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Please tick the appropriate box: Perspectives on patient reported experience

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Measurement

Please tick the appropriate box: Perspectives on patient reported experience

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**At the time when the study was accomplished*

Abstract
Patient experience surveys are increasingly used as a method for evaluating important aspects of quality of care and the results are used politically to support general decision-making. However, there have been limited attempts to summarize the newest and most essential knowledge on how to measure and interpret patient experience data. This paper aims to summarize knowledge on the association between delivered care and patient reported experience and the factors influencing this association, and to outline a conceptual model illustrating the association. The method employed is integrative literature review. Quantitative and qualitative studies as well as theoretical and discussion papers that specifically related to the concept of patient evaluations were included. Identified literature was scoped. Thematic analysis was conducted and the results were used to synthesize a model by integrating identified factors. Expectations, patient characteristics, survey timing, loyalty to health professionals, backing up own choices and questionnaire and item design where identified as factors influencing the association between delivered care and patient reported experience. The developed model suggests that there should be a clear differentiation between patient's experience and patient reported experience. The model derived from the literature underlines that the association between received care and patient reported experience is complex. Patient reported experience data should be interpreted with caution, as reported positive experiences might neither reflect high quality care nor satisfied patients.

Keywords
Patient experience, patient reported experience, measurement, model

Introduction

Inviting patients to give feedback on health care is an essential part of patient-centered care, and results of patient experience surveys are increasingly being used and acknowledged as an important parameter of quality.[1-4] Patients have exclusive knowledge about important aspects of care, and measuring patient experiences provide us with unique information that can be used for quality improvement. Furthermore, positive experiences reported by patients have shown to be associated with patient safety, health outcomes and clinical effectiveness.[5, 6]

The results of patient experience surveys have far-reaching consequences, as these are often used as a management tool and as a basis for political decision-making. For instance, patient reported experiences are used as a part of the quality management of hospitals where results are used to identify poor performing areas and make them subject for improvement activities. Furthermore, patient reported experience measures are used as a direct quality measure in pay for performance programs[7] in UK and US.[8, 9] This rest on the assumption that the association between delivered care and a positive reported experience is straightforward.

There is a lack of consensus on how to define and how to measure patient experience.[10-13] Although the literature on the subject is massive, there are limited attempts to sum up on knowledge about the exact mechanisms by which patient reported experience is formed and the factors influencing this process, and existing models are of older date.[12, 14-17] As the literature expands, and the knowledge base of the topic becomes more diversified, it is relevant to sum up on existing knowledge and re-conceptualize.

This paper aims to accumulate the most essential and the newest knowledge on the association between received care and patient reported experience and to develop a model linking these. Implications for interpretation and appropriate use of results from patient experience surveys will be discussed in the light of the outlined model.

Patient reported experience is an often used but poorly defined concept. Patient experience is used to describe both patient reports on objective facts and evaluations based on the patients' subjective views.[18] Thus, patient experience measures include both objective information on specific events (e.g. "*did you receive written information about possible side effects?*") and subjective evaluative measures (e.g.

"*were you involved in decisions as much as you wanted to be?*"). In this paper, the focus is on patient experience measures involving some kind of subjective evaluation in patient reported data.

Method

The literature about patient evaluation is massive and characterized by diversity including both theoretical, qualitative and quantitative approaches. Integrative literature review was chosen as method because it is a structured method for reviewing and synthesizing literature on a mature topic, such that new frameworks and perspectives on the topic can be generated. The integrative literature reviews use the literature for exploration and model development. This type of literature review examines all of the research on a topic rather than selecting a subset of studies that meet a limited set of criteria for study quality. It summarizes existing knowledge and conclusions regarding the current level of knowledge on the topic. The approach used in this paper includes the following steps: problem formulation, literature search, reviewing the characteristics and quality of the findings, analyzing findings, interpreting results and reporting of results.[19-21]

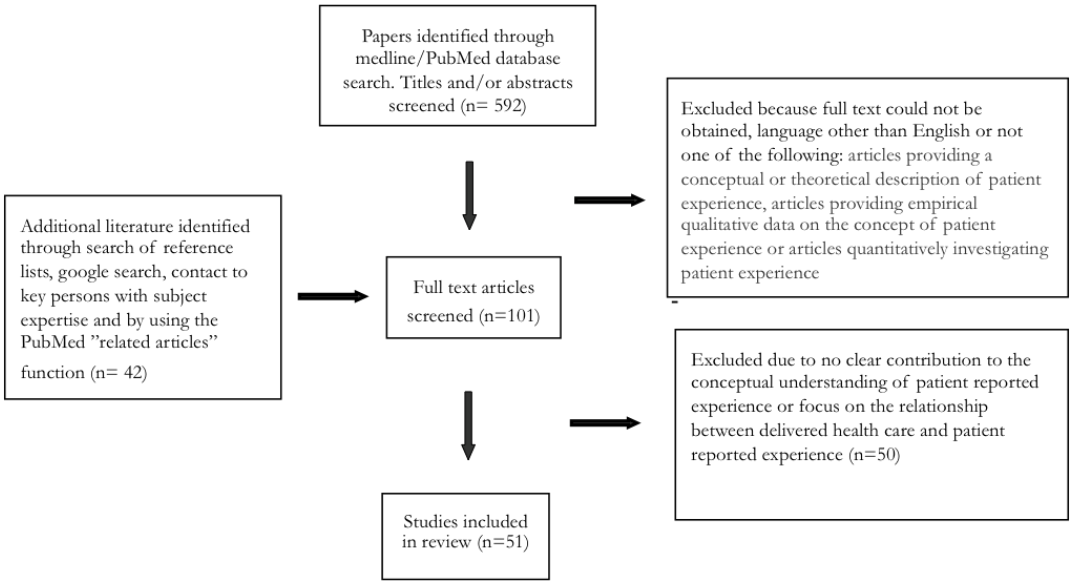
We applied a broad inclusion search methodology including both empirical and theoretical papers with the purpose of creating a thorough understanding of the association between received care and patient reported experience.

