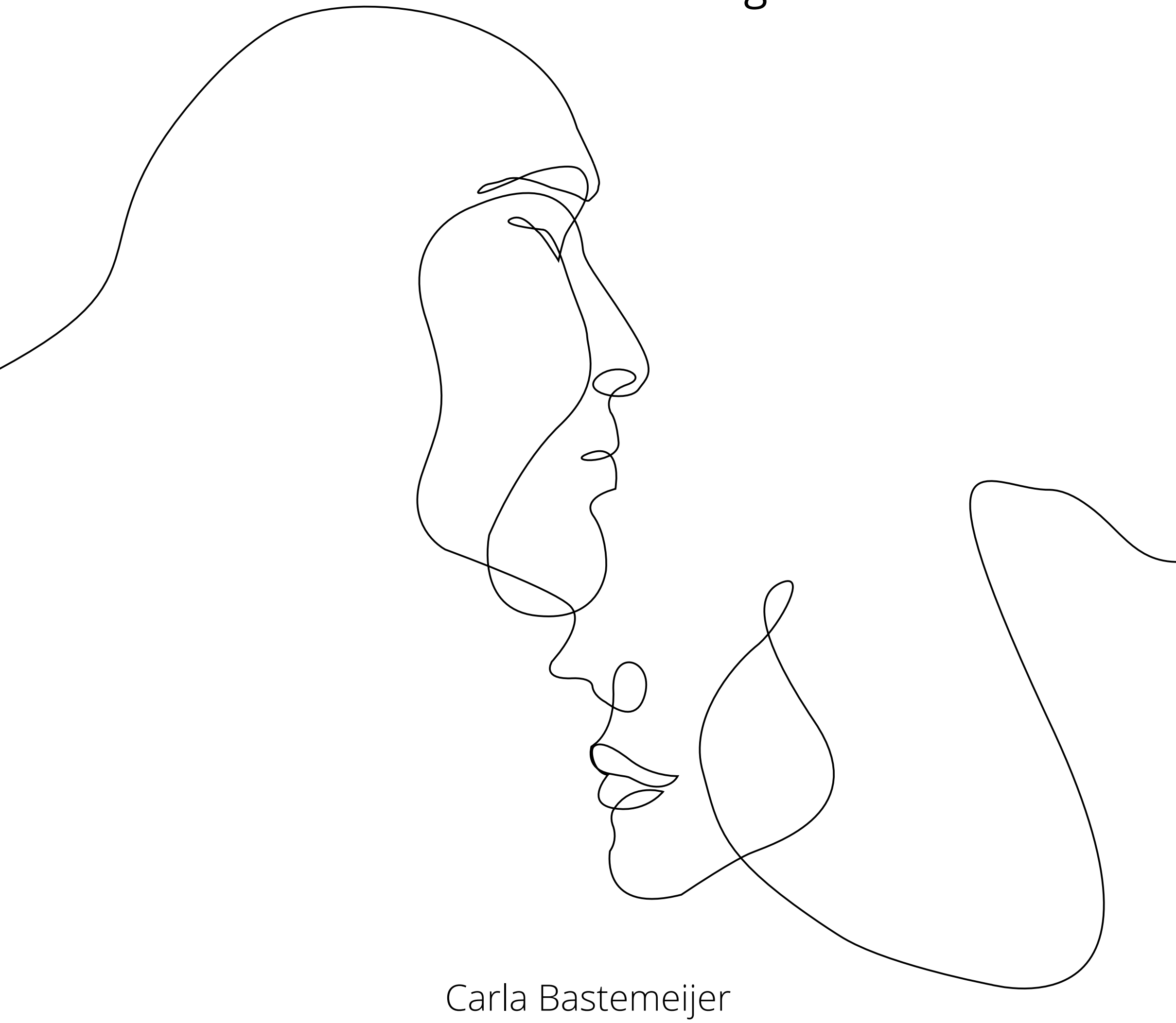
Patient Values

the Meaning for Healthcare



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Patient values, hun betekenis voor de gezondheidszorg

Patient Values, the Meaning for Healthcare

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Your beliefs become your thoughts, your thoughts become your words,
your words become your actions, your actions become your habits,
your habits become your values, your values become your destiny.

Mahatma Gandhi

Table of contents

Chapter
1

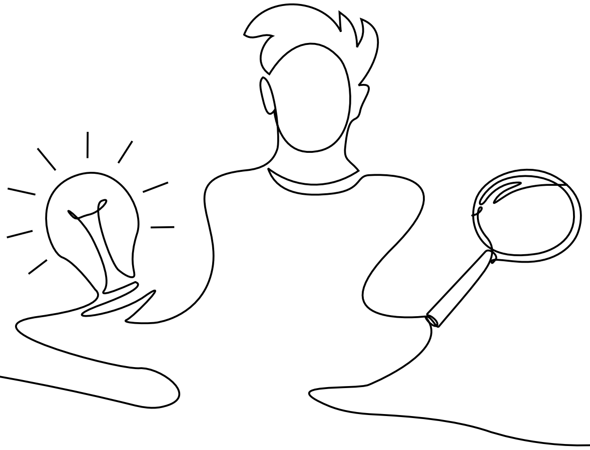
General introduction

What 'quality' in health care practices means and what we are currently missing

Healthcare professionals strive every day to deliver the best possible care for their patients. To achieve this ambition successfully, they have to balance between two worlds; 1) the rapidly evolving world of medical knowledge and technological possibilities, and 2) the individual values, preferences and needs of patients.[1,2] The blending of these two worlds in daily practice appears to be difficult and not straightforward. Where concepts such as Evidence Based Practice (EBP) attributes an equal role to scientific evidence, the clinical expertise of the professional and the patients' values, the focus of quality in care and research is still mainly scientific, biomedical and illness-oriented rather than patient-centered.[3-6] This biomedical course has become a criterion for quality and funding and dominates most audits and clinical guidelines. Examples are 'pay for performance initiatives'[7] and 'joint commissions standards'[8] that force healthcare professionals into the use of general clinimetrics or prescribing medication.[9] Increasing criticism has arisen on the weight of explicit, theoretical knowledge due to the fact that it results in a variety of guidelines and protocols where the relevance of the individual patient is lagging behind.[10,11]

Context

This conceptual problem could be an explanation for frequently marked concerns of patients with investigations or treatment, a perceived lack of interaction or respect and communication problems in daily practice.[12-14] Moreover, healthcare systems can sometimes harm our patients; one out of ten patients are affected by adverse events, most likely because of an underestimation of the problem, and almost half of these events were classified as preventable by communication.[15,16] Therefore, it is not surprising that an evident relationship between adverse events and poor communication or a lack of empathy has been found.[17] These miscommunications or misperceptions occur in primary care, specialized care and also in transfers between diverse settings, one can speak of an evident problem.[18-20] It seems clear that being more patient centered, with a focus on communication and seeing the patient as a partner could contribute to quality of care.[9,13,21,22]



Patient-centered care

Patient-centered care (PCC) is the practice of caring for patients (and their families) in ways that are meaningful and valuable to them.[13,23] The acknowledgement that the unique patient should be in the center of the clinical encounter is of primary importance in PCC-models. Healthcare providers should build a relationship with their patients and should listen attentively, provide understandable information and involve patients actively in their own care and context.[24-26]

Several attempts have been made for the provision of patient-centered healthcare. Institute of Medicine wrote a revolutionary report stating that to improve healthcare, professionals should ensure that PV guide all clinical decisions.[27]

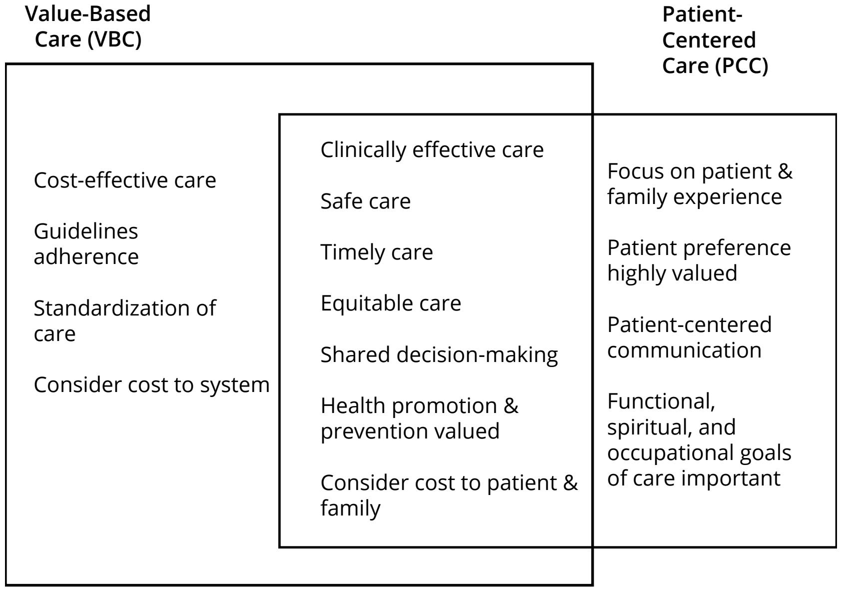
Figure 1 Crossing the quality chasm (IOM, 2001)

The IOM Six Aims are built around the core need for health care to be:		
1.	**Safe:**	Avoiding injuries to patients from the care that is intended to help them.
2.	**Effective:**	Providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit.
3.	**Patient Centered:**	Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.
4.	**Timely:**	Reducing waits and sometimes harmful delays for both those who receive and those who give care.
5.	**Efficient:**	Avoiding waste, including waste of equipment, supplies, ideas, and energy.
6.	**Equitable:**	Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Values Based Medicine (VBM) was introduced as a new approach for clinical decision making, with a scope on all occurring values, especially when they are complex and sometimes conflicting.[28-31] The most recent opinion, Value-Based Healthcare (VBHC), is searching for a balance in the best outcomes which matter for the patient and healthcare costs.

The definition of value for the patient here is the patient-relevant outcomes divided by the costs per patient for the entire cycle of care to achieve these outcomes.[32] The supporters of VBHC mainly emphasize the practical benefits for healthcare. Innovation management is given shape and becomes part of daily practice. Healthcare providers improve the value of care delivered by identifying and sharing best practices. The patient (together with their practitioner) chooses the care that best suits their personal situation.

