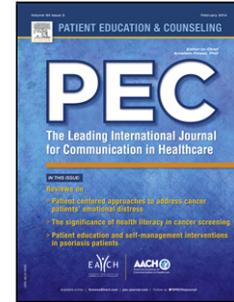


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Title page**What do patient values and preferences mean? A taxonomy based on a systematic review of qualitative papers**

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Highlights

- There is a lack of useful categorization of patient values **and preferences** for clinical and evidence based practice
- Patient values **and preferences** are diverse but can be summarized into seven key elements
- Conceptualization of patient values **and preferences** is a bases for quality improvements in healthcare

Abstract

Objective: In order to deliver good healthcare quality, it should explicitly be taken into account what patients value in healthcare. This study reviews qualitative studies in which patients express what they value. Based on this body of literature a preliminary taxonomy is designed.

Methods: A systematic review of qualitative papers on what patients' value.

Results: 22 studies out of a total of 3259 met the inclusion criteria. After critical appraisal, data extraction was carried out by two researchers independently and revealed values related to 1) the individual patient; 2) the expected behavior of professionals and 3) the interaction between patients and professionals. Seven key elements were recognized on the bases of content analysis; 1) uniqueness, 2) autonomy, 3) compassion, 4) professionalism, 5) responsiveness, 6) partnership and 7) empowerment.

Conclusion: This study gives a rich insight into what patients value in various contexts and provides a promising taxonomy in line with patient centered based theories. The taxonomy needs further empirical research for a deeper insight and clarification in its elements.

Practice Implications: This review and preliminary taxonomy contribute to the conceptualization of patient values as a bases for guidelines, policy and daily practice.

Keywords: patient values; patient preferences; patient centered; qualitative research

1 Introduction

Healthcare professionals strive to deliver the best possible care for their patients on a daily basis. To achieve this ambition, they have to balance the rapidly evolving medical knowledge and technological possibilities with an increasing number of chronic diseases, comorbid conditions, economic budgets, and patient expectations and preferences.[1, 2] Patient expectations and preferences are under scrutiny as the medical community and policymakers realize that these are important and are associated with treatment outcome, duration, and higher appreciation of the received care. For this reason, research into the aspects of the delivering of healthcare services that patient particularly value is important.

These ideas are currently reflected in the opinions of scholars and policymakers that advocate for health care models based on patient-centered care. Something all of these models has in common is the integration of scientific evidence with the needs or wishes of the individual patient.[3-5] One example of this line of thinking is the advice from The Institute of Medicine on the characteristics of healthcare quality. This advice says that healthcare must be 1) effective, 2) patient-centered, 3) safe, 4) timely, 5) efficient and 6) equitable. Patient-centered implies the provided care is respectful and responsive to individual patient preferences, needs, and values, and ensures that patient values guide all clinical decisions.[1, 6-8]

The Picker Institute defines patient-centered care as the practice of caring for patients (and their families) in ways that are meaningful and valuable to the individual patient.[9] It includes listening to the patient as well as informing them of and involving them in their care. The eight principles the Picker Institute conducted are respect for the patient's preferences, coordination and integration of care, information and education, physical comfort, emotional support, involvement of family and friends, continuity and transition, and access to care. With respecting patient values, preferences, and expressed needs they mean involving patients in decision making, and recognizing they are individuals with their own unique values and preferences.

However, the concepts and elements mentioned in these models, such as values and preferences are often loosely employed. It seems that the concepts are used interchangeably.[8, 10] Indeed, some scholars claim that patient values are at this moment still underconceptualized and underresearched.[11-13] A second consideration is that these concepts are not based on what patients themselves express what they value and prefer.

In our research we decided to focus on what patients value, without making a rigid demarcation between values and preferences, because that is not done in the existing frameworks on patient values and patient centered care, nor by patients themselves. As a more open approach we understand values as referring to a moral and ethical orientation, and preferences as an orientation to personal feelings. Or as Warren, McGraw and Van Boven suggest, values express what is desirable and (underlying) preferences are connected to attitudes.[14] In this sense, conflicts can arise between values and preferences. E.g. the patient wants to decide for him self (value) and thus prefers to be informed adequately and timely (preference). We can assume a contextual hierarchy in preferences in taking decisions,[14] but again, in the identified research, and in the state of art documents on patient centered care and patient values, those dynamic processes are not reported nor analysed.

Embracing the statement of the IOM and the Picker Institute that patients values should guide clinical decisions, we aim to design a taxonomy based on what patients value, expressed by themselves and in their own words.

2 Methods

This review has an exploratory nature. PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) were used to design this review.[15]

2.1 Eligibility criteria

This review explores what patients find to be important in healthcare by including articles that report on what the patient values or prefers from the patients' perspectives.

We specifically wanted to explore the authentic expressions from the patients' point of view. Therefore, the keywords qualitative analysis, qualitative research and qualitative to the thesaurus were included in the search string in addition as we expected it would lead towards studies concerning these authentic expressions or quotes.

2.2 Information sources and search parameters

The following databases were searched on March 31st 2014: Embase, Medline OvidSP, Web of Science, Cochrane Central, Pubmed Publisher and Scopus and Psycinfo. Keywords were derived from the research question and transformed to associated "Emtree" terms and free-text words. The following thesaurus was used in Embase:

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((patient* OR client* OR 'patient s') NEXT/1 (value*)):ab,ti OR (('patient preference'/de OR ('personal value'/de AND patient/exp) OR ((patient* OR client*) NEXT/1 (preference*)):ab,ti) AND ('qualitative analysis'/de OR 'qualitative research'/de OR (qualitative):ab,ti)).
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In addition, Medline OvidSP, Web of Science, Cochrane Central, Pubmed Publisher, Scopus and Psycinfo were searched in a similar fashion, making use of their own, relevant thesaurus.