Papers were identified by performing computerized literature search of MEDLINE/PubMed. Potentially relevant papers were identified using a number of predefined search terms. Papers were accepted for inclusion if they were published in English from the start of the database until Jan. 2016. Papers were included if they had the following search terms in the title: "patient experience", "reported experience", "patient satisfaction" or "reported satisfaction", "methodology (search term method*) in combination with search terms "predictors", "determinants", "conceptualization" in title/abstract. 592 studies were retrieved through the initial electronic MEDLINE/PubMed database search. More articles were identified by searching reference lists of key papers, conferring with key persons with subject expertise and by using the PubMed "related articles" function. Furthermore, a broad, but not systematic, open google search was performed (see figure 1).

Identified papers were initially scanned by title and/or abstract. Papers were selected for inclusion if they met the following criteria: Written in English and one of the following specific type of article: articles providing a conceptual or theoretical description of patient reported experience, articles providing empirical qualitative data on the concept of patient reported experience and quantitative articles investigating patient reported experience and/or the association between received care and reported experience. We did not make any in/exclusion criteria relating to type of health care or disease group, as this would potentially limit the range and depth of identified literature.

Evaluating quality in a literature review with a wide sampling frame, including both empirical and theoretical papers, is not straightforward, and no golden standard exists. This review included papers with a wide range of research methods. Literature was coded according to two

Figure 1: Flow diagram of the literature identification process



criteria: methodological or theoretical rigor and data relevance.[21] Low data quality of included papers could be due to small samples, incomplete data, inadequate methodological design to achieve aim etc. No paper was excluded on grounds of quality issues. However, papers that were considered low in methodological/theoretical rigor and data relevance contributed less to the analytic process.

After further scrutinizing, 50 papers were excluded because they did not explicitly contribute to the conceptual understanding of patient reported experience or focus on the relationship between delivered health care and patient reported experience. The identified papers were characterized by diversity. The main part of the literature was empirical studies with a focus on general evaluations of health care or the association between an event and patient reported experience. We only included reviews, most cited and newest papers for literature, relating to the association between demographic variables and patient experiences as the literature was massive for this specific group of papers. A minor part of the identified literature was theoretical papers, qualitative studies or viewpoint papers. These papers showed to be essential because of their specific focus on the concept patient experiences or methodology concerning patient experiences. Overall, 51 papers were included. These were coded according to: type of paper, study purpose, research design as well as its findings related to the concept patient reported experience and any proposed relationship between received care and reported experience (appendix A).

Strategies for data analysis in integrative reviews are poorly developed.[21] In this review, data were thematically synthesized and categorized to uncover the key elements in patient experience, and to explore the factors affecting the association between delivered health care and patient reported experience. We chose the thematic analysis as method, as it is a flexible method that allows the integration of different types of data. We extracted findings and themes from the papers, and coded them into descriptive themes, which resembled and kept very close to the original findings of the included studies. In the next step, we examined and combined codes to form overreaching themes and patterns in data. These themes were then synthesized into broad categories from which a model describing the association between received care and patient reported experience was developed. The categorization and model development were discussed between the authors, and decisions were based on group consensus. The included factors were chosen either because they were well-proven results, or because they offered new perspectives. The conclusions of the data analysis stage are presented in table 1.

Results

The knowledge emerging from the literature emphasizes the fact that patient reported experience is a multidimensional and subjective concept that involves complex elements such as expectations, previous experiences, priorities etc. Below we present the identified factors explaining and influencing the association between received care and patient reported experience.

Patient related factors

Expectations: The literature shows that expectation is an important predictor of patient experience. [6, 11, 12, 14-18, 22-33, 38] Furthermore, it is clear from the literature that the definition of expectations is multifaceted, and that the relationship between patient expectations and patient experiences is still not clear. Four different types of expectations have been suggested. *Ideal expectations* describe a desired outcome, whereas *predicted expectations* are expectations to what will happen according to personal experiences or experiences told by others/the media. *Normative expectations* are based on what an individual think should happen and lastly, *unformed expectations* are the situation that occurs, when individuals are unable, or unwilling, to articulate their expectations.[17]

Patient characteristics: It is well described that patient characteristics, such as age and health status, relates to patient experience.[6, 11, 14, 15, 22, 23, 27, 28, 32, 34-41, 73] It is suggested that a substantial part of the difference in patient evaluations are determined at the patient level rather than at the organizational level,[34-36] but the associations are complex and not fully understood.
Generally, older patients are more positive in their evaluations of health care,[11, 15, 22, 23, 27, 28, 32, 37-40] and some studies find that patients with low educational level are more positive in their evaluations.[11, 23, 32, 37, 39-41] Furthermore, positive reported experiences have shown to be related to health status so that patients with poor overall health are being more critical,[22, 28, 32, 38-41] with the exception of certain groups of chronically ill patients.[28] Findings regarding the influence of gender and ethnicity are inconsistent.