Figure 2 Value Based Care and Patient Centered Care: Divergent or Complementary? (Tseng, E.K. & Hicks, L.K., 2016)



Critics expect that VBHC will lead to more competition, bureaucracy and that provided care only must be measurable and standardized. Instead of putting the patient and collaboration at center stage, objectivity is still most often leading in the clinical encounter and put subjective aspects under pressure.[6,28,29,34]

Picker Institute distinguishes eight domains of person centeredness. Most of the domains are straightforward and to objectify without difficulty.[23]

Figure 3 Principles of Person-Centred care (https://www.picker.org/about-us/picker-principles-of-person-centred-care)

Access to care	Respect for patient's values, preferences & expressed needs	Coordination & integration of care	Information, communication & education
Physical comfort	Emotional support & alleviation of fear and anxiety	Involvement of family & friends	Transition & continuity

It's the current idea, which is reflected in the opinions of scholars who advocate for health care models based on patient-centered care, that quality of health care is at least partially based on PV and their experiences.[35,36] However, the concepts of values, preferences and needs turned out to be moderately defined and utilized.[3-5,25,37] It seems that these concepts are under-researched or used interchangeably, which could certainly hinder the provision of patient centered care. Therefore, the aim of this thesis is to explore the concept of PV, the role PV play in healthcare and how PV can contribute to quality of care.

The concept of Patient Values

In general, values can be seen as basic agreements within an individual, a group or a society regarding what is considered to be good, bad or desirable.[38] Current research into the field of human values describes them as long-term and stably rooted thoughts or beliefs that have been formed from an early stage in life.[38,39] They are shaped by personal life events, social contacts and education.[40] Values prove to be more deeply and more stably rooted in a human being than preferences and needs, which are driven by current feelings, fears and practical considerations.[37,39,41,42] Apparently, values transcend specific actions and situations and express what is desirable, the (underlying) preferences are connected to attitudes.[41]

As we see in the aforementioned theories of EBM, PCC, VBM or VBHC there is not a clear understanding of what PV imply and which specific roles they play in healthcare practice. Different interpretations are made and comparable terms like 'preferences', 'needs', 'concerns' and 'values' easily merge into each other and are used synonymously.[25] To gain a better understanding of PV in healthcare, an aim of this thesis is to enrich the concept of PV through literature review and patients' interviews.

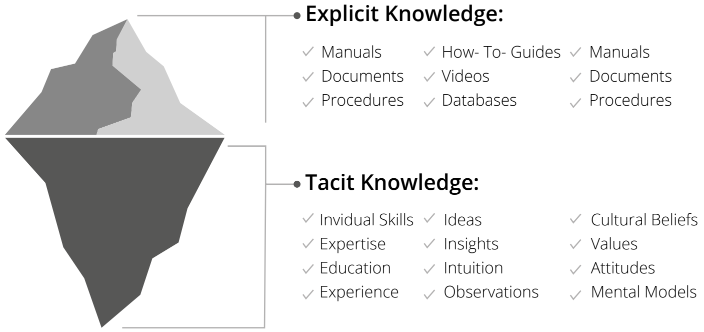
Patient Values in practice

Understanding PV and beliefs predicts patients' behavior with health and care, contributes to better communication and shared understanding of treatment and care, and leads to better outcomes.[43-45] It implies that the exploration and understanding of PV is an important part of the clinical encounter. However, not merely the personal values of the patient are involved, but also those of the professional. Both have their influence on healthcare and decision making processes, thus important to mention here.

The professional is guided, next to morality and personal values, by occupational values. These values are an important part of professionalism and formed by professional education, the identity and principles of the profession, clinical expertise and events. The four principles approach to healthcare ethics is exemplary in healthcare; 1) respect for autonomy, 2) non-maleficence, 3) beneficence and 4) justice. Compliance with these basic principles is considered to be common good.[46] However, values are wider than just ethical values. Moyo et all identified in a systematic review of literature even eleven values among healthcare practitioners such as authority, capability, pleasure, intellectual stimulation, critical-thinking, equality, altruism, morality, professionalism, safety and spiritality.[40]

All these elements can be found in the discourse of normative professionalization where all values and norms that steer professional action are seen as fundamental for day to day practice.[46] The theory is built on the concepts of reflexivity[48] and tacit knowledge[49] but also emphasizes to meaningfulness, existential essence and values of professionality.[50]

Figure 4 Explicit vs. Tacit knowlegde (https://www.rocketsource.co/blog/organizational-growth-via-digital-transformation/organizationalgrowth-24)



It underscores the importance of the professional's reflection on his actions in increased complex care, especially when conflicting values arise within the professional itself, as in balancing between the worlds of scientific evidence and moral values. A quote of Donald Schön[48] illustrates perfectly how professionals become increasingly under pressure by the need to meet both worlds;

> *In the varied topography of professional practice, there is a high, hard ground where practitioners can make effective use of research-based theory and technique, and there is a swampy lowland where situations are confusing "messes" incapable of technical solution. The difficulty is that the problems of the high ground, however great their technical interest, are often relatively unimportant to clients or to larger society, while in the swamp are the problems of greatest human concern. Shall the practitioner stay on the high, hard ground where he can practice rigorously, as he understands rigor, but where he is constrained to deal with problems of relatively little social importance? Or shall he descend to the swamp where he can engage the most important and challenging problems if he is willing to forsake technical rigor?*
>
> *Donald Schön, The reflective practitioner, 1983*

In conclusion, patients and professionals both have their own background and perspectives. At this time, in many cases, there is insufficient time (taken) in the encounter to explore each other's values, which may lead to misinterpretations of PV by healthcare providers.[12,43] Until now it is unclear where differences in perspectives emerge. For this reason, an aim of this thesis is to explore the beliefs among professionals about PV and how they play their role in daily practice.

Operationalization of Patient Values

Organizing PCC requires involvement of patients perceptions of the care they received.[44,51,52] Patient experiences gain insight in the impact of care on the patient's life and well-being, and can be used to meet the patients expectations as objectifiable derivatives of their values. A good experience corresponds with the underlying values and is positively associated with patient safety and clinical effectiveness.[53] This makes patient experiences appropriate for the improvement of PCC delivery.[14,23,27,51,53]

Figure 5 Evidence Based Practice (https://www.ciap.health.nsw.gov.au/training/ebp-learning-modules/module1/evidence-based-practice-is.html)

Patient experience has generated many definitions, but they all take into consideration that patient experiences are the perceptions of all interactions in an organization were patients' needs should be met.[55] It is important that what's measured, matters the most to the patient and incorporates the patient journey as a whole.[51]

Although there are many ways to measure patient experiences, basically there are two approaches; qualitative and quantitative measures. Interviews and focus groups are frequently used methods for qualitative measurement, a patient experience questionnaire is a quantitative method for large scale assessment of patient centeredness. The disadvantages of the quantitative methods are that patients cannot estimate the value of care by a lack of medical knowledge. It reflects immediate desires and outcomes are influenced by factors that are not associated with quality of care.[56,57] Despite these difficulties, large scale patient reported experience measurements (PREMs) have become a key quality indicator for healthcare, measuring and analyzing experiences this way is seen to support improvement in healthcare quality governance, public accountability and patient choice.[27,58,59] By continuing reassessment of patient experiences full circle can be made to make all clinical care and decisions patient value-driven. This is why an aim of this thesis is to develop PREMs for hospital care which reflect what matters most to the patient and incorporates the patient journey as a whole.

Implementation of Patient Experiences

Meanwhile, the use and effectiveness of PREMs to drive quality improvement (QI) has also been questioned.[57,60] The lack of QI may be linked to methodological barriers (e.g., using a survey with poor psychometric properties, infrequent data-collection, ineffective monitoring), hampering the assessment of effectiveness. The lack of local ownership for QI, limited training and education of staff for QI as well as the absence of an organizational culture for change can also have a negative effect on the improvement of patient experiences.[56,61] Additionally, patient experiences cover diverse domains which all require appropriate measurement and different QI initiatives.[62] The optimal approach for using experience data effectively seems lacking. As a result, an aim of this thesis is to review literature for best practices and barriers of QI initiatives.

Outline of the thesis

The aim of this thesis is to contribute to QI in healthcare by creating a deeper understanding of PV and integrate them in daily practice. At first, this thesis contributes to the conceptualization of PV by empirical research.

Chapter 2 describes the outcomes of a systematic review which was conducted to create an overview of the insights of PV from the perspective of patients themselves. This study reviews qualitative studies in which patients express what they value in healthcare and the healthcare provider. Based on this body of literature a preliminary taxonomy is designed.

Chapter 3 reports the results of a qualitative study of PV in the field of physiotherapy by which we deepen the insights of the previously conducted review and refine the preliminary taxonomy.

Chapter 4 describes a third perspective on PV to gain a deep understanding of the beliefs about PV by the professional. This qualitative study is also conducted in the field of physiotherapy practice for its opportunity to compare all perspectives.

Secondly, this thesis gives insight into the additional benefit of PV to improve care by using patient experiences as a objectifiable derivative.

Chapter 5 describes the development and validation of patient reported experience questionnaires in a hospital setting. To use the outcome of these measurements for hospital care,

Chapter 6 describes a review of current QI initiatives based on the use of patient experiences in hospital care.

Chapter 7 provides a reflection on the studies in this thesis with a discussion about perspectives on a future with PV as a reference point.

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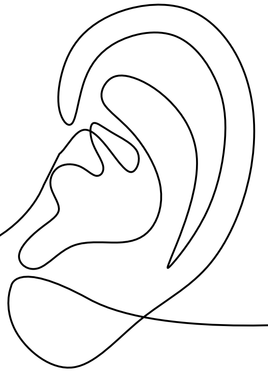
Chapter

2

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



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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.

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 an 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 under conceptualized 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 himself (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 centred 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.

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]

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.

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: ((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)). 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.

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.

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 meta synthesis; 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.

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

Reference	Aim, population and country	Method	Sample	Determinants
Main[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[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.

Reference	Aim, population and country	Method	Sample	Determinants
Schoot[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[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[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.

Reference	Aim, population and country	Method	Sample	Determinants
Lindberg[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[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[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.

Reference	Aim, population and country	Method	Sample	Determinants
Christians[21]	Explore clients' perceptions of quality of care in a hepatitis clinic in British Colombia, which aspects of care are important and their effect on coping.	Question-naires	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[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[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.

Reference	Aim, population and country	Method	Sample	Determinants
Garrett[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[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[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, discus the treatment, wanted the doctor to make the final decision, partnership in nursing care about daily life and care.
Halpert[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[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[37]	Investigate experiences of English inpatients with psychosis on trusting relationships, choice of treatment and balance of power in care.	Interviews	20	Trust, reciprocity of trust, professional expertise, hardworking, caring/kindness, continuity of care, reliability, delivering promises, listening, personal disclosure, positivity, 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[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.