2.3 Study selection

In order for them to be included, studies had to meet the following criteria; 1) patient values are explored from the patients' point of view; 2) the article is written in English; 3) the original article is available in full text.

Initially, the search results were screened based on title and abstract by CB. Studies that were found to meet all inclusion criteria were evaluated in full-text by two authors (CB, LV) before inclusion in the review.

2.4 Data items and collection

Information was extracted from the included articles. Our method is in line with the inductive analysis by Sandelowski and Barosso.[16] As they suggest, we distinguished three stages for qualitative metasynthesis; 1) the extraction of determinants per article; 2) the grouping of determinants on similarity; 3) the abstraction of findings into patterns, overlaps or comparisons. All stages were performed simultaneously by two authors (CB, LV). The results of the first stage were presented in an evidence table (Table 1). This information refers to the aim, the patient population and country of origin of the studies, the study design, the sample size and all founded determinants. CB and LV discussed and reread the results several times, and after discussion and analysis they extracted three perspectives in patient valuing and seven key elements. These findings were discussed with all authors.

2.5 Risk of bias in individual studies

The methodological quality of the included articles was assessed with the Critical Appraisal Skills Programme tool.[17] The CASP can be used to assess studies employing various qualitative methods. In the first stage the appraisal was carried out independently by two researchers (CB, LV). Thereafter the items of dissension were discussed. If consensus could not be met a third opinion was asked of JH.

2.6 Summary measures

The principal outcome of this review was patient valuing, which was also the main issue in the included studies. Patient valuing refers to what patients value in their interaction with professionals. The terms *client/ patient value or preferences* were used in 30% of the cases, common aliases are patients' views, perspectives, perceptions, experiences, priorities, needs, and beliefs.

3 Results

3.1 Study selection

Due to the extensive range of the research question, a total of 3259 studies were initially identified (Figure 1; Study selection procedure).

By scanning the titles and abstracts, 2613 studies were found without a relationship to the concept of patient values and were excluded. After an initial scanning of the texts, 646 studies remained and were categorized into six subgroups; 1) *theoretical* (n=125), which theoretically describes why patient values must be integrated in healthcare decisions, consists of articles, papers, and editorials; 2) *costs* (n=93), which contains articles concerning integrating patient values in medicine and the effect on cost-effectiveness; 3) *treatment* (n=184), containing studies of patient involvement in decision making or 'shared decision making'; 4) *professional* (n=117), consisting of articles about the interpretation of patient values by professionals and the (education in) integration of patient values in their practices; 5) *satisfaction* (n=32), consisting of surveys on patient satisfaction, in which the questionnaires were composed from the point of view of the researchers rather than that of the patients; 6) *meaning* (n=95), a category in which patient values per se are researched. Only 22 articles from this category were included: 39 articles were not empirical studies and the other 34 articles did not examine patient values from the patients' point of view but rather discussed the thoughts or assumptions of caregivers or institutions about patient values.

3.2 Quality assessment

The quality of the studies was assessed with the CASP for qualitative studies by two independent researchers (CB, LV).[17] They reached 84% consensus after the first blinded round. There was complete consensus about four articles, five articles had a dissension on one item, ten articles on two items and three articles on three items. The results of the appraisal are represented in table 2.

According to the CASP screening questions three studies are methodologically thoroughly and correctly executed. The other studies showed varying degrees of ambiguity in the fields of the research question, the research design, data-saturation, the role of the researcher, ethics approval and the data-analysis. Our impression is that qualitative studies reveal rich data, but that there is a lack of a consistent format which we attribute to the

fact that patient value as a concept is an underconceptualized area. Besides this, we consider the methodological quality of all studies to be sufficient to be included in the data in our review.

3.3 Determinants of patient values

As mentioned before the characteristics of the included studies are summarized in Table 1. The studies were carried out in different contexts in the Western world (except Lee, et al.[18]) and were all based on a qualitative research design. 19 studies used focus groups or (semi structured) interviews to collect their data. The other studies were a mixed- method study,[19] a study that used expressive writings[20] and a cross-sectional study with two questionnaires including an open-ended questionnaire to receive richer data.[21] In total 1309 patients were interviewed.

After thoroughly reading the articles and through constant comparative analysis[22] we found 414 factors related to patient values from the patients' perspective, which we called *determinants*. These can be defined as the factors that patients value in healthcare and which contribute to good healthcare practices from the patients' perspective. After summarizing all 414 determinants and arranging them on the bases of synonyms and content, 86 different determinants were recognized (table 3). Then, we recognized the determinants could be assigned to three categories. The first category encompasses values related to the patient and his personal context. The second category is related to the characteristics of the professional that are valued by the patient. The third category is related to the interaction between the patient and the professional. In this categorization, we could not avoid a certain overlap, content analysis resulted in an allocation to the dominant category. Subsequently, we identified within the main categories a consistency of determinants that led to seven key elements. We identified within the category of *the patient* two key elements that we called *uniqueness* and *autonomy*. Within the category *the professional* we identified the key elements *compassion*, *professionalism* and *responsiveness* and within the category *interaction* the key elements *partnership* and *empowerment*.

3.4 Definitions in concept

In Table 3 we organized all determinants in seven boxes, providing a picture of the essence, broadness, and variety of the seven key elements. Provisionally, we will define the key elements as a first conceptualization for investigating patient valuing.