Backing up own choice: Patients might evaluate health care positively in order to justify the time and effort they invested in receiving treatment.[11, 15] Research demonstrates that patients, who themselves choose and pay for health care report more positive experiences compared to patients who do not choose themselves.[28] In addition, it is shown that patients having chosen their physician report more positive experiences compared to patients, who have been assigned one.[42, 43]

Loyalty to health care professionals: Patients are loyal to the health care professionals and generally reluctant to criticize and they evaluate treatment and care relatively to the terms

Table 1: Results of thematic analysis

Expectations	Patients' expectations of health care influence their experiences with health care • Prominent theme in literature (21 papers) • Type of papers: 10 literature studies, five quantitative/explorative studies, three qualitative/descriptive studies, three discussion/viewpoint papers) • 11 papers published between 2001-2014 and 10 papers were published before 1998
Patient characteristics	• Prominent theme in literature (18 papers) • Type of papers: eight literature studies, eight quantitative/explorative studies, two discussion/view papers • Five papers were published after 2010, eight between 1998 and 2010. five papers were published before 1997
Age Health status Education	• High age is associated with positive reported experience (11 papers) • Patients with better health tend to report more positive experiences with health care (seven papers) • Patients with high educational level tend to be more critical (seven papers)
Backing up own choices	Patients that actively choose their health care are more positive in their reporting (three papers) • Type of papers: one literature study, two quantitative/explorative studies • Papers published in 1997, 2002 and 2003
Loyalty to health care professionals	Patients do not want to put blame on health care professionals that are having poor terms of delivering high quality care (six papers) • Type of papers: one quantitative/explorative studies, five qualitative/descriptive studies • Four papers were published after 2004, and the two others in 1998 and 1999
Timing of survey	A tendency towards more negative experience with increased time • Eight papers • Type of papers: two literature studies, five quantitative/explorative studies, one discussion/viewpoint paper • Five papers were published between 2001-2010 and three papers after 2010
Questionnaire and item design	Tools and questions influence patients' answers • 15 papers • Type of papers: two literature studies, three quantitative/explorative studies, seven qualitative/descriptive studies, three discussion/viewpoint papers/book) • Nine papers published between 2001-2010; two papers before 1998 and four papers after 2011

and working conditions of health care professionals.[44-48] Only if the patient believes that a negative event is under direct control and the responsibility of the health care professionals the patient will report a negative experience.[12]

Survey and design related factors

Timing of survey: The time when questions are asked might influence patients' answers.[6, 13, 22, 27, 49-51] Results of studies investigating the impact of survey timing are contradictory.[28] Although some studies find that patients tend to be more critical with increased time between a given event and evaluation of this event[49-51] others find little and not straightforward effect of survey timing.[52]

*Questionnaire and item design***:** The tools and questions used to assess patient experience affect reported experience.[27, 53]. Patients' answers are sensitive to wording[29, 54-56] and generally patients tend to be more critical if they have the possibility to explain their criticism.[44] Patients tend to answer more positively to general questions about their overall experience despite having reported critical events.[57]

The use of open-ended questions as a supplement to closed questions adds nuances to patient reported experiences.[58, 59] The understanding of and answer to a question is affected by the previous questions.[60, 61] Also, the administration of the questionnaire (face-to-face, telephone, postal) has an effect on patient reported experience[60, 62, 63], though the effect is not completely disentangled. Furthermore, people have a tendency to give social desirable answers.[11, 60, 62]

Model associations

The model, in figure 2, sums up knowledge on the association between received care and patient reported experience.

Through the synthesis of the literature it appeared that there should be a distinction between the patient's experience, understood as the patient's internal feeling of being content or not, and patient reported experience. Consequently, the model differentiates between "patient experience" and "patient reported experience" and suggests that "patient experience" is an intermediate factor between received care and patient reported experience.

Expectations, patients' sociodemographic characteristics and the timing of survey are, in addition to the quality of actual care delivered, identified as factors influencing and leading to the formation of the experience.

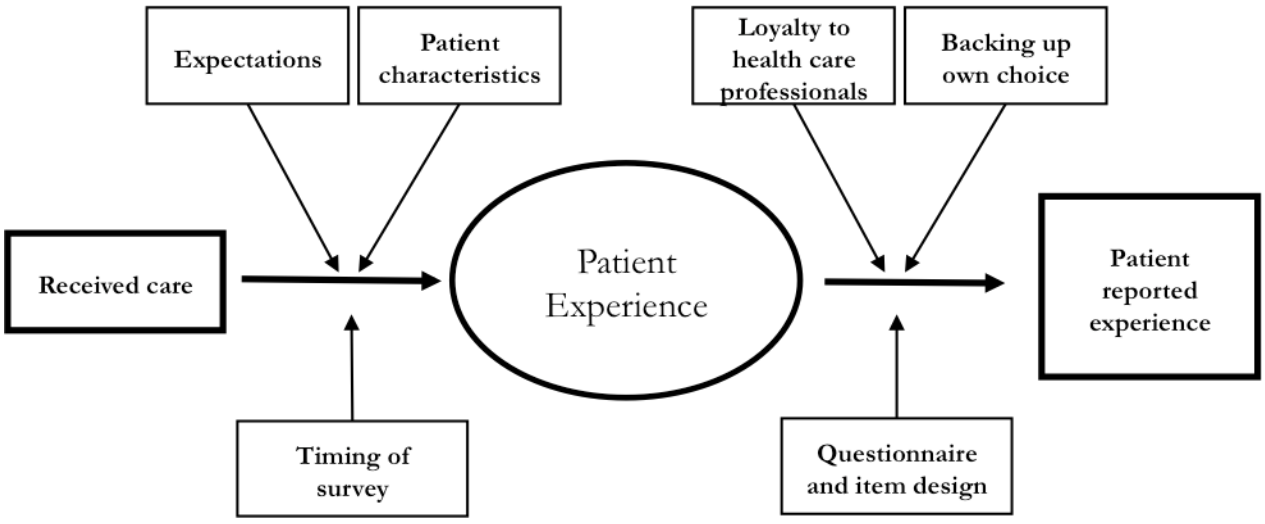
Subsequently, the association between patient experiences and patient reported experience is influenced by a number of factors including: questionnaire and item design, backing up own choice, and loyalty to health care professionals.