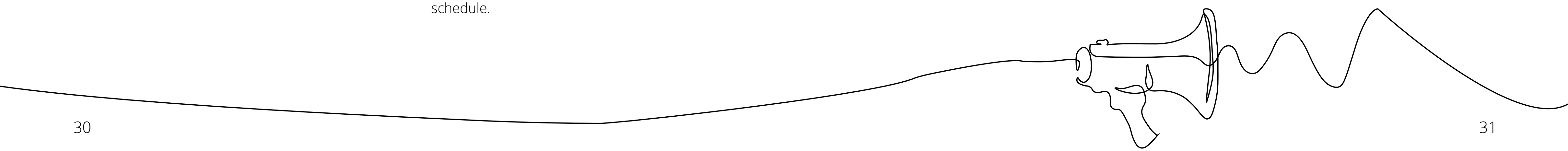
Reference	Aim, population and country	Method	Sample	Determinants
Van Eijk[30]	Explore needs and expectations of Dutch outpatients with RA for rheumatology nursing care.	Focus groups	20	Appropriate, tailored and timely information, self-management strategies (dealing with, communicate with), understanding, 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[19]	Explore experiences and expectations of Dutch chronically ill adolescents regarding providers' qualities for in- and outpatient care.	Mixed methods study	31/34/ 990	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[26]	Determine Belgium outpatients priorities of physiotherapy care.	Question-naire	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[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.

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.

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.



Results

Study selection

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

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:	**3259**	
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:	32 117 184 93 125	Satisfaction Professional Treatment Costs Theoretical
		95	**Meaning**
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:	**56**	
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:	**22**	

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.

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 dissention on one item, ten articles on two items and three articles on three items. The results of the appraisal are represented in table 2.

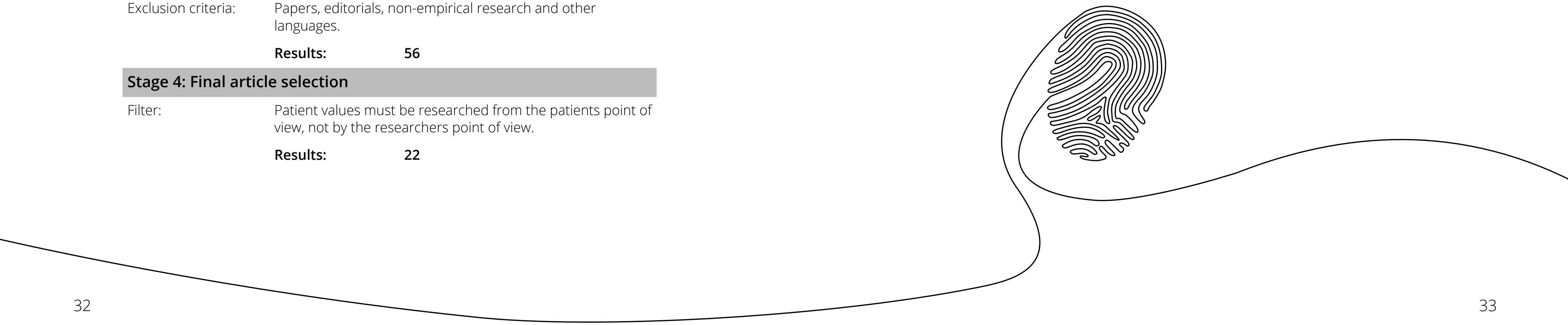


Table 2 CASP quality assessment of included papers

	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	Yes	Yes	Yes	Yes	Yes	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	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Robben[38]	Unclear	Yes	Unclear	Yes	Yes	Unclear	Yes	Unclear	Yes	Valuable
Kvale[36]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	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	Yes	Yes	Yes	Yes	Yes	Yes	Yes	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?

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 under conceptualized area. Besides this, we consider the methodological quality of all studies to be sufficient to be included in the data in our review.

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 writings20 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*.

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.

Table 3 Reported determinants sorted and summarized per key element

Key element	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;[19,23,2,31-33] 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;[2,19,23,26,33,3,37,39] Reassuring;[20,24,25,33] Make patients feel comfortable;[21,2,27,30,34] 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;[1] 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]

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.

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.

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.

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.

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.

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.

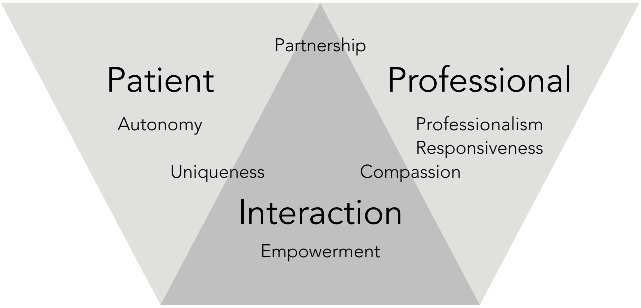
Empowerment

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.

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).

Figure 2 Taxonomy of patient values and preferences



Discussion and conclusion

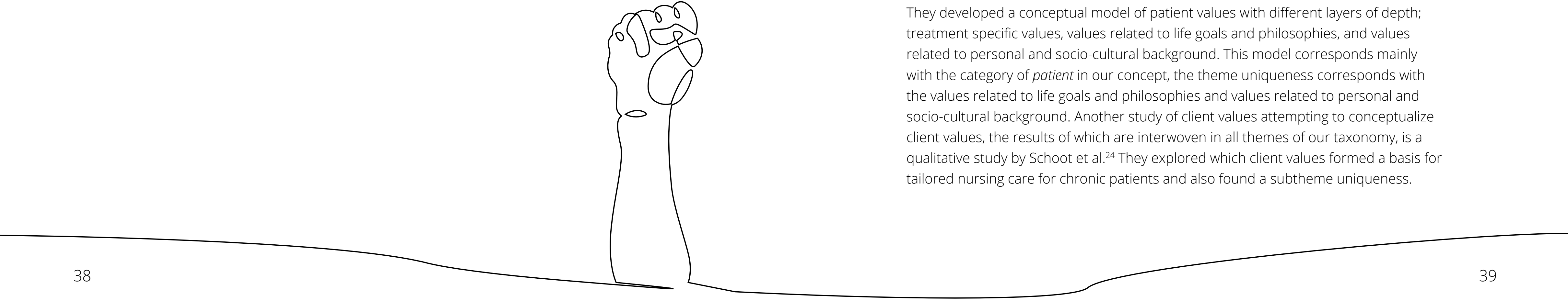
Discussion

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).

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 knowledgeability, 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.[27,24,43] 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 s 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.

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.

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.

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

The authors have no conflict of interest that could have influenced this paper.

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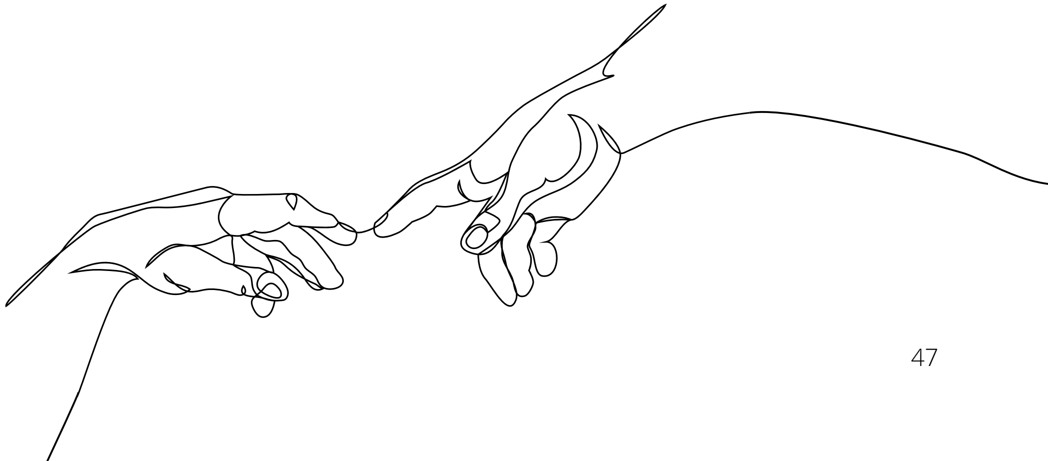
Chapter
3

Patient values in physiotherapy practice, a qualitative study



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Abstract

Objective: Physiotherapy is, like all healthcare professions, relational and value-laden. Patient centered care (PCC), evidence-based practice (EBP) and value-based practices (VBP) are concepts in which patient values lie at the heart of high-quality health care practices. Nevertheless, physiotherapists have limited awareness of what patient values are in the physiotherapy encounter. The purpose of this study is to explore these patient values.

Methods: A qualitative study design using content analysis was used involving 17 adult participants with chronic or recurrent musculoskeletal pain. Data was collected during July 2015-July 2016 in 3 primary care physiotherapy facilities in Rotterdam, The Netherlands. Two researchers analyzed the interviews and derived relevant codes from the data. After an iterative process of comparing, analyzing, conceptualizing and discussing the data, a pre-existing analytic framework was refined in which distinct values were delineated.

Results: Emerging patient values were encompassed in three themes, each consisting of 2-4 elements; 1) values about oneself (uniqueness and autonomy), 2) values regarding actions of the professional (technically skilled professional, conscientious professional, compassionate professional, responsive professional) and 3) values regarding interactions between patients and the professionals (partnership and empowerment).

Conclusion: This study emphasizes the need for discussing patient values in the clinical encounter and helps physiotherapists to understand what deems to be important for patients with musculoskeletal pain in physiotherapy practice. The results of this study contribute to the existing body of knowledge of this important aspect of the quality of physiotherapy practice and may inspire clinicians and educators to actively implement patient values in clinical practice and the physiotherapy education.

Introduction

Physiotherapy is, like all healthcare professions, deeply relational and value-laden. It can be characterized by the nature of complex interactions between physiotherapists and their patients. This complexity results from the often multifactorial nature of health problems, the limited evidence base of physiotherapeutic interventions and the unique and personal contextual aspects of the personal health problem. The clinical encounter is the place where the separate worlds of patient and healthcare professional meet and ideally merge. This merging of professional and layman knowledge, professional and patient experiences and professional and patient values is however, not straightforward. Physiotherapists experience tensions between the choice of treatment they feel is best for their patients and the beliefs and attitudes of patients themselves.[1] In their turn, patients in physiotherapy practice often experience a lack of feeling believed or being understood by their physiotherapists.[2-5] This lack of understanding can be the consequence of limited attention of healthcare professionals for the personal needs and values of their patients.[6] One reason for this may the fact that the meaning of the concept of patient values is currently incomplete, too abstract and/or undertheorized.[7-9]

Values are basic principles that individuals, groups or societies have about what is deemed to be good, bad or desirable.[10] They are formed from an early stage in life and are further shaped by life events, social contacts and education.[11] Rokeach defines values as enduring beliefs that influence a specific mode of conduct or end state of existence that provide us with our moral framework.[12] Patient values are parts of the concepts 'evidence based practice' (EBP), 'value based practice' (VBP) 'patient centered care' (PCC) and are also embodied in the declaration of Helsinki.[13-16] In these concepts, patient values are considered to lie at the heart of high quality healthcare practices and underscore the importance to consider aspects that people value in health care practices such as being taken seriously, being treated by a competent professional, feeling safe and being involved in decision making.[17-20] This latter meaning of patient values refers to peoples preferences and expectations regarding medical interventions or procedures.