3.4.1 Uniqueness

Uniqueness expresses the wish of patients to be seen and respected as a person rather than as a patient with a health problem. On top of that, it expresses the wish to be recognized as a person with a personal history and belonging to a family and a community. It includes the personal wisdom, experiences, preferences, and knowledge of the patient. The health problem is merely a small part of this person as a whole.

3.4.2 Autonomy

From the patients' point of view, autonomy is respecting the patient's capacity for making his or her own decisions on the essential issues in the treatment and care. Autonomy asks for room to allow for decision making or participating in decision-making by patients and maybe relatives. However, patients – or their relatives – can

leave the decisions to the professionals, for different reason, including for example in case of emergency, of serious illness, or extreme vulnerability. In those cases, it is the autonomy for giving the power of decision to professionals that patients deem important.

3.4.3 Compassion

Compassion refers to a professional attitude of being truly concerned and an ability and willingness to empathize with for the person. Compassion is far from pity or commiseration; it is much more about attentiveness and human interest from an understanding, caring, honest, reassuring professional, who inspires trust.

3.4.4 Professionalism

Patients value a competent, experienced professional with knowledge, skill, and an adequate attitude, not only in the field of direct treatment but also in communication, information, collaboration with the patient and with colleagues, and in openness to discuss alternatives.

3.4.5 Responsiveness

Responsiveness expresses the importance of a committed and responsible execution of treatment and care, including respecting uniqueness and autonomy. It also includes feeling responsible for a fair and humane approach and dealing with boundaries, such as idiomatic, cultural, or religious values on the part of the professional. With regard to the treatment the professional is expected to be responsive to the need for proper diagnosis and a method with a low risk of damage, negative side effects, and pain. Finally, responsiveness is about feeling responsible for organizational limitations such as a lack of coordination, a lack of care and caregivers, no continuity of care, and bad access or availability of care, time, and information.

3.4.6 Partnership

Patients value an interaction with professionals based on equality. Being able to talk easily and deliberately with professionals is important, as patients perceive professionals as partners in an open and understanding ongoing dialogue and deliberation. Partnership expresses mutual respect and recognizing the existing interdependency. It is about taking responsibility from both sides.

3.4.7 Empowerment

Empowerment is understood as professionals enabling patients to keep control of their own situation, to trust in themselves, the interaction and the professionals, and to support or educate them in learning to deal with the problem and treatment. Empowerment is helping patients towards self-management and prevention.

3.5 Taxonomy

The found key elements are not isolated phenomena: they are interrelated, partly overlapping and interwoven. Together they cover all the found determinants. We suggest the relevance of a certain sequence: recognition by professionals of the patient's uniqueness and autonomy, leads to the professional behaving compassionate, professional, and responsive, and creates interaction based on partnership and empowerment (figure 2).

4 Discussion and conclusion

4.1 Discussion

The main goal of this literature review was to explore what patients value in healthcare and to synthesize all findings towards a taxonomy for patient valuing across all levels of healthcare, health problems, and professionals. After we distinguished three perspectives with seven key elements out of all determinants (table 1), the eighty-six summarized values (table 3) led to a tentative proposal of the key elements. Subsequently, we proposed a first taxonomy of patient values and preferences (figure 2).

4.1.1 Reflections on existing literature

The findings fit seamlessly into the evidence based debate in medicine with calls for more balance between science, clinical expertise, and patient values.[3-5, 8, 40-42] In this section we will reflect on the key elements and their similarities to existing literature and research on the conceptualization of patient values, which partly overlap with our taxonomy, but nevertheless support our findings.

The theme *uniqueness* of our preliminary concept is in line with a qualitative systematic review of the patients' and physiotherapists' perceptions of factors that influence their interaction.[43] They found twelve codes; according to uniqueness, the code *individualized* means that patients felt a stronger bond with their therapist when their treatment was individualized and related specifically to their story. Similarly, a systematic review and narrative synthesis of patients experiences of personal recovery in mental illness found five categories, two of which correspond with the theme uniqueness; *identity* and *meaning in life*.[44] Identity refers to the attention paid to the various dimensions of the patient's identity and the rebuilding or redefining of a positive sense of identity. Meaning of life corresponds with attention for experiences with illness, spirituality, and living meaningful life with regard to social positions and goals. After carrying out a critical interpretative synthesis, Entwistle et al. developed a conceptual map, explaining which experiences of health care delivery matter to service users and why.[7] They divided all found experiences in three main groups and most themes correspond with our findings. The group entitled "enable me to be and do what I value being and doing within and beyond my health care encounters" corresponds with the theme of uniqueness. In a qualitative study Lee et al. explored patient values among people with type 2 diabetes in medical decision making.[18] They developed a conceptual model of patient values with different layers of depth; treatment specific values, values related to life goals and philosophies, and values related to personal and socio-cultural background. This model corresponds mainly with the category of *patient* in our concept, the theme uniqueness corresponds with the values related to life goals and philosophies and values related to personal and socio-cultural background. Another study of client values attempting to conceptualize client values, the results of which are interwoven in all themes of our taxonomy, is a qualitative study by Schoot et al.[24] They explored which client values formed a basis for tailored nursing care for chronic patients and also found a subtheme uniqueness. They characterized uniqueness by a lack of recognition, such as treating the patient as a number, "[sacrificing the patient] to their protocol", "[sheltering] behind protocols", and automatism.