Discussion

Discussion of model: This model summarizes reported knowledge on the association between received care and patient reported experience. The model integrates new perspectives with previous theoretical work on patient evaluations and offers a new framework for understanding the association. At the heart of the model is a differentiation between "received care", "patient experience" and "patient reported experience", and it emphasizes that the association between these three dimensions is affected by a number of factors.
Other older models exist,[12, 14-17] but, to our knowledge, this model is the first one to make a clear distinction between patient experience and reported experience. The model emphasizes that it is important to be aware of the difference between received care, patient experience and reported experience, and that it is also important to be careful about making conclusions across these dimensions. A patient's response to a question about quality of care might reflect neither the quality of received care nor the patient's actual experience of the quality due to the modifying and potentially confounding factors. Some influencing factors are predefined and established before entering the health care system (sociodemographic background and some types of expectations) and some influencing factors are formed in the meeting with the health care system.[23]

The factors identified relate to the design of the survey (timing and questionnaire design) and to the patient and the circumstances surrounding the health care system (expectations, patient characteristics, loyalty to health care professionals and backing up own choice).

Figure 2: Proposed association between received care and patient reported experience and the factors modifying this association



The researcher can to some extent control *factors related to the survey design*. Patient reported experience data derived from well-designed surveys, using validated questions, will generate more comparable data and data that more accurately can identify areas for improvement. If there is a significant lag of time between patient experience and completion of the questionnaire, there is a risk of recall bias due to changes in perception and patients neglecting aspects that used to bother them.[27] Surveys conducted while patients are still treated do not allow patients to comment on the entire process and patients might hold back criticism with the purpose of maintaining a good relationship with the health care professionals involved in their treatment. This is an important consideration when comparing results from surveys with different data collection procedures.

Factors relating to the patient or circumstances surrounding the health care system can not usually be controlled, but it is essential to consider which effects they might have on the results.

Fulfillment of *expectations* is an important predictor of patient satisfaction, but is seldom included in empirical studies of patient experience,[28] as there are massive challenges associated with measuring expectations and investigating their effect on patient reported experience. A patient with low expectations will tend to give more positive evaluations compared to a patient with high expectations.[27] In this way, a positive experience does not necessarily indicate that the service was excellent. Delivered care can be a positive experience to one patient (meet the expectations) and a negative experience (not meet the expectations) for another patient. Furthermore, the media's portrayal of the health care system might affect patients' evaluations of care.[29] Media criticism of a specific area of health care will presumably lower expectations leading to the paradox that a negative debate about the health care system might result in more positive reported experiences, when the quality exceeds the patients' low expectations. Also the political values defining a system might have an influence on evaluations as patients seem to have different expectations about the performance of a private versus a state-funded health care system.[64]

The differences in reported experiences between different demographic patient groups might fully or partly derive from different expectations between these groups.[26] Sicker patients tend to be more critical with the possible exception of some chronic diseases.[28] Expectations change with time and accumulated experience.[17, 27] Positive reported experiences among patients with chronic diseases have been suggested to be an expression of patients over time having developed tolerance and adjusted their expectations to a given level of quality.[65]

Patients can, independent of the actual delivered service, choose to give strategic answers according to a message they want to either give, or not want to give. Positive evaluations in patient experience surveys therefore could be an expression of patients being supportive and *showing loyalty to health care professionals*, who has poor conditions for delivering high quality care.

Box 1 presents a case illustrating how different factors might affect a patient's answer, making it difficult to draw conclusions on the quality of delivered health care based on a person's reported experience

Box 1: **Case illustrating how different factors might affect patients reported experience**

A 75-year-old woman receiving cancer treatment was asked to fill out a questionnaire. The woman was very thankful that the system took care of her when she became ill. She had great belief in the competence of the doctors and she thought that the nurses were very nice to her. She had experienced several not optimal events, like nurses forgetting her medication, and letting her wait for a long time when she was in need for help. Nevertheless, she acknowledged the great work pressure that was put on the nurses. Therefore, when she was asked if she felt well looked for by the hospital staff, she answered "always", as she did not wish to put blame on the overburdened nurses.

Another factor that could have been included in the model is *priorities of care*. Different aspects of care may be more or less important to different patients. The quality of received care in combination with the relative priority the patient assign to the given aspect of care will influence the patient experience.[14, 18, 30, 31] Therefore, a delivered service that is objectively the same might result in different experiences for different persons. Priorities of care was not included in the model because it has been shown that patients with different characteristics give different priorities to different aspects of health care,[66, 67] and it is unclear whether priorities entirely or only partly are a result of patient characteristics. There have been attempts to identify the relative importance of different aspects of care, but the results are difficult to interpret due to substantial differences in included measures, population, setting etc.

Limitations of the model: Although the literature search intended to be extensive it was not exhaustive and we might not have identified all relevant literature and thereby all relevant factors. Broadening the search terms and expanding the search could have generated more knowledge.

The papers included were mainly found through medical databases, and they focused on patient evaluations. The

more general topic "consumer evaluations" is a huge research field and a broadening in focus to include literature on consumer evaluation could have added further perspectives and insights to the model.

The relationship between the constructs needs to be tested. Not all included factors in the model are supported by strong empirical evidence, and the model do not account for how the different factors of the model more exactly relate and the effect size of each association.

Therefore, the model outlined should not be considered an absolute model but a conceptual framework for understanding, how patients' experiences are formed and reported and how this process is influenced by a number of factors.

Implications for quality work: This paper stresses, that patient reported experience should be interpreted with caution, as the association between received care and reported experience is complex, and several factors influence it.

Politicians and decision makers often use high or rising levels of reported positive experiences as an argument for the health care system's success. The literature problematizes this assumption in several ways. High levels of positive evaluations could be partly independent of both the patient's experience and actual health care quality or even a result of declining quality. The last-mentioned is the case if patients show their support to overburdened health care professionals by not wanting to blame them through negative evaluations.