Results of our earlier systematic review of qualitative studies regarding the content and meaning of the concept of patient values, shows that patient values in healthcare can be divided into three categories; 1) values concerning the life and philosophy of the patient, such as the wish for autonomy and the desire to be considered a unique person; 2) values related to the characteristics and behavior of the professional, such as being responsive, compassionate and professional, and 3) values regarding the relationship between the patient and the professional, such as the wish for partnership and empowerment.[21] Until now, it remains unknown how these values and expectations merge (or not) with professional interpretations of complex health problems and shape clinical encounters in physiotherapy.

The aim of this study is to describe the aspects of physiotherapy practice that people with musculoskeletal pain value in high quality care. These findings will be used to further develop our earlier found taxonomy of patients values in healthcare.

Methods

Design

This study is designed as an explorative qualitative study using content analysis.[22] The 32-item COREQ (COnsolidated criteria for REporting Qualitative research) checklist is used to design and report the study.[23]

Participants and setting

Seventeen participants were recruited from 3 primary care physiotherapy practices in Rotterdam, The Netherlands. These sites were assumed to be high quality care practices judged by independent auditors. The participants were asked to enroll into this study by their physiotherapist, who was instructed regarding inclusion criteria by the principal investigator (CB). Participants were eligible if they sought consultation for chronic or recurrent musculoskeletal low back, neck and shoulder pain. Those are among the most prevalent pain problems in primary care, known for their complex biopsychosocial character and therefore appropriate health problems suited for the aim of this study.[24] Purposive sampling was used to achieve variation in terms of gender, age and level of education given the fact that values have been formed during life, by personal life events, social contacts and education.[11] From each location, 5-7 participants were recruited of which nine were female and eight were male, aged between 33 and 79 years (57 years on average). Eleven of the participants suffered from chronic or recurrent low back or neck pain and 6 of them from shoulder pain. Nine participants had at least tertiary education (Table 1; Characteristics of participants).

Table 1 Characteristics of participants

Participant	Sex	Age	Education	Musculoskeletal condition	Experience with physiotherapy
P01	F	62	≥ tertiary education	Shoulder pain	Over 20 years intermittent
P02	F	71	< tertiary education	Shoulder pain	Over 20 years intermittent
P03	F	66	≥ tertiary education	Shoulder pain	One and a half year
P04	M	55	≥ tertiary education	Low back pain	Over 20 years intermittent
P05	F	33	< tertiary education	Neck pain	3 years intermittent
P06	F	61	≥ tertiary education	Neck pain	Over 20 years intermittent
P07	M	69	≥ tertiary education	Shoulder pain	Over 10 years intermittent
P08	F	44	≥ tertiary education	Low back pain	1 year
P09	M	65	< tertiary education	Shoulder pain	Over 10 years intermittent
P10	F	48	< tertiary education	Low back pain	Over 7 years intermittent
P11	F	42	≥ tertiary education	Neck pain	Over 10 years intermittent
P12	F	44	≥ tertiary education	Shoulder pain	Over 30 years intermittent
P13	M	70	< tertiary education	Neck pain	Over 30 years intermittent
P14	M	79	< tertiary education	Low back pain	Over 30 years intermittent
P15	M	46	< tertiary education	Low back pain	Over 10 years intermittent
P16	M	71	< tertiary education	Low back pain	Over 10 years intermittent
P17	M	48	≥ tertiary education	Low back pain	Over 10 years intermittent

Participants were informed about the aim of the study and received written information about participating in medical scientific research prior to the start of the study. After 5 days, eligible participants were contacted by the principal researcher (CB) by telephone for definitive enrolment into the study. An interview was scheduled at a location of their choice.

Data collection

Following two pilot interviews, which were discussed by all authors regarding scope and sufficient depth, 17 face-to-face open interviews were conducted between July 2015 and July 2016. The interviews were executed by the principal researcher (CB), a practicing physiotherapist and PhD-researcher with 20 years clinical expertise in primary care as a physiotherapist and with post-graduate training in qualitative research methods. There was no prior relationship with the participants.

Based on the results of the systematic review on the content of patient values in health-care practices, three topics were addressed in the interviews: 1) personal values of patients regarding humanity and physiotherapy care; 2) patients' values regarding actions and behavior of the physiotherapist and 3) the patients' values regarding the interaction with the physiotherapist.21 These topics and other, (non-)related topics were discussed in depth and participants were encouraged to illustrate their thoughts with lived experiences. Data collection was ended when saturation was obtained (where the last three interviews contribute little or no new understandings).[25]
The interviews lasted 35-64 minutes (53 minutes on average), were audiotaped and transcribed verbatim by an independent administrative assistant. All participants verified the verbatim of their own interview as part of a member checking process. The findings and quotes were completely anonymized by the interviewer.

Data analysis

Content analysis as described by the procedures and criteria of Krippendorf was used to explore the acquired data.[22] The unit of analysis were the transcriptions of interviews. To familiarize the researchers to the transcripts and audio files, two researchers (CB, LV) separately read and re-read the interviews to code meaningful words, sentences or paragraphs. Both manifest (analytical) content and latent (interpretative) content was analyzed. Subsequently, both researchers discussed their mutual interpretations and together formed a shared understanding of the data. Then they investigated whether analytical and interpretative (sub-)elements that arose by discussing and organizing the initial codes could be organized in the themes and elements as found in our earlier review.[21] Datapoints that were ambiguous or non-placeable were discussed by the two primary investigators to determine appropriate organization within the (sub-)elements which helped to sort the experiences of patients with physiotherapy practice. All aforementioned steps of the analysis were discussed with the whole research team in order to prevent (unconscious) bias, to verify the analysis and provide analyst triangulation. Atlas.ti was used for data management and further organization and interpretation of the themes, elements and sub-elements.

Trustworthiness of the study was addressed by enhancing credibility, dependability, conformability and transferability.[27] Credibility was addressed by the method of data collection (open interviews), thus allowing participants to express a variety of perceptions, experiences and values. The member checking process with regard to the transcripts and summarizing the findings during and after the interview allowed participants to verify interpretations. Furthermore, the data were peer-checked by two authors (CB, LV) during the analytical process to reduce risk of bias. Data were triangulated by obtaining and comparing data of former research in this field.[17-20,28]
Dependability was addressed by the assessment of pilot interviews by all authors. Carefully documenting the steps and choices in the whole research process obtained transparency. The interviews were recorded and the data were anonymously processed during research in Atlas.ti. Confirmability was enhanced by maintaining field notes during the process of interviewing and memo writing during the analysis process. Transferability was achieved by providing clear descriptions of the participants, setting, data-collection and data-analysis.

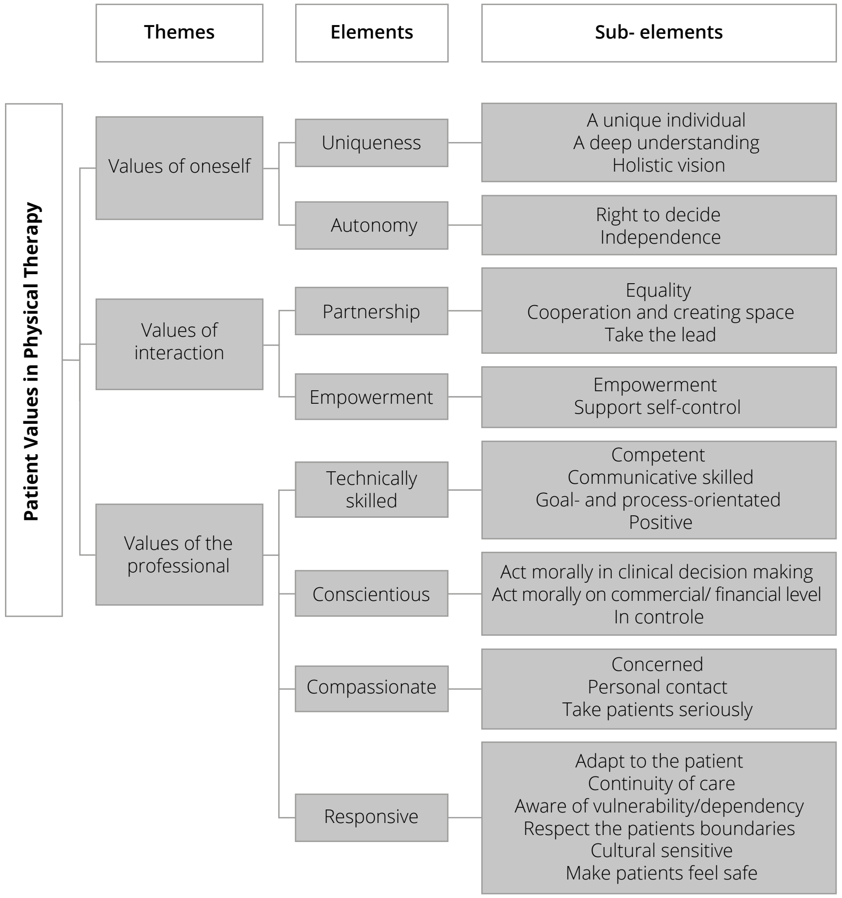
Ethical approval

Ethical approval was given by the Institutional Review Board Erasmus MC Rotterdam in the Netherlands, case number MEC-2015-260.

Results

A previously designed scheme[21] was used to organize the data into three themes; 1) values of oneself; 2) values of the professional and 3) values of interaction. Two to four elements per theme were identified; 1) uniqueness, 2) autonomy, 3) technically skilled professional 4) conscientious professional, 5) compassionate professional, 6) responsive professional, 7) partnership and 8) empowerment. The previously designed taxonomy of patient values is enriched and slightly adapted by the results of this study. Some new elements were distinguished and illustrated with meaningful statements of participants (see Figure 1).

Figure 1 Results



Theme 1: Values of oneself

This theme includes values that reflect the broad ideas of participants about health and healthcare and comprises two elements: 1) uniqueness and 2) autonomy.

Uniqueness

The majority of the participants indicate that personal recognition and the wish to be seen as **a unique individual** is important.

> *P02 Sometimes specialists make you feel as if they are just checking things off a list ... It would be better not to see them as they have already made up their minds about you.*

Participants expect **a deep understanding** and acceptance of their personal environment and life choices. Physiotherapists should be able to empathically understand their patients and fully accept their choices.