We found that *autonomy* was also a key value for patients. The review of O'Keeffe et al. extracted the code "taking the patient opinion and preference into consideration" which is characteristic for the patients' own views

and contribution in therapy.[43] Entwistle et al. confirm this value with the patient experiences formulated as “develop my capability’s for autonomy and self-care” and “[involve me] in decisions about my care” in the first main category (“enable me to be and do what I value being and doing within and beyond my health care encounters”).[7] In Lee’s conceptual model of patient values, autonomy is assigned to the first layer of depth, the treatment specific values.[18] They suggest practicing shared decision making and studying the patient’s narratives in order to stimulate the patient’s own contribution. Schoot et al. also recognized the theme autonomy, which was characterized as a lack of recognition by patronizing being paternalistic and arrogant.[24]

The theme *compassion* was of high importance to patients. This is in line with the findings of O’Keeffe et al.[43] Four out of twelve codes can be attributed to the theme of compassion; empathy, friendliness, confidence and nonverbal communication. The meaning of these codes is underlying to our theme of compassion. Entwistle found that several patient experiences in her main group “have characteristics that equip and motivate them to deliver consistently good care” which relates to compassion.[7] We did not find a clear match between this conceptual map and the taxonomy, because the conceptual map describes behavior of professionals in order to meet the values of patients, while our taxonomy describes the values of patients on their own. However, content-wise there is much conformity. Schoot et al. summarize the aspects related to compassion within the term *attentiveness*. [24] Attentiveness requires verbal and non-verbal communicative skills: sensitivity, being alert, receptiveness, empathy, real attention, pleasure in work, asking questions, and listening. All this we classified under compassion, except “pleasure in work opposite to routine, so often experienced by patients and clients”.

In line with the literature, the finding *professionalism* proves to be important. The second theme O’Keeffe et al. found is related to the physiotherapist’s practical skills and contains the codes “patient education” and “physiotherapist expertise and training”. [43] These codes are mostly related to the treatment in itself. Entwistle et al. also found more general patient experiences such as knowledgeable, competence, keeping him or her informed, ability to work well together to provide coordinated care, explanation, discussion, etc. [7] These experiences correspond with our determinants towards professionalism. Recognition and dialogue emerged as recurrent themes in the study of Schoot et al., both of which we attribute to professionalism. Pleasure at work, positivity, humor and confidence were also ascribed to professionalism. [24, 44]

Schoot et al. define *responsiveness* as an active, committed, and responsible execution of care guided by respect for the client’s identity. [24] Their qualitative study was a major contribution to the realization of our theme of responsiveness. This is endorsed by Entwistle et al., whose research outcomes include the patient’s desire for the professional to “attend to [his or her] health issues promptly, competently and thorough” and to “[be] responsive to [his or her] individual needs and values”. [7] Responsiveness also consists of organizational factors. This is in line with other concepts; Entwistle et al. calls this “provide an appropriate environment for care” as an example of the main group “have characteristics that equip and motivate them to deliver consistently good care”, Schoot et al. found that clients value that professionals deal with organizational boundaries, and O’Keeffe et al. recognized the theme “organizational and environmental factors” like having enough time for the patient and being flexible with appointments. [7, 24, 43] The theme responsiveness also stands for the moral-ethical part of care which is endorsed in the concepts of Schoot et al. and Entwistle et al. [7, 24]

The theme *partnership* is endorsed by the category *connectedness* as formulated by Leamy et al.[44] They found that the caregiver must invest in the relationship, be part of the relationship and give support. Schoot et al. also found partnership to be a client value.[24] They describe what they value but did not experience, such as a lack of recognition or by acting as an opponent, use protocols as weapon in the fight, and giving no opportunity for involvement of family caregivers. Entwistle et al. confirm this by stating that “patients want and develop good relationships with health professionals”, “[they] want to be a partner with health professionals”, and “[they] want professionals to work with them and not just on their health”.[7]

Empowerment is the fifth category in the preliminary conceptual framework of Leamy et al.[44] In the analysis it represents giving the patient personal responsibility and control over his or her own life, and focusing upon strengths instead of weakness. O’Keeffe et al. formulated the theme *encouragement*, which consists of motivation, empowerment, and strengthening the bond between patient and professional.[43] Schoot et al. found the theme “developer of client competencies for participating in their own care”.[24]. This means that the professional should enable the client to use attitude, skill, and knowledge to deal successfully with their illness. In her dissertation, Huber introduced a new, dynamic concept of health.[45] Her message is that we not only have to treat the disease but also strengthen the patient’s resilience and self-control. All concept mentioned above endorse our theme of empowerment.

4.1.2 Limitations

Although we employed a systematic search for all relevant studies, there is always a possibility that relevant studies have been missed. It is quite remarkable how few studies eventually researched patient values as formulated by the patient him- or herself. Seemingly, this reflects the prevailing medical model.

Another limitation of this review is the lack of clear definitions of values, needs and preferences in the selected studies. Definitions of terms such as values, expectations, needs, preferences, and beliefs are often used interchangeably. We choose to adhere to what patients value, in order to be consistent and avoid ambiguity, and included all different words patients use to express what they value. We decided to use values and preferences in combination as most dominant words, referring on the one hand to the ethical and moral dimension and to the personal feeling and liking on the other.

A third limitation is that this review is based on partly comparable studies and merely identifies elements. These elements are clustered according to the interpretation of the authors, an interpretation based on the reading and re-reading of the statements of the interviewees and the focus groups, and the conclusions of the researchers of the original studies. This could have created bias, firstly through the interpretations of the data by the original researchers, and because their role and contribution during the data collection was often unclear. Secondly our interpretation and clustering of the data could have caused bias.