Many of the challenges of measuring patients' experiences are well known and consequently the focus of the most widely used surveys in Europe and the U.S.[68, 69] have shifted towards using patients as informants reporting objectively on specific experiences or events. Despite this shift in focus, the questionnaires used still include questions with subjective evaluation, which are subject to a number of influencing factors.

Some large scale surveys still use measures of overall evaluation of health care,[70, 71] and it is noteworthy that these global measures are quite often highlighted when synthesizing survey results.[72] However, as outlined in this paper scores on general questions most probably are over-estimated.

Patients have a tendency to give positive answers and they are generally reluctant to criticize.[44, 46, 73] Patients' reported experiences are influenced by gratitude, loyalty and a need for maintaining a good relationship with health care professionals,[44, 46, 47] but if the patient experiences errors, neglect or injustice, the patient will report their negative experience.[48, 56, 74] It is shown that negative answers tend to be more reliable[12, 74] and, therefore, negative answers should be given more attention than positive answers.

It is important to be careful about making straightforward conclusions when comparing patient reported data between different health care units. Comparisons of patient reported experiences between different health care providers or units who do not serve the same patient profile are likely to be misleading unless adjusted for case mix.[39, 63, 75] Consistency in the study design is another condition for making usable comparisons, and in practice it is very difficult to even out all bias and influencing factors. Furthermore, patient's expectations to different health care professionals and services differ.[25] Therefore, comparisons should always be done with caution.

There are great gaps in the existing knowledge of factors affecting patient reported experiences, and more research is needed. There should be a future focus on refining methods and survey instruments.

Conclusion and Recommendation

This paper examines the association between delivered care and patient reported experience. We find that patient experience ought to be seen as an intermediate factor and that a number of factors including: expectations, patient characteristics, loyalty to health care professionals, backing up own choices, and questionnaire- and survey design, affect the association.

Measures of patient experiences are important information and should be a priority for health care managers. However, there are significant challenges with regard to analyzing and interpreting data, thus practitioners must be cautious when using the information in quality assessment and in decision-making processes.

It is important to be aware of the differences between received care, patient experience and reported patient experience as these are very different concepts and a number of factors influence the associations between them. This awareness is especially important when using data for decision-making purposes. Measures of patient experienced quality should not be used to conclude that the quality of care is good (focus on absolute score). Instead, patient satisfaction surveys should be used as a management tool for identifying areas of improvement (focus on relative scores). For instance, if 87 % of the patients report being very satisfied with information about the risk of late affects it is very hard to judge whether this is actually an acceptable result. Whereas the knowledge that patients in general rated information about the risk of late effects much worse than information about surgical procedure and information on possible side effects provides a clearer idea that information on possible side effects should be improved. In this way, using patient

experience scores relatively can be used to identify potential problems and priorities for quality improvement initiatives

There is conceptual and methodological uncertainty regarding what constitutes patient experience, and how it should be measured. There is a need for developing an explicit and accepted model and robust methods for the measurement and interpretation of patient reported experiences. The model depicted in figure 2 is a starting point.

The complexity of the concept should not stop us from using patient experience data. We just need to use them in a better way. Whatever theoretical challenges there are, we need to overcome them because the patient perspective on quality of care is crucial if we want to achieve a patient-centered health care system.

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Appendix A. Identified papers

Author /year	Studytype	Aim	Design	Findings
Aday & Cornelius 2006	Book	To present a comprehensive framework to help guide survey planners	NA	Order and context of items impact respondents' answers Answers can be affected by social desirability considerations and administration of questionnaire
Ahmed et al 2014	Literature study/Discussion/Viewpoint	To explain why patient experience is important in its own right, and its relationship to other domains of quality	NA	Quality is a multi-dimensional concept. Patient experience positively associated with clinical quality, but differences in experience scores between groups may in part reflect differences in expectations of different population groups
Ammentorp et al 2006	Quantitative /Explorative	To investigate determinants of patients' priorities and satisfaction, and to examine the relationship between fulfillment of expectations and satisfaction	Two self-administered questionnaires among 300 parents of children in a pediatric acute care	Correlation between fulfillment of expectations and satisfaction were found
Baker et al 1997	Quantitative /Viewpoint	To redesign a model of patient satisfaction in general practice and to discuss the components of the models	NA	The components of the model was confirmed with results from questionnaires in several studies: characteristics of patients (age, sex, culture, experience of care, expectations, others), requirements for personal care, priorities by patients, elements of care, interaction with health care and behavior
Bjertnæs 2012	Quantitative /Explorative	To estimate the effects of different predictors of overall patient satisfaction with hospitals	Self-administered questionnaires mailed to 24,141 patients.	Most important predictors for overall patient satisfaction are patient-reported experiences and fulfilment of expectations. Age was not found to be a significant predictor
Bjertnæs et al 2012	Quantitative /Explorative	To assess the association between survey timing and patient-reported experiences with hospitals	10,912 (45%) patients answered a postal questionnaire after discharge from hospital.	Survey time was significantly and negatively related to patient
Bleich et al 2009	Quantitative /Explorative	To explore what determines satisfaction with the health care system above and beyond their experience as patients.	Data from the World Health Survey for 2003	Patient experience was significantly associated with satisfaction and explained 10.4% of the variation around the concept of satisfaction. Patient expectations, health status, type of care, and immunization coverage were also significant predictors of health system satisfaction. Together they explained 17.5% of the observed variation, while broader societal factors may largely account for the unexplained portion of satisfaction with the health-care system.
Bowling et al 2012	Qualitative/ Explorative/ Literature study	To assess the literature on the concept and measurement of patients' expectations for health care and to develop and test a measure of patients' expectations	Narrative review (211 papers) Semi-structured exploratory study and surveys of GP patients and hospital outpatients before and after surgery/clinic visit to measure pre-visit expectations and post-visit experiences	Literature of expectations are generally weak and sparse. Overall, pre-visit realistic expectations were lower than patients' ideals or hopes. Most post-visit experiences indicated some unmet expectations and some expectations that were exceeded.
Chow et al 2009	Literature study	To provide an overview of the concept of patient satisfaction	NA	Determinants of patient satisfaction: expectations, patient characteristics. Satisfaction components: Affability, accessibility and availability, and ability.