> *P13 The therapist asked me questions such as "You have grandchildren, do you play actively with them?"... I replied that I love to play and horse around with them... I was then asked whether this subsequently made me feel unwell again, which it did, but the way I see it is, if I have had a fun day and it made me feel good then I'll suffer the consequences and see how it goes.*

As a result, problems like impairments and functional limitations should not be seen as isolated phenomena but as part of a process of suffering in which the patient as a whole entity is involved. Participants recognize that social and psychological factors play an important role in health problems and are willing to share this personal information, provided that it influences care and treatment. They should expose **a holistic vision** on health.

> *P05 I think it is important that the physiotherapist is aware of how I am in my family and working life and whether or not these factors play a role or create added stress or tension to my situation.*

Autonomy

This emerging element was discussed in the interviews as the patient's **right to decide**. The participants want to be well-informed by the professional in order to make a good decision by themselves or to understand why a certain decision by the professional is the correct one.

> *P03 That is very important for me... I am not used to passing the initiative or the problem to someone else and then just sitting back and waiting to see what they come up with. I like to be the one who decides...*

Respecting the patient's input in treatment and care by physiotherapists is important to all participants. An essential issue mentioned was **independence**.

> *P01 If you can do things for yourself then you feel less dependent. Feeling dependent is awful, it's always there when you need care but it is good if you can minimalize the feeling.*

Theme 2: Values of the professional

This theme reflects the views of participants about professional behavior and management of practice by physiotherapists which involves also moral-ethical considerations that go beyond the personal lifeworld of the individual. Four elements could be identified across the manifest data; 1) technically skilled professional, 2) conscientious professional, 3) compassionate professional and 4) responsive professional.

Technically skilled professional

All participants value a physiotherapist who is **competent**, experienced and has **good communicative skills**, such as being open, direct and honest.

> *P03 Having an experienced person is important. Not someone who just talks the talk, but someone who can really help and knows what they are talking about.*

Participants value a thorough analysis and a clear explanation and information on the health problem which requires a **goal- and process-orientated** physiotherapist. Each treatment should be designed for working in a safe, effective and directed way. Prognosis or expectations of treatment should be tailored and adjusted when necessary.

> *P02 The bursitis was really very difficult and painful in my shoulder. There seemed to be very little progress so a colleague was brought in for a second opinion. The physiotherapist then consulted my GP as to the best remedy to ease the pain.*

Both during treatment and in the business operations, the professional should be **positive**.

> *P17 When someone really shines at what they are doing and they really seem to enjoy their work, then you can see that it's not just about earning money...*

> *P11 This physiotherapist looked at me... and said "It will be better". And then I am pleased.*

Conscientious professional

Conscientious behavior refers to the critical attitude of the practitioner and his moral consciousness in which the patients' interests must prevail. At first, participants value a professional who **acts morally in clinical decision making**. The physiotherapist must establish an ongoing commitment to the patient and remain honest, even though the problem or situation is complex. He must not lapse into a routine action and respect his own professional boundaries and honor existing commitments.

> *P13 In the period when they didn't actually know what was wrong with me I had treatment regardless, I wasn't assessed at all, just continual treatment. Almost ritually. He stopped evaluating if I was doing OK. Then it would be better if he'd just say: I don't know how to proceed. I can't do anything for you anymore.*

Secondly, conscientious behavior refers to **act morally on a commercial and financial level**. Participants think that finance should not override patient interests, and treatment should not simply revolve around health insurance.

> *P09 All I had to do was call...they always had time for me... The therapist only needed five or ten minutes. The first time I went to another physiotherapist he worked with me for thirty minutes to mobilize me and I thought to myself "What was the other one doing then?" I think it was a question of money...*

Lastly, the physiotherapist has to be **in control** and responsible for decision making in treatment within his discipline. Participants are of the opinion that loss of control on the part of the physiotherapist due to regulations of their health insurers leads to too much generalization and protocoled treatment at the expense of the quality of individual care.

> *P06 No, this morning, the physiotherapist filled in an evaluation form to measure any progress saying that there hadn't been any progress at all. I just thought: "What would you do that for?" Because it was a compulsory form which didn't fit my criteria. In my opinion we had achieved a lot.*

Compassionate professional

A substantial part of the interviews could be assigned to the element of compassion, which can be understood as a deep sympathy for the patient. The participants value a **concerned** professional who is able and willing to empathize with a person and his or her unique history and questions.

> *P05 I also felt that there was always time for my questions. There was a lot of attention to detail. Because of this I felt as if I was actually being listened to and heard. This instilled confidence in me to be more open and we were able to get to the core of the problem.*

Consultations can result in a deeper relationship by an increased number of consultations or increased consultation length. This allows for a more comfortable situation and a mutual exchange of thoughts by **personal contact** with the physiotherapist.

> *P05 No, you naturally have a connection with some people. You chat about how your week was etcetera... I had appointments a few times a week, then you don't just talk about your complaints.*

To be **taken seriously**, turned out to be a very important patient value. The physiotherapist should not generalize and trivialize the health problem of the patient.

> *P01 The specialist doesn't have to be too familiar or too amicable. But nothing is worse than a professional who makes you feel as if you are overreacting. This can and does happen.*

Responsive professional

Data analyses revealed the importance of a committed and responsible execution of treatment and care by a physiotherapist who **adapt to the patients'** needs and circumstances. For example; providing information is important, but the professional must adjust the depth of information to the extent of the patient's needs.

> *P07 Understandably, they don't need to tell me exactly which muscle is which, or be too specific medically. That's not necessary, I would rather it was kept simple.*

The physiotherapist should also consider **continuity of care**.

> *P02 Yes, I don't think that patients should be passed from one professional to another. There should be a valid explanation should this happen. However, this can also be a positive thing as a different perspective can be good.*

Participants explicitly mentioned the value of being **aware of vulnerability and dependency**. In contrast to the element independence in theme 1, this element is focused on the fact that in certain situations patients are dependent on the knowledge and skills of the professional. While the patient value 'autonomy' in decision making, they also value an awareness on the part of the physiotherapist for the patients vulnerability when independent decision making is not possible.

> *P01 Patients are often in a vulnerable position because there is something that they are worried but often don't know what it is and they are dependent on the professional.*

On the same note, the physiotherapist must **respect the patient's boundaries** concerning his or her personal pain threshold and intimacy. All women interviewed referred to the awareness of incongruity in the patient-provider relationship according to touching, undressing and personal space. Half of the women often felt uncomfortable in their underwear, especially in the presence of men.

> *P08 Because, to me, what a physiotherapist does can be quite intimate at times. Someone is literally working in your personal space… I remember during the first few treatments I talked a lot and asked a lot of questions to distract from my nakedness. Maybe that is why I began exercise-based treatments. By keeping my clothes on I felt more comfortable and safe.*

Some participants highlighted the possible importance of **cultural sensitivity** by taking into account language barriers and religious differences.

> *P01 I think this could be quite difficult in clinics where there are a lot of immigrants as they may have difficulties communicating and then more time is necessary to be able to communicate with them to help them properly.*

Participants mentioned that the outer appearance of facilities with regard to hygiene and soundness contributes to a sense of **feeling safe**. The practice should be clean, hygienic and in order.

> *P12 Most important is the quality of care, but the treatment should be carried out in a clean and hygienic environment, not in some scruffy clinic. That gives the right impression and makes you feel more comfortable and safe.*

Theme 3: Values of interaction

This theme reflects the process of interaction between the patient and the professional itself, where partnership and empowerment are the core elements. Notably, "values of oneself" and "values of the professional" are intertwined as such as in values for cooperation. The elements in this theme can be distinguished from the other themes by reciprocity and an expectation for a bidirectional effort and commitment.

Partnership

Participants value that interaction with the professionals is based on **equality** and involves mutual respect in an open and understanding ongoing dialogue. They should be able to talk easily and deliberately.

> *P13 Yes, you would assume that the person treating you is an expert, you should be able to comment if you feel the treatment isn't going according to plan. You should not feel that you are unable to make any comments because you are so dependent on them.*

Participants value **cooperation and creating space** for their contribution. Both sides should acknowledge the existing interdependence and must take responsibility.

> *P03 I like to contribute information by telling my specialist about my activities whether I have been able to exercise, what went well, what didn't etcetera …*

> *P06 I can't expect the specialist to solve everything alone.*

Participants would like to have a certain influence on their treatment, but they expect the professional **to take the lead** in this collaboration due to the professional's superior knowledge.

> *P06 The discussion is equal, however, I am seeing a professional for their expertise otherwise I wouldn't be seeing them.*

> *P08 Sometimes it is difficult as a patient to understand the problem, medically the professional should be able to do this. You can't do this as a patient.*

Empowerment
The majority of the participants value empowerment by the physiotherapist. It enables them to keep control of their own situations and support or educate them in how to deal with the problem. Empowerment also includes professionals who help patients towards self-management and prevention.

> *P01 I think it is important that the patient is aware that they have some control over the situation. It is important that the professional encourages you to cooperate in the healing process. Even though they are helping you, you are the most important factor in the process of healing and improvement.*

Lastly, the physiotherapist should, among other things, provide tips, tools and exercises to **support self-control**.

> *P18 That someone explains and demonstrates how and why you have to do the exercises… so that you can go back home motivated to do them.*

Discussion

This study aimed to further substantiate our knowledge about the content of patient values in physiotherapy. The findings of this study show that patient values can be categorized into three themes; 1) values of oneself; 2) values of the professional and 3) values of interaction. These themes can be subcategorized into eight elements; 1) uniqueness, 2) autonomy, 3) technically skilled professional 4) conscientious professional, 5) compassionate professional, 6) responsive professional, 7) partnership and 8) empowerment. These results are in line with our previous systematic review about the content of patient values in health care practices.[21] The interviews enriched and expanded on current insights of patient values which has resulted in an adaptation of the preliminary taxonomy. The element 'professionalism' is refined by the partitioning into 'conscientious professional' and 'technically skilled professional' and by renaming the elements compassion and responsiveness. By integrating the results of this study into the taxonomy, the latter was enriched and adapted to the context of physiotherapy practice (Figure 1).