4.1.3 New insights

New to our proposed taxonomy is the threefold perspective we took to study values and preferences: 1) values and preferences are concerned with the life and philosophy of the patient; 2) values in relation to the

characteristics and behaviour of the professional, and 3) values in relation to the relationship between the patient and the professional. The taxonomy also shows that a certain interconnection exists between the key elements. For example: if the patient has an opinion on his or her health problem and wants to have a say in the treatment (autonomy), and thus wants to explore the health problem together with the professional (partnership), the professional should co-operate by creating space for the patient's contribution and by adapting to one another (responsiveness). This requires communication skills (professionalism) and equality and attention (compassion) of the professional. As an example to describe the difference between values, needs and preferences: if a patient wants to be autonomous and decide for himself, he needs adequate information and has as preference to receive the information digitally.

Secondly, this research is unique in that it is based directly on how patients express themselves and on the bottom-up conceptualized of seven key elements. The findings of this review will inform healthcare professionals on which elements matter to patients in daily practice. The elements as such are not unique as we can find similar or comparable terms in many publications but not in this form. Until now our findings have led to a preliminary taxonomy based on existing studies, but should be tested for strength and consistency. Moreover, the preliminary first descriptions of the key elements require further substance by further research and development. For that reason, after having identified the key elements based on this research, we will move to an empirical research among patients and practitioners, testing the taxonomy and enriching it with the dynamics between preferences and values and the possibility of conflict between the preferences and values of the patient and those of the professional. This dynamic process is presumably observable within each key element.

4.2 Conclusion

Patient-centeredness is an important issue in healthcare. This review offers a unique possibility to systematically research qualitative data and to get a rich insight in what patient valuing means within healthcare, based on existing research. This creates an overview of the desired characteristics of a professional and the interaction between him and the patient, seen from the patient's point of view. We assume a professional who is truly involved with his patients will recognize the descriptions of the key elements in his daily practice, because the key elements are not new. However, the completeness, necessary objectification, and taxonomy of the themes has not been investigated before and this makes implementing patient valuing in a more systemic way as a base for patient-centered healthcare possible. Further study is needed to validate these findings and to create a possibility for the development of a tool, meter, or questionnaire in the future. By researching what patients value in healthcare we hope to provide an input on quality improvement in clinical guidelines, policy, and the daily practice of healthcare.[6, 40]

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Conflict of interest

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Figure 1; Study selection procedure

Stage 1: Initial stage	
Electronic search:	Embase, Medline OvidSP, Web of Science, Cochrane Central, Pubmed Publisher, Scopus, Psycinfo
Keywords:	Patient OR client value, personal value, patient OR client preference AND qualitative, qualitative analysis, qualitative research
Limitations:	Articles in english
Results:	<u>3259</u>
Stage 2: Screening of results	
Filter:	Titles examined for initial relevance
Filter:	Relevance of abstract examined in order to assess whether data on patient values are presented in the study
Results:	32 <i>Satisfaction</i> 117 <i>Professional</i> 184 <i>Treatment</i> 93 <i>Costs</i> 125 <i>Theoretical</i>
Results:	<u>95</u> <u>Meaning</u>
Stage 3: Initial article selection by two reviewers	
Inclusion criteria:	Empirical research for patient values
Exclusion criteria:	Papers, editorials, non-empirical research and other languages
Results:	<u>56</u>
Stage 4: Final article selection	
Filter:	Patient values must be researched from the patients point of view, not by the researchers point of view
Results:	<u>22</u>

Figure 2; Taxonomy of patient values and preferences

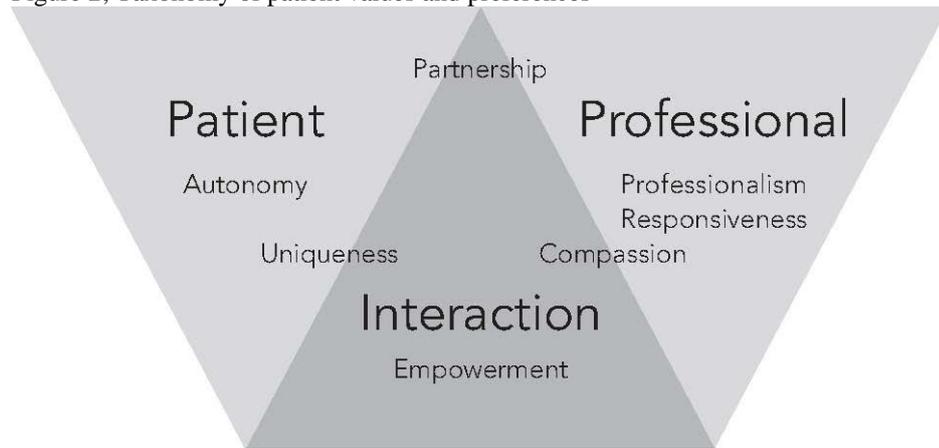


Table 1 Evidence table of the included studies which researched patient values and preferences