Cohen et al 1996	Qualitative/ Quantitative	To examine the consistency of survey estimates of patient satisfaction with interpersonal aspects of hospital experience.	Interview and postal surveys, evidence from three independent populations	For some items, there was substantial disagreement among the surveys, possibly due to differences in wording.
Collins & O'Cathain 2003	Qualitative/ Descriptive	To explore how patients describe what it meant to them to be either satisfied or very satisfied with healthcare	In-depth interviews with 30 dermatology patients	Patients differentiated between being satisfied or very satisfied with healthcare. Being satisfied with healthcare was described as care and management had been 'acceptable' or 'sufficient' but not 'outstanding.' Being very satisfied was described as service ranged from 'better than average' to 'outstanding'
Coyle 1999	Qualitative/ Descriptive	To provide insight into the meaning of dissatisfaction by exploring how dissatisfied users attribute cause, responsibility and blame for their experiences	41 people identified as experiencing problems with their health care were interviewed in depth	A number of normative expectations through which health work was routinely criticized included respondents casting aspersions on the professional and preserving their own moral identity through demonstrating competence, knowledge, rationality, reasonableness and concern for others. Patients had recognition of factors outside the control of the health care provider.
Crow et al 2002	Literature review	To summarize the results of studies investigating methodological issues of satisfaction, to identify determinants of satisfaction with healthcare in different settings, to explore gaps in existing knowledge	128 articles identified through systematic literature search. A further 48 articles were added after exploring reference lists and updating the electronic search	Methodological issues: Interview method, survey design issues. Determinants of satisfaction: expectations, prior experiences, health status, age, patient-practitioner relationship, choice of service provider
Cleary & McNeil 1988	Literature study	To provide a brief overview of the satisfaction literature	NA	More personal care is associated with higher levels of satisfaction. Patient characteristics and expectations correlates with satisfaction
De Vaus 2014	Book	To provide clear advice on how to plan, conduct and analyse social surveys.	NA	The order and context in which the items are placed has an impact on the meaning of certain questions, and how respondents answer them. Answers can be affected by social desirability considerations and the administration of the questionnaire
Edwards et al 2004	Qualitative/ Descriptive	To investigate the pressures that promotes patients to make allowances for poor care, and avoid evaluating it negatively	Using a longitudinal design and in-depth qualitative interviews, the patient's process of reflection was explored	Three psycho-social pressures affected patients' answers: the relative dependency of patients within the healthcare system, their need to maintain constructive working relationships with those providing their care, and their general preference for holding a positive outlook
Elliott et al 2009	Quantitative /Explorative	To evaluate the need for survey mode adjustments to hospital evaluations and to develop appropriate adjustments	Questionnaire survey. Patients randomized to mail, mixed modes, telephone and active interactive voice response	Patients randomized to the telephone and active interactive voice response modes provided more positive evaluations than patients randomized to mail and mixed modes. Mode effects are generally larger than total patient-mix effects
Hall & Dornan 1990	Quantitative /Explorative	To examine the relation of patients' socio-demographic characteristics to their satisfaction with medical care	Questionnaire survey	Greater satisfaction was significantly associated with higher age and less education, and marginally significantly associated with being married and having higher social status
Hekkert et al 2012	Quantitative /explorative	To determine whether differences in patient satisfaction are attributed to the hospital, department or patient characteristics	Cross-sectional surveys of Dutch patients.	A substantial part of the difference in patient satisfaction scores are determined at the patient level, while the variance to a lower extent can be attributed to the hospital/department level.

Hills & Kitchen 2007	Literature study and model development	To develop a theory to underpin the concept of satisfaction in physiotherapy	NA	A theory of patient satisfaction with physiotherapy is developed. The fundamental components of the model are fullfilment of need and expectations being met
Jackson et al 2001	Quantitative /explorative	To explore correlates of patient satisfaction at varying points in time	Correlates of patient satisfaction at varying points in time were assessed using a survey with 2-week and 3-month follow-up in a general medicine walk-in clinic, in USA	Immediately after the visit 52% patients were fully satisfied with their care, increasing to 59% at 2 weeks and 63% by 3 months. Patients older than 65 and those with better functional status were more likely to be satisfied. At all time points, the presence of unmet expectations markedly decreased satisfaction
Jensen et al 2010	Quantitative /Explorative	To determine if the interval between an outpatient visit and the assessment of the quality of care influences user satisfaction between questionnaires completed at different time	Group one completed an electronic in the outpatient clinic and a paper questionnaire 3-6 weeks after the visit; group two completed a paper questionnaire in the outpatient clinic and a paper questionnaire 3-6 weeks after the visit; and group three completed a paper questionnaire 3-6 weeks after the visit. A total of 1148 patients	User satisfaction was significantly lower when the assessment was made after a visit to the outpatient clinic compared to an assessment made at the clinic.
Jenkinson et al 2002	Quantitative /Explorative	To determine what aspects of healthcare provision are most likely to influence satisfaction with care and willingness to recommend hospital services to others and, secondly, to explore the extent to which satisfaction is a meaningful indicator of patient experience of healthcare services	Patients (3592) were asked to evaluate their overall experience of an episode of care and specific aspects of their care	Age and overall self-assessed health were only weakly associated with satisfaction. Some patients who reported satisfaction with care did also indicated problems with their inpatient care. 55% of respondents who rated their inpatient episode as "excellent" indicated problems on 10% of the issues
Johansson et al 2002	Literature review	To describe the influences on patient satisfaction with regard to nursing care	Literature search identified 30 studies	Eight domains influences patient satisfaction with nursing care: the socio-demographic background of the patients, patients' expectations, the physical environment, communication and information, participation and involvement, interpersonal relations between nurse and patient, nurses' medical-technical competence, and the influence of the health care organization on both patients and nurses.
Judge et al 1992	Qualitative/ Quantitative	To review trends in public opinion during the 1980s and to show how the reporting of the public's perceptions can be influenced by methodological issues	Comparison of results of two different surveys of patient experience	A range of demographic, socio-economic and health status characteristics, as well as media coverage of health-related issues, are found to be related to expressions of satisfaction, in addition to recent experience of using health services. Experiences can also be crucially affected by wording of questions, political and peer group cultures and the media can also influence by highlighting specific issues
Kalda et al 2002	Quantitative /Explorative	To evaluate the association between choosing one's own primary care doctor and patient satisfaction with primary health care. To	Cross-sectional study using a pre-categorized questionnaire sent out to a random sample of Estonian adult population	Presence of a personal physician appeared the most important predictor of high satisfaction. Practice size, patient age and health status also influenced patient satisfaction