Although patient values are considered important in high value care and are explicitly a part of concepts as evidence based practice (EBP), value based practice (VBP) and patient centered care (PCC), they are largely unclear and unknown how to be 'integrated' in clinical decision making.[7-9] This vagueness is an important topic to consider as this conceptual flaw may have negative consequences for the quality of physiotherapy practice. Research shows that patients with chronic musculoskeletal pain are often dissatisfied about the quality of the care they receive.[4,5] Important aspects of dissatisfaction are the feeling of not being heard, understood or even not being taken seriously.[2,3] Arguably, our results were not surprising given recent focus on patient-centered care and mutual decision-making, but regardless, the findings solidify our assumptions of what patients' value during care. Harnessing the findings in physiotherapy practice might have important consequences for the quality of physiotherapy practice.[20,28,29]

The explication of the content of patient values and the categorization of separate values into a taxonomy is important as it may form a background against which physiotherapists (clinicians, researchers, educators) can discuss the implementation of patient values into clinical practice, research and education.[30] The taxonomy can form a counterweight against an overreliance on scientific evidence as the cornerstone of clinical practice. Although evidence and values are nicely balanced in the definition of 'evidence based practice', patient values are easily forgotten, pushed away or seen as less important in daily practice where standardization, objectivity and accountability are all guiding principles for high quality care.[31,32]

This study has some strengths and weaknesses. To our knowledge, this is the first study that aims to describe the content of patient values in physiotherapy practice and to organize these values in a taxonomy. An earlier taxonomy is enriched by integrating the results of this study, enabling further research on this topic. We collected patient values via interviews using an open format, giving participants room to describe the aspects they explicitly value in physiotherapy practice. The pre-defined taxonomy served as a guide for these interviews but was not used as a compelling tool. Themes of this taxonomy were openly discussed and adjustments could be made. Thematic analyses were carried out by two experienced researchers in the field of physiotherapy and were further discussed with a team to protect the conclusion drawn from implicit bias. Theoretical saturation was used as criterium to end further data collection. Weaknesses of this study involve the choice of including participants with spinal or shoulder pain, which are common health problems in physiotherapy practice, but maybe give an incomplete representation of results.

Further research on the importance of patient values should go in different directions. A first direction is how sensitivity for patient values can be learned during physiotherapy education. Becoming a conscientious, compassionate and responsive professional may require specific educational strategies and training and needs to be addressed accordingly. Secondly, further research is needed whether the implementation of strategies that harness patient values in daily practices lead to higher perceived quality of care by clients. Thirdly, more theoretical reflections are needed to clarify the relation between scientific knowledge and patient values. The integration of the different kinds of 'knowledge' (scientific evidence versus moral values) cannot easily be integrated and may therefore lead to clinical dilemma's when evidence and the patients' values point in different directions.[1,31,32]

Conclusions and Practice Implications

The findings of this study help physiotherapists to understand what patients with musculoskeletal pain value in physiotherapy practice. Three themes were defined and categorized in a (pre-existing) taxonomy in order to gather knowledge about the nature of patient values in physiotherapy practice; 1) values of oneself; 2) values of the professional and 3) values of interaction. Two to four elements per theme were identified; uniqueness, autonomy, technically skilled professional, conscientious professional, compassionate professional, responsive professional, partnership and empowerment. This knowledge characterizes individual clinical encounters and may help physiotherapists to be patient centered by the integration of moral values in scientific evidence. The results of this study may contribute to further research into this important aspect of the quality of physiotherapy practice and inspire clinicians and educators to actively implement patient values in clinical practice and the education of physiotherapists.

Conflict of interest

The authors declare no conflict of interest.

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Author contributions

Carla M. Bastemeijer contributed to this study by collecting data through interviews, data analysis and writing all drafts of the study. Johannes P. van Ewijk and Jan A. Hazelzet contributed to this study by approval of data analysis, correcting of all drafts of the study and approved the submitted manuscript. Lennard Voogt contributed to this study by data analysis, correcting of all drafts of the study and approved the submitted manuscript.

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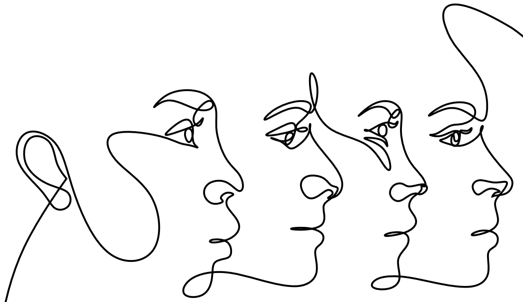

Chapter
4

Physiotherapists' Perspectives on the Meaning of Patient Values and its Place in Clinical Practice: a qualitative study

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Objectives: Patient-therapist encounters are complex interactions, mainly determined by the implicit or unspoken exchange of experiences, expectations and values. Daily practice and literature research indicates frequently experienced discrepancies or misunderstandings of that which patients value and physiotherapists deem to be important. The aim of this study was to gain more insight into the beliefs of physiotherapists about patient values (PV).

Methods: An explorative qualitative focus group method was used involving 23 physiotherapists of 21 different primary care physiotherapy practices in The Netherlands. Data was collected in March-May 2021. Two researchers analyzed the interviews and derived relevant codes from the data. After an iterative process of comparing, analyzing, conceptualizing and discussing the data, major themes arose for a thematic framework which is illustrated with meaningful quotes.

Results: Physiotherapists indicate that PV play a major role in daily practice and associate PV with the psycho-social aspects of the profession, not the technical or biomedical aspects of the encounter. However, taken PV into account is mainly an unconscious process. Responsiveness turned out to be the central element in this study, all values require interaction in which aligning with the individual patient forms the basis of treatment. Barriers arise at times where alignment can't be achieved.

Conclusion: The concept of PV is tacit knowledge; the competent professional subconsciously attunes as fellow human being to the values and expectations of the individual patient in order to arrive at the optimal help and treatment. With this study we contribute in finding a balance and mutual reinforcement of implicit and explicit knowledge. With all the experiences and insights found, we are able to make the concept of PV more explicit in physiotherapy practice and give it more detail in order to create a framework for education and research in the future.

Introduction

Patient-therapist encounters are complex interactions, determined by the implicit or mainly unspoken exchange of experiences, expectations and values. To reach a shared understanding of the patient's individual health problem, patients and therapists need to know each other's personal and professional knowledge and expectations as a starting point for therapy, especially since high quality patient-professional interaction is essential for good outcomes.[1-3] Unfortunately, daily practice and literature research often indicates discrepancies faced between patients values and what therapists deem to be important. Patients experience at times a lack of involvement, taken seriously, or an open interaction of the professional.[2,4-7] Sequentially, therapists are confronted with the conflicting beliefs and attitudes of patients and the professional knowledge and choices of themselves.[8] Research on the complex nature of patient-therapist encounters in physiotherapy practice is scarce and the way in which physiotherapists deal with these complexities during their daily work is largely unknown. This applies in particular for a concept of patient values (PV) and its role in physiotherapy practice.

Patients and physiotherapists both bring their values to the clinical encounter where they become part of a, often implicit, process of blending, sharing, colliding or negotiating.[9] Professional values are defined as the basic and fundamental beliefs upon which a professions' very existence rests.[10] Professional values in physiotherapy are outlined and updated by the American Physical Therapy association, who identified seven core values; accountability, altruism, compassion and caring, duty, excellence, integrity and social responsibility.[11] These concepts should be achieved and demonstrated in physical therapy education and clinical practice but they are still rather abstract and may hamper a solid position in physiotherapy theory and practice.[12]

In our earlier systematic review on the content and meaning of PV from the patients' point of view we concluded that three central themes should be taken into account; 1) values concerning the life and philosophy of the patient; 2) values related to the characteristics and behavior of the professional and 3) values regarding the relationship between the patient and the professional.[13] In a following qualitative study on patient perspectives on the meaning of PV in physiotherapy practice we enriched our preliminary taxonomy and concluded that the three themes could be subcategorized into eight elements; 1) uniqueness, 2) autonomy, 3) technically skilled professional 4) conscientious professional, 5) compassionate professional, 6) responsive professional, 7) partnership and 8) empowerment.[14]

The aim of the current study was to gain a deep understanding of the beliefs of physiotherapists about PV in physiotherapy practice. The following research questions were addressed:

- What is the meaning of PV for physiotherapists in daily practice?
- How do physiotherapists take PV into account in daily practice?
- What are barriers and facilitators for taking PV into account?

Method

Design

This study was designed as a qualitative focus group study using Ritchie & Spencer's framework analysis.[15] The 32-item COREQ (COnsolidated criteria for REporting Qualitative research) checklist was used to design and report the study.[16]

Participants and setting

Based on diversity in socio-economic background of the practice area, convenience sampling via social media and telephone was used to recruit participants of divers primary care physiotherapy practices in The Netherlands.17 Participants were eligible if they had more than 5 years of working experience.

Participants were contacted and asked to enroll into this study by the principal investigator (CB). She informed them about the aim of the study and its procedures. The participants provided verbal and written informed consent.

Data collection and procedure

Three focus group interviews including 7-8 participants were scheduled, conducted and recorded twice in March-May 2021 via an online videoconferencing tool because of the Covid problems. The groups were moderated by one of the researchers (LV/ CB), both physiotherapist and experienced interviewer. Reflective notes of observations and meaningful statements were made during the interviews by the other researcher (CB/ LV).

The first interview (three focus groups) was held with the aim of making an inventory of thoughts, experiences and opinions regarding the concept of PV.
The research questions were used as topics;

- What is the meaning of PV for you in daily practice?
- How do you take PV into account in daily practice?
- Do you experience barriers and/or facilitators by taking PV into account?

These topics and other (non-)related topics were discussed in depth and participants were encouraged to illustrate their thoughts with lived experiences.

Central themes of the first interviews were identified, related and compared with the existing taxonomy to highlight the differences and similarities.[14] All of this was the starting point for the second interview.

The purpose of the second interview was to gain more depth and detail into the discussion and was preceded by sharing the aggregated responses of the first interviews compared to the existing taxonomy.[14] Participants could respond, complete, or reconsider their first answers. Subsequently, the eight elements of the existing taxonomy (uniqueness, autonomy, technically skilled professional, conscientious professional, compassionate professional, responsive professional, partnership and empowerment) were explicitly discussed in depth. Again, participants were encouraged to illustrate their thoughts with lived experiences. After data analysis the written syntheses of all data was shared with the participants for approval or adjustment as a final member check to ultimately arrive at a true consensus.

Data analysis

Framework analysis as described by Ritchie & Spencer was used to explore the acquired data, involving five interconnected stages; 1) familiarization, 2) identifying a thematic framework, 3) indexing, 4) charting; 5) mapping and interpretation.[15] The unit of analysis were the transcriptions of the video-recorded interviews. To familiarize the researchers to the transcriptions and video files, two researchers (CB, LV) separately studied the interviews to code meaningful words, sentences or paragraphs and read the observational notes taken during interview and summary notes written immediately after the interview. Then both researchers shared their mutual interpretations and together formed a shared understanding of the data where major themes began to arise for a thematic framework. In the third stage, indexing, the data was sorted out on quotes and comparisons were made both within and between cases. The fourth stage, charting, involved lifting the quotes from their original context and re-arranged them under the major themes of stage 2. At the last stage, mapping and interpreting, the relationship was sought between the quotes and the data as a whole.

All aforementioned steps of the analysis were discussed with the whole research team in order to prevent (unconscious) bias, to verify the analysis and provide analyst triangulation.