Reference	Aim, population and country	Method	Sample	Determinants
Main et al. (2002)[2]	Explore north-American patients perspectives on doctors of the future in primary care.	Focus groups	78	Latest knowledge, alternative medicine, explore patients culture, medical history, family, community, value patients knowledge, patients' needs for information, caring/compassionate, honesty, holistic, preventive, listen, communicate open, trust, respect, continuity, involve/ educate patients.
Lee et al. (2013)[18]	Explore patient values of Malaysian diabetics in medical decision-making around insulin therapy.	Interviews	21	Professionals should pay attention to beliefs and feelings about the treatment, health, career, finance, hierarchy of life priorities, avoiding suffering, fatalism, not being a burden, religion, personal and family background.
Schoot et al. (2005)[24]	How do Dutch chronically ill patients and their family experience the interaction with nurses and tailored care and what competencies need professional caregivers from their point of view.	Focus groups	7	Uniqueness (individual human beings with own life story, beliefs, culture and background), comprehensiveness (integral human beings, part of family system, pay attention to emotions and difficulties, collaboration and documentation between caregivers), continuity of life (getting the care needed and flexibility in the moment, content and amount), fairness (having the right to ask for needed care), autonomy (be who you are, self-determination, making own choices and decisions, being in control, has the final say, involvement of family if needed), equality, experience based knowledge, partnership (accountable, active, collaborating, committed, have pleasure in work), all partners should take responsibility, communicate and respect expectations and boundaries, shared care plans), interdependence (mutual receptiveness, understanding, reliance), recognition (being seen or heard, being accepted and respected, treated seriously), dialogue, attentiveness (sensitiveness, being alert, receptiveness, empathy, real attention, pleasure in work, asking questions, listening), responsiveness (active, committed, responsible execution of care, respect for client identity, use of guidelines, find out if patient want to direct,

				deals with personal, professional, and organizational boundaries, give and ground professional opinion, saying what can be offered, searching for compromise, convincing, self-assertiveness, ethical reasoning, professional knowledge, reflective, developer of client competencies, given the opportunity, motivate, facilitate participation, the way of discussing information, making shared care plans, being alert, being a role model, referring to patient support group
Sbaraini et al. (2012)[25]	Explore Australian dental patients experiences of the relationship with dentists especially towards preventive care.	Interviews	17	Recognise historical elements, personal in control, treated/ related to as a person, having more treatment options, gaining new knowledge, boundaries (side-effects, competing priorities, existing habits), listened by, efforts of help, feel respected, reassured, transparency in interaction, caring, trust, transparency, without blaming, educated, monitored, make aware of.
Price et al. (2012)[33]	Explore American older adults views of existing informed decision-making and their additional items.	Focus groups	65	Open discussion about involvement in decision making or not, understandable discussion, relationship of trust and confidence, communication skills, good medical knowledge, discussion of alternatives, discussion of pros and cons, discussion and help of uncertainties, honesty and reassurance, assessment of patients understanding, exploration of patients preferences, inviting involvement of trusted others, exploring the impact of decision on the context of this patients.
Lindberg et al. (2013)[32]	Explore what participation means to Swedish patients in spinal cord injury rehabilitation.	Semi structured interviews	10	Treated as individuals, respect for personal wishes and preferences and way of being, respect (time to listen), integrity, involvement in planning and decision making, getting information and knowledge, both responsible, being motivated and encouraged to join in, involvement of family.
Bastiaens et al. (2007)[31]	Explore older adults views of involvement in their primary health care in Europe.	Semi structured interviews	406	Able to talk to GP and ask questions, being listened to, receiving information, related to individual needs, personal approach, confidential relationship (supportive, engaged,

				trusted, tailored), active participation or decision making or not, GP is an expert, GP is facilitator of involvement, encourage to ask questions and participate, not feel inferior, both responsible, spending enough time, easy access, same GP, involvement of relatives.
Dima et al. (2013)[35]	Identifying treatment beliefs of English low back pain patients in primary care.	Focus groups	75	Holistically, credibility, proper, make sense, right practitioner, effectiveness, costs, safety, individual fit (age, injury, life style), not standardised, diagnose, willingness to change, self-management, good practitioner, knowledgeable, conscientious, empathic, respectful, trustworthy, personal control or doctors.
Christianson et al. (2009)[21]	Explore clients' perceptions of quality of care in a hepatitis clinic in British Columbia, which aspects of care are important and their effect on coping.	Questionnaires	115	Courtesy (politeness, caring, respectful, sensitive, felt comfortable, non-judgemental, treated as a person, feel comfortable by provider, encouraged), professionalism (knowledgeable, informative, specialized, experienced, working as a team, privacy), education (how to cope with, information, learning about), continuity of care (easy access, follow up treatment, availability), autonomy (having a say, alternative therapies).
McCaffrey et al. (2007)[29]	Explore patient values and beliefs for a combination of conventional and alternative medicine in America.	Focus groups	37	Combined approach (CAM), holistic view, general nutrition is important for health, prescription medication as a last resort, discuss CAM with GP, be respected, taken seriously, given guidance, open to alternatives, good listening, enough time, opportunity for shared decision making, insurance covering.
Moreau et al. (2012)[34]	Explore the perceptions of patients in France with different health problems in primary care towards decision-making.	Focus groups	25	Considers the patient as a person, transferring knowledge, medically competent, use patients expertise, a dialogue, empower patients, active patient participation, getting objective information/ advice, possibility for second opinions, seeking for alternatives, trust, empathic relationship, feel at ease, attentive and benevolence listening, confidence, be guided, feel that it's his decision, biomedical skills, deliberative process, support patients choices, paternalistic role was most often rejected (except for elderly), in emergency patients want the dr.'s decision, autonomy, don't