		evaluate factors related to population's satisfaction with primary health care	(N=997).	
Kmietowicz, 2012	Discussion/ Viewpoint	To present problems with the use of a specific instrument in order to measure patient experience	NA	Patients objected to certain words, did not understand word or misinterpreted words
Koné Péfoyo & Wodchis 2013	Quantitative /Explorative	To determine the dimensions of patient satisfaction, and to analyze the individual and organizational determinants of satisfaction dimensions in hospitals.	Patient and hospital survey data as well as administrative data from more than 30,000 patients	More than 95% of variation in patient satisfaction scores was attributable to patient-level variation, with less than 5% attributable to hospital-level variation. Individual patient characteristics (severe illness, higher education) were associated with lower ratings.
LaVela & Gallan 2014	Literature study	To explore and describe what is known about measures and measurement of patient experience and describe evaluation approaches/methods used to assess patient experience.	NA	Patient experience is a complex, ambiguous concept that lacks a common definition and there are multiple crosscutting terms. The timing of measurement must fit the need at hand, and make both practical and purposeful sense and be interpreted in light of the timeframe context.
Linder-Pelz 1982	Quantitative /Explorative	To test expectations, values, entitlement and perceived occurrences as determinants of patient satisfaction	Before attending a doctor 125 patients were asked to rate their expectations, entitlements and values. After the encounter the same patients were asked to rate different aspects of health care	Social psychological variables together were found to explain only a small proportion of the variance in satisfaction, although their contribution varied with the dimension of satisfaction. Expectations consistently explained most of the variance in satisfaction ratings; particularly noteworthy was the direct effect of prior expectations of the doctor's conduct on subsequent satisfaction
Manary et al 2013	Discussion/ Viewpoint	To present critics of patient experienced measures and to argument for proper use of these measures	NA	Issues of timing, expectations and confounding factors are discussed
Marcinowic h et al 2002	Quantitative / Qualitative	To compare replies to open-ended and closed questions about patient satisfaction with family doctors	A self-administered questionnaire was mailed to 1000 Polish patients (response rate 57.9%)	There were some discrepancies between the closed-question response and the open-ended question replies. Some of those who replied good or very good to the closed question expressed negative views in response to the open-ended questions Answers to open-ended questions provide information that answers to closed questions may not elicit
O'Malley et al 2005	Quantitative /Explorative	To develop a model for case-mix adjustment of Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospital survey responses, and to assess the impact of adjustment on comparisons of hospital quality	Questionnaire survey of 19,720 patients discharged from 132 hospitals	The most important case-mix variables are: hospital service, age, race, education, general health status, speaking Spanish at home, having a circulatory disorder, and interactions of each of these variables with service. Case-mix adjustment has a small impact on hospital ratings, but can lead to important reductions in the bias in comparisons between hospitals
Perneger 2004	Litterature study	To descripe a model for case-mix adjustment of satisfaction scores or patient report scores.	NA	Patient characteristics are associated with type of health care received, how care is experienced, expectations regarding care, and a global tendency to give a positive or negative opinion.