Ethical considerations

This study did not include patients, nor medical or biomedical aspects and therefore didn't require an approval of an ethics review board. The paper contained only non-identifiable person-specific information. Patient stories of participants were used for illustration and were anonymized.

Results

Characteristics of participants

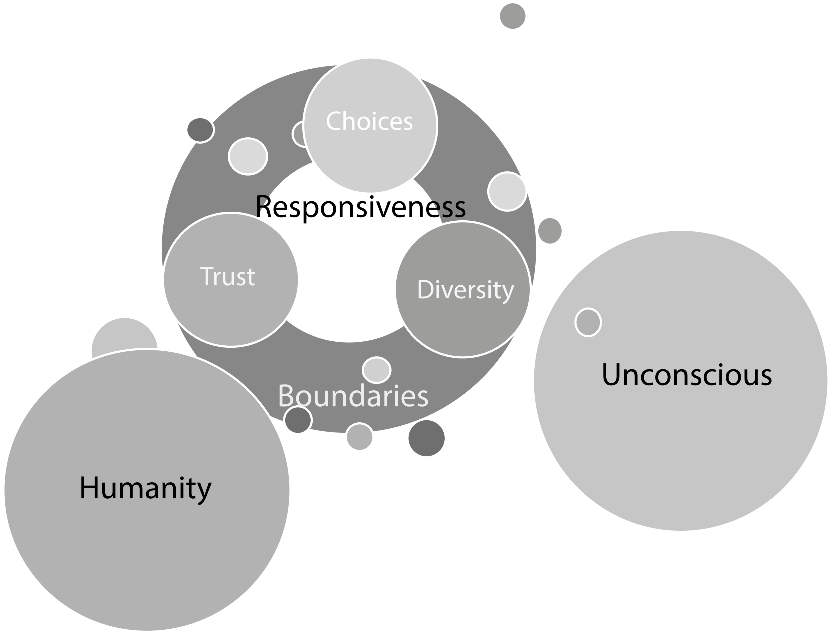
Twenty-nine physiotherapists were recruited by the principal researcher (CB) of which 23 physiotherapists of 21 different primary care physiotherapy practices in The Netherlands participated, based on their interest in participating and availability of time schedules. Of these physiotherapists, 11 were female and 12 were male, aged between 29 and 63 years (45 years on average). They have working experience between 6 and 41 years (23 years on average) (Table 1; Characteristics of participants).

Table 1 Characteristics of participants

Participant	Interview FG1-6	Sex	Age	Work experience	Expertise
P1	1, 6	M	55	30	Physiotherapist/Acupuncturist
P2	1, 5	M	59	38	Manual Therapist
P3	3, 5	F	43	21	Manual Therapist/ Oncology Manual Therapist
P4	2, 4	F	54	32	Manual Therapist/ Extended Scope Physiotherapist
P5	2, 5	M	47	26	Manual Therapist
P6	1, 4	F	34	11	Oncology Physiotherapist
P7	1, 5	F	54	33	Manual Therapist
P8	3, 6	F	32	12	Manual Therapist
P9	2, 6	M	29	6	Manual Therapist
P11	2, 5	F	36	14	Psychosomatic Physiotherapist
P12	3, 5	F	55	34	Manual Therapist/ Oncology/ Extended Scope Physiotherapist
P13	2, 6	M	40	16	Manual Therapist
P14	1, 5	M	35	12	Manual Therapist
P15	2, 6	F	32	11	Manual Therapist/ Extended Scope Physiotherapist
P17	3, 4	M	59	36	Manual Therapist
P18	3, 4	M	40	13	Physiotherapist
P19	1, 4	F	55	34	Pelvic Physiotherapist
P20	1, 4	M	49	27	Manual Therapist
P21	3, 4	M	33	13	Manual Therapist
P22	1, 5	F	43	21	Manual Therapist/ Extended Scope Physiotherapist
P24	2, 4	M	47	27	Sports Physiotherapist
P25	3, 6	F	63	41	Oncology Physiotherapist/ Lifestyle coach
P27	2, 6	M	31	10	Physiotherapist

The interviews lasted 75-89 minutes (81 minutes on average).The findings and quotes were completely anonymized by the principal researcher. A thematic framework arose as a result of the data. At first we found that the meaning of PV for the physiotherapists was mostly 1) unconscious knowledge, refers to 2) humanity in care and 3) alignment towards the patient; responsiveness. Within the theme responsiveness we distinguished four subthemes; a) trust, b) choice, c) diversity and d) boundaries (figure 1).

Figure 1 Results



Unconscious

Taking PV into account is an unconscious process for most physiotherapists, clarifying PV as a definition or concept appears to be difficult. Reckoning with PV proceeds intuitive and develops over the years and through experience. Apparently, it's something you do, not what you know.

> *P21 FG3: Of course, it is not an operationalized process...and that makes it so...fuzzy... but how is it secured? Yes, not as in a tangible thing... We secure it, I think... mainly unconsciously... in the relationship we build with our patients and whether they are happy enough to come back to us or whether or not they return with reluctance...*

Humanity

PV are seen to be important by the participants and are closely associated with humanity within the consultation and much less with process aspects such as clinical reasoning, technical competency, exercise therapy, etc.

> *P18 FG3: And patient values may also be about ... what does the patient actually find the most important interaction between you and the patient ... not just in the applied treatment. So I think, these values can be especially important in interaction, because patients feels you are kind and helpful and they feel comfortable with you .... whether you are actually good at what you do or not... I tell my trainees, patients don't know that...*

PV are seen in contrast to scientific evidence within the profession and the policy of health insurers, which is associated with clinimetrics, guidelines and protocols.

> *P24 FG2: I am not one for using questionnaires I have to say honestly...I think it is far more important to focus on the patient.*

Responsiveness

All the main themes found in our earlier research into PV are sometimes explicitly but more often implicitly reflected in the interviews. All participants agreed to the taxonomy and the interwovenness of elements.

> *P22 FG1: ...and then I start a physical examination. And when we have a connection, if that is the case, I will explain a little. By this I actually help them to understand, that there is some recognition and navigation, so that they can think with me. Well, then we can discuss how we are actually going to handle the medical care and then I will give an approximate time frame, how long it will require before they notice any progress... and after two or three consultations we can evaluate whether progress has been made or whether a change of course should be made.*

Responsiveness appears to be the central element in the interviews; physiotherapists continuously attune to the patient. For an optimal patient-therapist relationship, examples were given of continuous monitoring, adjustment and assurance of the patients values and expectations with respect to physiotherapists values and his professional boundaries.

> *P17 FG3: ...the interaction between physiotherapist and patient, that it will be driven by values of them both. They sometimes cross over, sometimes they even collide. For me it is the ability to finally say that there is something similar to fusion.... to achieve the best results for both. That means that the patient also has his input as well as I... that is what I have realized more and more during the last ten years ...*

Choices

The choice of therapy is considered to be important in clinical practice regarding PV. Most barriers were described concerning this theme: hands-on treatment as the patient's preferred option versus hands-off treatment and becoming self-reliant as the physiotherapists' choice. This can be contrary when the patient wants the problem to be solved solely by the physiotherapist. If then, the physiotherapist does not clarify his professional boundaries to the patient early enough it becomes harder to return any patient responsibility. Because of this patients may be treated unnecessarily. However, when the physiotherapist indicates his preferences (in line with the guidelines or protocols) it can intensify the situation. The patient may feel misunderstood due to different expectations. The physiotherapist thus experiences being trapped between the autonomy of the patient and the professional guidelines and protocols (conscientious action).

> *P7 FG1: ...when you and the patient agree, starting a course of treatment, the patients has their own ideas, the things they need to do... and after two or three times... and then you ask: How are you getting on? You hear; 'I Didn´t do those exercises because... I didn't have time for it'... I am mentioning something small practically. And when this continues, the patient is only coming to me to receive hands-on treatment. The patient then moves into a passive role and puts the expectation onto me... which could be to the detriment of the whole trajectory...*

Boundaries

Difficult situations can come to light when taking PV into account, especially when the physiotherapist appoints (moral) professional boundaries that the patient doesn't want to take it into consideration. Examples include stopping treatment in the event of insufficient progress, or too many psychosocial problems as a hindrance factor, or because the final goal has been achieved when there is still financial remuneration available. Or conversely, if the goal cannot be achieved because there is actually no remuneration available.

> *P20 FG1: …a kind of patient population, where I actually had difficulty in getting people out of the practice. That sounds rather direct, but because the patient simply felt that they were entitled to the total number of treatments in their insurance package (regardless of whether they were necessary or not).*

> *P19 FG1: …the defining aspect how someone is insured… Some people have such limited insurance policies and there is so little coverage in a basic insurance policy that you already have a conflict of conscience…*

Being genuinely interested and putting the patient foremost can also cause problems. The physiotherapist can be too compassionate towards the patient. When this occurs, it is more difficult for the physiotherapist to be totally honest, to confront the dilemma and refuse to treat more often than actually is necessary.

> *P24 FG2: Specifically, this is what I do, I listen completely to the patient's story and their social situation. Maybe I have carried on treating them for too long… in my eyes….or maybe I haven't been clear enough about my competence, my professional boundaries…actually being too sympathetic… if that is possible…*

Diversity

The diversity of patients and the complexity of health problems can have as a consequence, that according to the participants, it is more likely that guidelines are deviated rather than followed. The use of guidelines seem to be at odds with the elements of responsiveness and uniqueness.

> *P18 FG4: Non-specific low back pain for example… it is clearly described what should be done in these cases…Well, I think that these cases can be so complex that you can throw protocols out of the window, so to speak… I actually don't do anything with those. This is often the case in practice… I think the guidelines are too specific and therefore not non-specific… because patients, they are unique, that it is precisely why it is actually different for each individual.*

Furthermore, the time required to fully discuss and align treatment with a patient is often limited, even more when the physiotherapist experiences barriers in language, religion or culture.

> *P20 FG1: … the whole spectrum of patient values… from A to Z … and you try to meet all of them within half an hour, so to speak, … Mmm, then I actually feel that I have to make concessions, often in the depth of their story. And when this happens…indeed, yes… did I really deliver the quality in care that I endeavor to achieve?*

Also, not all patients are as self-reliant by nature or have insufficient health literacy. In order to empower these patients, they may need to be treated for a little longer, or further steps need to be taken (e.g. by involving social networks) and the time and space for that is not always available.

