healthcare around the needs of the patient. For example through making it easier for patients to participate in their care and through healthcare providers take into consideration the experience of patients when making decisions about the patient's care. The person-centered approach was covered in great detail by Vinnova and Myndighet för Vårdanalys (Andreasson & Winge 2009; Myndigheten för vård- och omsorgsanalys. 2018) and we found clear similarities between the topics in our interviews and the concept as discussed by Vinnova and Myndighet för Vårdanalys. The latter, however, are somewhat collectively exhaustive lists of different concepts that patient value – they do not attempt to analyse how the factors come in to play as we have done in this thesis. Person-centered healthcare would benefit from a more analytical discussion as to how patients construct their evaluation of the care that is given to them. Our thesis is an attempt to provide this discussion.

We find support in our study that patients, according to representatives of their interests, do actually derive increased value from the goals that are sought by person-centered healthcare.

Conclusions

Research question

How is patient value created in healthcare?

Answer

Our study has led us to the conclusion that the following model can be used as a tool to understand how patient value is created in healthcare:

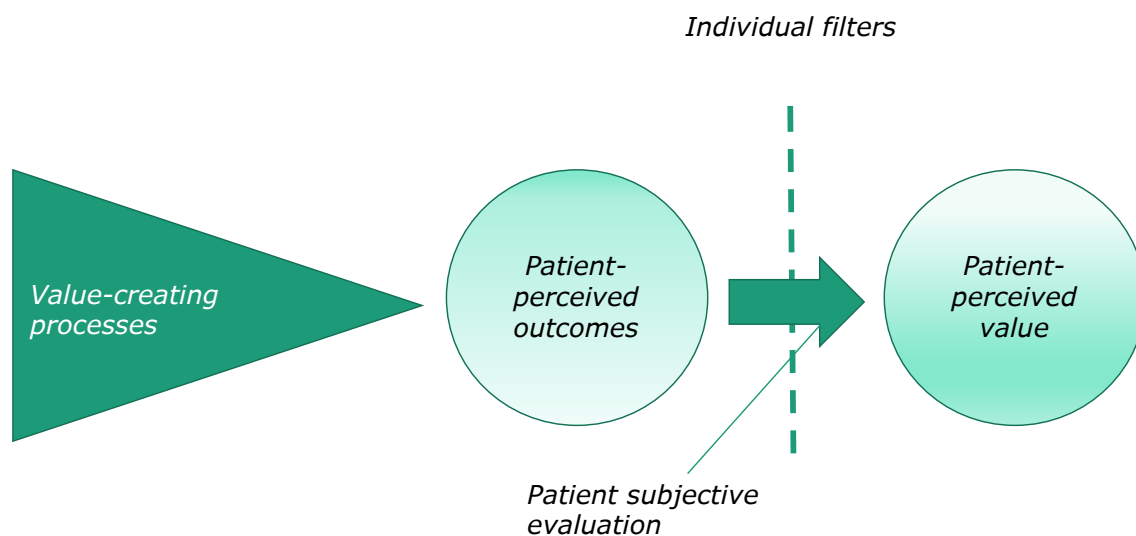


Figure 6: Theoretical model for value creation in healthcare

We find that patients interpret value subjectively by evaluating perceived outcomes from healthcare. Value-creating processes form value propositions that are translated into functional and emotional outcomes of healthcare for patients. Outcomes are evaluated using patients' individual filters such as needs, expectations and prior experiences of healthcare. Furthermore, individual and situational filters are not fixed. Healthcare providers may increase perceived value for patients by either improving processes and/or moderating patients' filters through dialogue.

There are two ways in which the healthcare system can improve patient's perceived value:

1. Improve value-creating processes. Several healthcare processes that were thought by interviewees to be value-creating were also considered to be lacking in today's healthcare system. By improving quality and frequency of these healthcare processes, patients could potentially perceive more positive outcomes such as

feeling secure, having a higher quality of life and reaching their individual goals through their care. The end result of improvement in those processes deemed to be of value-creating to patients is a higher patient value in healthcare.

2. Communicate with patients to ensure their expectations of their care are realistic. By ensuring that the expectations are realistic in regard to what can actually be achieved, the patient's perceived outcomes will be compared to that benchmark. The end result will be perceived to be of higher value when expectations are realistic.

Our results indicate that current healthcare value frameworks do not consider patients' subjective evaluation of outcomes when defining value. Current frameworks disregard emotional outcomes that patients may perceive as highly valuable. Suggestions for future research include exploring patients' individual filters, how they evaluate outcomes from healthcare and their implicit assumptions about which healthcare processes lead to value.

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Appendix I: List of interviews

Respondent	Organisation
Elisabeth Wallenius	Funktionsrätt Sverige
Eleonor Högström	Parkinsonförbundet
Kjell Holm	Strokeriksförbundet
Maritha Sedvallson	Astma- och allergiförbundet
Owe Persson	Mun- och halscancerförbundet
Malin Grände	Sällsynta diagnoser
Stephanie Juran	Sällsynta diagnoser
Margaretha Herthelius	Schizofreniförbundet

Table 2. Data about participant organisations

Organisation	Diagnoses	Number of members	Number of members with diagnosis	Incidence (antal per år)	Prevalence	Revenue
Funktionsrätt Sverige	41 different chronic diseases.					
Parkinsonförbundet	Parkinsons disease.	9000	6300	2000	22000	8.200.000 kr
Strokeriksförbundet	Stroke	9014	5376	360	145000	15.000.000 kr
Astma och allergi-	Asthma, allergies	17652	*	*	6 to 7% of adult population	*
Mun- och halscancer	Mouth and neck cancer	1350	900	1600	*	4.711.219 kr
Sällsynta diagnoser	7000 different rare diseases	15500	3791	1000	500000	5.872.000 kr
Schizofreniförbundet	Schizophrenia	*	*	*	*	*
Riksförbundet för social och mental hälsa	A large variety of psychiatric diagnoses	7000	6500	¼ mental illness at some point in life.	10% of population.	20.000.000 kr

*Information has not been delivered by organisations.

Appendix II: Interview manual

Bakgrund

- Medgivande inspelning, frivilligt deltagande
- Berätta om dig själv! Hur kommer det sig att du började jobba med dessa frågor?

Mikro

- Bakgrund till studien, diskussion om värde/kvalitet/nytta i sjukvården.
- Vad är värde inom sjukvården för dig?
 - o Värde för vem?
 - o Hur skapas det?
 - o Hur mäts det? Går det att mäta?
 - o Skillnad mellan begreppen värde, kvalitet, patientnytta?
 - o Kommunikation vårdgivare kontra patient – läkare.

Meso

- Hur ser du på värde som representant för en patientorganisation?
 - o Skillnad mot individuellt värde?
 - o Motsättning mellan gruppens behov och individens behov?

Makro

- I en samhällskontext, vad anser du att sjukvården har för uppdrag att skapa värde?
 - o För vem? Medborgare, sjukvårdhuvudmän, samhället i stort?
 - § Vilka patienter/insatser skall prioriteras? Hur avgörs detta?
 - § Indirekt: hur jämföra olika behov?