				want to be a burden by asking too much, not wanting to much information.
Garrett et al. (2008)[28]	Explore what non-English-speaking patients value in acute care in Australian hospitals.	Focus groups	59	Professional interpreters, bi-lingual staff, family involvement, patient beliefs (spiritual, religious, faith in healthcare, folk remedies, gender issues), compassionate caring, respectful, empathy, effective communication, language facilitation, well explained, active engagement, consultation, information, competent, humanness, attention to healthcare rights, fairness, advocacy needs, service (safe, quality, availability, accessibility).
Robben et al. (2012)[38]	Explore frail older Dutch adults at home for preferences of receiving information.	Semi structured interviews	22	Trusted and caring professional, trusting/ good relationship, limited or extensive information (verbal, visual, leaflets), advocacy, check their understanding, involvement of children, being empowered by asking towards own info and questions, searching own information, both responsible, time spent with, provider continuity.
Kvale et al. (2008)[36]	Get insight in the perceptions of cancer inpatients in Norway of the importance of being respected as partners and shared decision-making.	Interviews	20	Empowerment, respect, listened to, given honest information, feeling valued, sense of control, shared decision making, being informed, discuss the treatment, wanted the doctor to make the final decision, partnership in nursing care about daily life and care.
Halpert et al. (2011)[20]	Examine American irritable bowel syndrome patients' perspectives on their relationship with health care providers and how this can be maximised.	Expressive writings	49	Empathy, supportiveness, listen to me, helpful, understanding, educate me, be reassured, prescribe more meds, make it go away, professional knowledge, expertise, stay up to date, available, conduct more tests.
Mulvaney et al. (2011)[27]	Analyse American outpatients' preferences for relational styles with mental health clinicians across different racial/ethnic groups.	Semi structured interviews	51	Listening, value patients own knowledge, be attentive, make patients feel comfortable, understanding the complexity of patients feelings choices and life circumstances, managing differences, adapting to the patients level, connecting, not judging the social differences, spending time.
Laugharne et al. (2012)[37]	Investigate experiences of English inpatients with psychosis on trusting	Interviews	20	Trust, reciprocity of trust, professional expertise, hardworking, caring/kindness, continuity of care, reliability, delivering promises, listening, personal disclosure, positivity,

	relationships, choice of treatment and balance of power in care.			honesty, patients own experiences with illness, power to staff, having a say, balance in power, need for knowledge and information, time with staff, humanity, sharing responsibility, clinicians sharing responsibility of compulsory detention with others, trusting relationship, personal touch/ disclosure of provider.
Skea et al. (2014)[23]	Explore English urological cancer outpatients experiences of care and what they value in interaction with health care providers.	Interviews	26	Related to as a person, treated as someone who mattered and is worthy of care, interacting warmly and personal recognition, anticipating to care needs, being recognised and responded as a unique individual with a particular social context circumstances and preferences, be honest, admit mistakes, partnership, understand and contribute to discussions, respected, trusted as partners, experiencing support for autonomy, contribute to self-respect and self-trust.
Van Eijk et al. (2013)[30]	Explore needs and expectations of Dutch outpatients with RA for rheumatology nursing care.	Focus groups	20	Appropriate, tailored and timely information, self-management strategies (dealing with, communicate with), understanding, listening ear, clear and supportive communication, easy to talk to, empathic, well organised, coordinated and accessible care, knowledgeable professionals, collaborative professionals, considers me as a whole.
Van Staa et al. (2011)[19]	Explore experiences and expectations of Dutch chronically ill adolescents regarding providers' qualities for in- and outpatient care.	Mixed methods study	31/34/9 90	Expert/ competent, trustworthy, honest, caring, understanding, listening, showing respect, focused on me, trusted relationship, meaningful, helpful, attractive outpatient surroundings, answering all questions, attending to the needs, clear/ concise information, short waiting times.
Peersman et al. (2013)[26]	Determine Belgium outpatients priorities of physiotherapy care.	Questionnaire	53/358	Expert, be honest, treatment works, prevention, adjust treatment, enthusiastic, serious, guidance of the team, hygiene, privacy, motivate, discreet, sufficient assistance, clear communication, friendly, safety, on good terms, explaining, discuss with professionals, comfortable setting, involvement, room is clean, available, confidence, affordable, helpful, awareness of history, humour,

				information, free choose, stay up to date, decision involvement, empower, examine, experienced, continuity, takes wishes and needs into account, have a chat, follows instructions, accessibility, time schedule.
Luthy et al. (2005)[39]	Explore the descriptions of Swiss inpatients of good and bad doctors.	Interviews	68	Scientifically proficient, sensitive to emotions (listen and understand patients' needs and emotions), positive personality (kind, warm, smiling), adapts to each individual patient, shared decision making, available/ devotes time, skilled in communication/ information, tells the truth/ be honest.

Table 2 CASP quality assessment of included papers

	1	2	3	4	5	6	7	8	9	10
Main[2]	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Valuable
Lee[18]	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Valuable
Schoot[24]	Unclear	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	Yes	Valuable
Sbaraini[25]	Yes	Unclear	Yes	Valuable						
Price[33]	Yes	Unclear	Unclear	Yes	Unclear	Unclear	Yes	Unclear	Yes	Valuable
Lindberg[32]	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Unclear	Yes	Valuable
Bastiaens[31]	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	Yes	Valuable
Dima[35]	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Valuable
Christianson[21]	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Unclear
McCaffrey[29]	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Yes	Valuable
Moreau[34]	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Yes	Unclear
Garrett[28]	Yes	Valuable								
Robben[38]	Unclear	Yes	Unclear	Yes	Yes	Unclear	Yes	Unclear	Yes	Valuable
Kvale[36]	Yes	Valuable								
Halpert[20]	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Valuable
Mulvaney[27]	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Valuable
Laugharne[37]	Unclear	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Valuable
Skea[23]	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	Yes	Valuable
Van Eijk[30]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Valuable
Van Staa[19]	Yes	Valuable								
Peersman[26]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Unclear	Valuable
Luthy[39]	Yes	Yes	Unclear	Yes	Yes	Unclear	Unclear	Yes	Yes	Valuable

1) Was there a clear statement of the aims of the research? 2) Is a qualitative methodology appropriate? 3) Was the research design appropriate to address the aims of the search? 4) Was the recruitment strategy appropriate to the aims of the research? 5) Was the data collected in a way that addressed the research issue? 6) Has the relationship between researcher and participants adequately considered? 7) Have ethical issues been taken into consideration? 8) Was the data analysis sufficiently rigorous? 9) Is there a clear statement of findings? 10) How valuable is the research?