Papanikolau & Ntani 2008	Quantitative /Explorative	To assess patient satisfaction	Questionnaire survey of 367 patients measuring overall satisfaction and satisfaction with different aspects of care Participants were also asked to indicate, in an open-ended question, the most positive and the most negative aspects of their care	Patients' bad experiences with aspects of their care was not directly reflected in low levels of satisfaction. Patients had to wait long hours to get an appointment with a doctor or after their examination to be admitted to the hospital. Many patients had to rely on a personal nurse and to pay extra money to the medical and nursing staff. They considered lack of staff as the main drawback of the hospital. However, their overall satisfaction was very high.
Pascoe 1983	Literature study	To review the literature on patient satisfaction in primary health care settings	NA	Satisfaction is seen as patients the health care recipient's reaction to the context, process, and result of the experience Patients might express satisfaction in order to justify the time and effort they invested in receiving treatment
Rahmqvist & Bara 2010	Quantitative /Explorative	To examine the relation of respondents' characteristics and perceived quality dimensions of health care to overall patient satisfaction	A questionnaire was sent to 724 patients in out-patient medical care	Patients with perceived better health status and those with less education were more satisfied
Riiskjaer et al 2012	Quantitative /Qualitative	To analyse patients' inclination to comment in generic patient surveys and to evaluate how these comments were received and used for quality improvement by the hospitals	The study is based on data from four rounds of patient satisfaction surveys (75 769 patients) from 1999 to 2006. Questions and their applicability were evaluated by hospital and department management teams (173) in a survey and by hospital employees and leaders (24), in semi-structured interviews	76% of the patients added one or more comments to the questionnaires. The patients' inclination to comment increased over time. The patient's inclination to comment was highest for the most and the least satisfied patients. Comments seem to make patient satisfaction measurements more informative and patient-centered
Saal et al 2005	Quantitative /Explorative	To compare patients' assessments of anaesthesia care after three different periods of time following discharge from hospital	Patients were assigned to receive a standardized, validated psychometric questionnaire either one, five or nine (748, 743, and 723 patients) weeks after discharge from hospital	The response rate was significantly lower at nine weeks compared with one and five weeks after discharge. The total mean problem score remains unchanged but certain fields show fewer problems after nine weeks compared with one and five weeks
Salisbury et al 2010	Quantitative /Explorative	To explore whether responses to questions in surveys of patients that purport to assess the performance of general practices or doctors reflect differences between practices, doctors, or the patients themselves	Data analysis of data from a study of access to general practice (150 different doctors in 27 practices), combining data from a survey of 4,573 patients	Only 4.6% of the variance in patients' satisfaction ratings were a result of differences between practices. The remaining variance resulted from differences between patients plus random error. In contrast, when asked to report on their experience with usual time they had to wait for an appointment, more than 20% of the variance in responses was a result of differences between practices
Schmittdiel et al 1997	Quantitative /Explorative	To compare satisfaction between patients who chose their primary care physician and patients who were assigned a physician	Cross-sectional mailed survey with 10,205 respondents (response rate of 71.4%)	Patients who chose their personal physician (n=4,748) were 16-20 % more likely to rate their satisfaction as "excellent" or "very good" than patients who were assigned a physician (n =5,457) for nine satisfaction measures

Schneider & Palmer 2002	Qualitative/ Descriptive	To discusses challenges and difficulties involved in researching and interpreteting user views using different approaches	337 closed-ended facility exit interviews and 14 open-ended community-based focus group discussions to obtain users' views on the same set of primary care providers	Users evaluated providers against their experiences with other health care services and responses are thus highly context specific. More negative picture in the exit interviews, suggesting that where and how views of health services are elicited has a large bearing on the results obtained. Focus group discussions appeared to encourage dramatic representations
Sitzia & Wood 1997	Literature review	To review issues and concepts related to patient satisfaction	Review of more than 100 articles relating to the concept of patient satisfaction	Expectations seems to be an important component of patient experience. Older patients and patients with lower educational level seem to be more satisfied with care. Less evidence for the association between social class, gender, and ethnic origin and patient satisfaction. Patients answers according to social desirability, to justify time spend and indifference. Dissatisfaction only at extreme events.
Sixma et al 1998	Literature study	To develop a conceptual framework for measuring quality of care	NA	Patient/consumer satisfaction is regarded as a multidimensional concept based on a relationship between experiences and expectations.
Staniszewska & Henderson 2004	Qualitative/ Descriptive	To explore the way in which patients express their evaluations	Semi-structured interviews with 41 outpatients. Patients were interviewed before and after appointment. Six were re-interviewed six weeks after the appointment to explore whether evaluations had changed	Patients were reluctant to offer negative criticisms. They needed particular conditions in which to express their negative evaluations, and used a variety of adaptive strategies to overcome social pressures that inhibited negative evaluation and promoted positive evaluation
Steinberger	Qualitative/ Descriptive	To investigate the effect of context on responses to questions	Pairing two questions related to anger experience and expression in development. Item response theory analysis was performed.	Pairing the questions changes the item's context. For some of the items, responding to a single or paired question affected the extremity of responses.
Stevens et al 2006	Quantitative /Explorative	To investigate whether the assessment of patient satisfaction at different time points resulted in different outcomes	152 orthopedic patients filled in a questionnaire at hospital discharge and one to 12 months after discharge	Satisfaction ratings decreased significantly at follow-up. Satisfaction with postoperative information decreased the most after discharge
Thompson & Sunol, 1995	Literature review	To distill the main definitions of expectations, to illustrate practical models of the relationship between expectations and satisfaction, to identify the influential personal and social variables, and to consider the special nature of health care	A review of 18 journals and a number of relevant books	Main definitions are presented and a model illustrating the relationship between expectations and satisfaction and influencing social and personal variables. Identifies different types of expectations (ideal, predicted, normative, unformed)
Tremblay et al 2015	Quantitative /Explorative	To report on patients' perceptions of cancer services responsiveness and to identify patient characteristics and organizational attributes that are potential determinants of a positive patient-reported experience	A cross-sectional questionnaire survey with 1,379 Canadian cancer patients	The individual determinants of overall responsiveness found to be significant were: good self-assessed health status, high age, and low education level. Organizational determinants were academic affiliation and geographic location of the clinic

Ware 1983	Qualitative/ Quantitative	To develop a patient satisfaction questionnaire	Field test over a four year period including formulations of models of patient satisfaction, construction of measures of those dimensions, empirical tests of the measures and models.	Significant effects of patient expectations and value preferences on satisfaction ratings were noticed. These effects were small relative to the impact of experiences reported by patients.
Williams et al 1998	Qualitative/ Descriptive	To identify whether and how service users evaluate services	Unstructured in-depth interviews with 29 users of mental health services and structured discussion around their responses on a patient satisfaction questionnaire	Patients frequently described their experiences in positive or negative terms. However, the process by which these experiences was transformed into evaluations of the service was complex. Consequently, many expressions of satisfaction hid a variety of reported negative experiences