Table 3 Reported determinants sorted and summarized per keyelement

Keyelement	Determinants
Patient Uniqueness[23, 24]	Individual human beings with own life story, history, culture and background;[2, 18, 24-26] Understanding the complexity of patients feelings, choices and life circumstances;[23, 27] Own beliefs about (alternative) healthcare, treatment and life style;[18, 21, 24, 28, 29] Beliefs of spirituality, religion and folk remedies;[18, 28] Holistic approach to patient care;[2, 29, 30] Related to individual needs, wishes and preferences;[19, 23, 26, 31-33] Comprehensiveness;[24] Avoiding suffering, fatalism, not being a burden.[18, 34]
Patient Autonomy[23, 24, 26, 34]	Personal decision for being in control or not;[24, 25, 34, 35] Personal decision for participating in decision-making or not (elderly, patients with cancer and patients in emergency want the doctor to decide);[24, 31, 33, 34, 36] Has the final say;[21, 24, 37] Searching own information;[38] Involvement of family, relatives or professional interpreters if needed.[24, 28, 31-33, 38]
Professional Compassion[2, 38]	Listening;[2, 19, 20, 24, 25, 27, 29-31, 34, 36, 37] Respectful;[2, 19, 21, 24, 25, 28, 29, 32, 35, 36] Empathic;[20, 24, 28, 30, 34, 35] Caring;[2, 19, 21, 25, 28, 37, 38] Trustworthy;[2, 19, 24, 25, 34, 35, 37, 38] Honest;[2, 19, 23, 26, 33, 36, 37, 39] Reassuring;[20, 24, 25, 33] Make patients feel comfortable;[21, 26, 27, 30, 34] Understanding;[19, 20, 30, 38] Supportive;[19, 20, 25, 26, 30] Treated seriously;[24, 26, 29] Attentive;[24, 27, 34] Sensitive;[21, 24] Positive personality;[23, 26, 37, 39] Polite;[21] Personal touch/disclosure;[26, 37] Make patients feeling valued.[23, 36]
Professional Professionalism[21]	Knowledgeable;[20, 21, 24, 30, 33, 35] Stay up to date;[2, 20, 26] Informative (elderly, patients with cancer and patients in emergency wants mostly limited or extensive information (verbal, visual, leaflets));[2, 19, 21, 24-26, 28, 30-32, 34, 36, 37] Skilled in communication;[2, 26, 28, 33, 39] Expert;[19-21, 26, 37] Experienced;[21, 26] Competent;[19, 28, 34, 35, 39] Open to alternatives;[2, 24, 29, 34] Open for reflection and professional collaboration;[21, 23, 24, 26, 30, 34, 37] Saying what can be offered.[19, 20, 24, 28]
Professional Responsiveness[24]	Committed and responsible execution of care;[24, 25, 30] Conscientious and hardworking;[24, 35, 37] Fairness;[24, 28, 32, 37] Humanity;[28, 37] Advocacy;[28, 38] Privacy;[21, 26] Pay attention to emotions, needs and difficulties;[23, 24, 27, 39] Ethical reasoning;[24] Communicate and respect personal, professional and organizational boundaries such as:[24] Respect and recognize client identity and context;[23, 24, 27, 33, 35] Not judging differences;[21, 24, 25, 27] Organisation and coordination;[19, 21, 24, 26, 30, 35] Side-effects;[25] Competing priorities;[25, 35] Existing habits;[25, 35] Treatment credibility;[26, 28, 35] Treatment costs;[26, 29, 35] Treatment safety;[26, 28, 35] Hygiene;[19, 26] Spending enough time;[27, 29, 31, 32, 37-39] Easy access;[21, 26, 28, 31, 40] Provider continuity;[21, 26, 31, 37, 38] Availability.[20, 21, 26, 28, 39]
Interaction Partnership[23, 24, 27]	Equality;[24, 27] Considers the patient as a person;[19, 21, 23, 25, 31, 32, 34, 39] Find out if patient want to direct;[24, 33] Involvement in planning and (shared) decision making;[24, 26, 29, 32, 36, 37, 39] Assessment of patients understanding;[24, 33, 38] Value patients own knowledge;[2, 24, 27, 34, 37] Both responsible;[24, 31, 32, 37, 38] Confidential relationship (supportive, engaged, trusted, tailored);[19, 23, 26, 28, 31, 33, 34, 36-38] A dialogue;[25, 26, 29, 31, 34, 36] Deliberative.[23, 24, 33]
Interaction Empowerment[21, 24, 26, 28, 38]	Educate;[2, 20, 21, 25] Give the opportunity;[24] Encourage and facilitate participation;[21, 24, 25, 31, 32, 38]; Being a role model;[24] Motivate;[24, 26, 32, 34] Contribute to self-management and trust;[2, 23, 24, 26, 30, 35] Give guidance.[25, 29, 34]