> *P4 FG2: The dilemma for me is if the patient has limited health literacy and finds it better to be taken by the hand, so to speak. While you would prefer, of course, that the patient could have a better understanding of their complaints themself. If they don't have the necessary competencies, or if the opportunity is not available, what you should do? I find that rather difficult…*

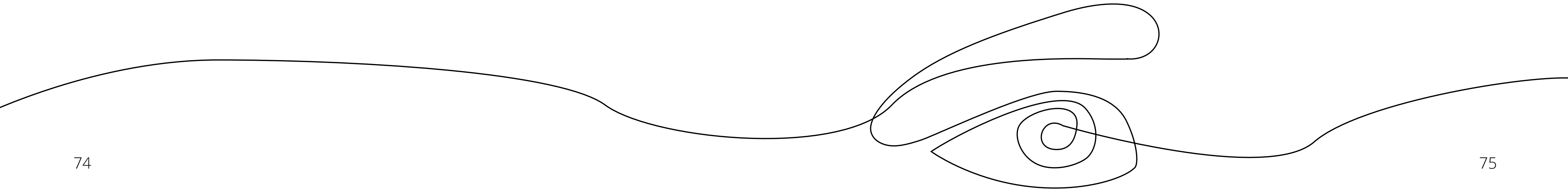
Trust

The patient's confidence in the physiotherapist is perceived as conditional within the patient-therapist relationship. Lack of trust is seen as a barrier. One reason for this is insufficient professional hierarchy; 1) Based on age or lack of work experience, 2) Due to the position of the physiotherapist, for example as the junior physiotherapist, and 3) If the referrer has already determined, through the referral letter or during the consultation, which treatment should take place. Conjointly, the patient may come in with prior information or their own ideas so that they are no longer open to the professional's perspective and knowledge.

> *P7 FG1: Now, I see a patient in front of me, who has a rock solid belief, that she has fractured something in her neck; she has already been on a number of multidisciplinary trajectories, but she continues to remember the words …"it's just"…if she refuses to budge then we cannot move forward.*

Moreover, the physiotherapist sometimes experiences pressure from the profession based on scientific research to be cautious with high cervical spine manipulation or hands-on treatment in general. It feels like an infringement of professional autonomy and self-confidence.

> *P11 FG2: In physiotherapy education… massage, hands-on treatment, well, you could say, it's almost not done anymore. And then, a GP specifically referred someone to me and she went back to the GP completely dissatisfied saying 'This physiotherapist doesn't do massages any more'. The GP said to me : What a pity, you could improve people's attitude to their health just by making contact, by putting your hands on her back.*



Discussion

This study aimed to gain more insight into the beliefs of physiotherapists about what patients' value in high quality physiotherapy care. We have seen that PV play a major role in daily practice, that therapists consider PV as important, but also that it is mainly an unconscious process. The physiotherapist puts the patient at the center of the treatment and listens to him seriously and sincerely. By considering the patient's complaint, pain and situation, a feeling of trust and co-creation ought to be sought; a collaboration in which both patient and physiotherapist influence the process ending with a valuable result.Aligning with the patient and his expectations, being responsive, is central in this process.[18] At the same time, this adjustment is the most commonly mentioned barrier in the physiotherapeutic encounter. Situations were described as how insufficient alignment leads to uncomfortable situations, difficult conversations or even discontent.The values that physiotherapists mentioned that they thought to be important for patients correspond to the taxonomy previously found.[14] According to the participants, the patient is seen from a biopsychosocial framework in its unique context, which corresponds to the literature.[19,20] Responsiveness was the key element in this research, all values require an interaction where alignment with the individual patient forms the basis of the treatment. This corresponds to studies that show that good therapist interaction contributes to positive health outcomes.[1-3]

Our research confirms how important it is to enter into a dialogue with the patient, with yourself and with others. Values do not turn out to be static quantities, they require continuous adjustment and tuning.[9] We found that values are often preverbal and are taken into account unconsciously. This aligns in literature referring to the phenomenon of tacit knowledge.[21] Tacit knowledge is described as a form of individual knowledge that is difficult to put into words. This form of knowledge often contains (cultural) values, experiences and attitudes and is visible in actions, intuition and routines. Explicit knowledge distinguishes itself from tacit knowledge by its objectivity through literature and science. Tacit knowledge is not by definition sufficient, it requires development, learning, reflection and correction.[22] Participants indicate that taking PV into account is developed by work and life experience, which corresponds to the development of tacit knowledge.

The description of PV is often by practical examples, and it is noticeable to see that these examples often show the tension between taking PV into account and safeguarding professional values. The integration of the different kinds of 'knowledge' (scientific evidence vs. moral values) don't easily merge and sometimes leads to clinical dilemma's, especially when the professionals' values and the patients' values don't match.[8] We have seen that values are not only to be met but also to be negotiated. The physiotherapist wants to massage or manipulate once more, if the patient then exhibits healthy behavior. They agree to disagree.

This study has strengths and weaknesses. To our knowledge, this is the first study that aims to gain more insight into the beliefs of physiotherapists about what patients in physiotherapy practice value in high quality care. We collected their thoughts and experiences via focus group interviews using an open format, giving participants room to describe all aspects they think patients' value. Elements of the taxonomy of PV served as a guide for the second interviews.[14] Thematic analyses according to the framework analysis of Ritchie and Spencer[15] were carried out by two experienced researchers in the field of physiotherapy and were further discussed with the team to protect the conclusion drawn from implicit bias. Member checking was done twice. The written syntheses of the data of each round of interviews was shared with the participants to ultimately arrive at a true consensus.
Weaknesses of this study involve the choice of including participants by convenience sampling via social media and telephone. This could have given an incomplete representation of results by the fact that perhaps these participants were already more interested or read more into the subject than on average.

PV are a fundamental characteristic of concepts like 'evidence based care', 'value based care' and 'patient centered care' and should be acknowledged and developed in physiotherapy education and clinical care.[23-25] Further research on the importance of taking PV into account should go in different directions. A first direction is how sensitivity for PV can be learned during physiotherapy education. Becoming a responsive physiotherapist may require specific educational strategies and training which need to be addressed accordingly. In addition, it is important to share the gained explicit knowledge about PV in education in order to make actions more transparent and transferable. Secondly, further research is needed on how to find a more equal balance between explicit knowledge such as scientific evidence, and implicit tacit knowledge. The therapists mainly take a somewhat holistic, intuitive approach but that does not absolve them from rationality and systematic reflections. The professional experiences a conflict between these two worlds on a daily basis and feels valued mainly on the objectifiable, scientific basis of the profession. The different kinds of 'knowledge' don't easily merge yet and lead to clinical dilemma's in daily practice.[8,26,27]

Conclusions and implications for clinical practice

The findings of this study help physiotherapists to understand what PV mean in daily practice and how they can take them into account. Unconsciousness, humanity and responsiveness are the main themes demonstrated in the interviews. PV are tacit knowledge; the competent professional aligns continuously, but unconsciously, as a fellow human to the values and expectations of the individual patient in order to achieve the optimal care and treatment. Within being responsive we can distinguish four subthemes; a) trust, b) choices, c) diversity and d) boundaries.

The disadvantage of tacit knowledge is that it is difficult to objectify and that it requires reflection, learning and correction. However, explicit knowledge and skills may be very objective and transferable, but there is a risk of ending in rigid regulations. This article is intended to help us find a balance and mutually reinforce implicit and explicit knowledge. With all the experiences and insights mentioned, we are able to explain the concept of PV in physiotherapy practice and give more substance to create a framework for education and research.

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Conflict of interest

The authors have no conflict of interests that could have influenced this paper.

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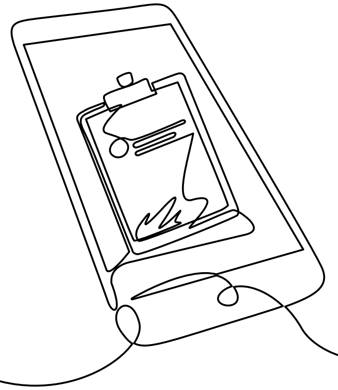

Chapter

5

Patient Experience Monitor (PEM): The development of new short form Picker experience questionnaires for hospital patients with a wide range of literacy levels

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Abstract

Purpose: Several patient reported experience measures (PREMs) were developed through the years. These questionnaires are frequently found to be inappropriate for people with lower literacy levels. This paper describes the development of patient experience questionnaires for hospital patients with a wide range of literacy levels, while enabling the potential for quality improvement.

Methods: Mixed methods were used to adapt Picker Institutes patient experience questionnaires: selection of items and adaptation towards language level B1 (the language level of which patients can express their own opinion and describe experiences, events and expectations) by expert panels, usability tests with patients, analysis of psychometric properties and member checking. A theory-driven approach was followed for definitive enrolment of items, meaning that the items eligible for exclusion had been carefully reviewed by the expert team and representatives of a patient council before definitive exclusion.

Results: A pilot study was performed in an University Medical Centre in The Netherlands among in- and outpatients after discharge. Two provisional questionnaires of 22 items, designed by an expert panel, were reduced towards a final selection of 14-15 items. This led to two short form questionnaires, called Patient Experience Monitor (PEM) Adult Inpatient and PEM Adult Outpatient. To illustrate, the results of the PEM Adult Outpatient questionnaire are presented.

Conclusion: PEMs are short and valid questionnaires specifically developed to measure patient experiences of hospital patients with a wide range of literacy levels. Acceptance of the questionnaires for both lower and higher educated patients is confirmed by usability tests. The respondents of the pilot study represent both groups. The developed questionnaires should be seen as a dynamic entity and part of a continuous effort to evaluate and improve patient experiences. Future studies are needed to examine the usability of these new questionnaires for quality improvement.

Introduction

The concept of patient-centered care (PCC) is considered fundamental for high-quality health care systems.[1-4] The foundation of PCC lies in understanding and respecting individual patient values, preferences and expressed needs, which should be the basis of the clinical encounter and guide all clinical decisions.[3,5-7] Patient experiences have become a key indicator to examine patient centeredness and quality of healthcare.[8] To get insight in patient experiences, a number of tools can be used to capture the complexity of hospital care. Questionnaires are commonly used because of their capability to include a large number of patients in a standardized manner.[9,10]

Through the years, several generic and disease-specific patient reported experience measures (PREMs) were developed. The choice of an instrument as such should be determined by a balanced consideration of different aspects of utility such as costs (a large standardized sample can be expensive), acceptability by their users (healthcare professionals and patients) and educational impact (can healthcare be improved with the results).[10] Also, it should be kept in mind that characteristics of PREMs which may lead to an overall low response rate or non-response bias should be avoided. A frequently found characteristic of questionnaires is that these are less appropriate for people with lower literacy levels.[11,12] The language used by healthcare professionals is usually too difficult to understand for this population, and this language often occurs in surveys as well.[13] Furthermore, questionnaires often include a large number of questions while a more concise questionnaire has a better response rate.[14-16] The result may be an instrument that due to the lack of comprehensibility, length, or low response rates, has a reduced educational impact.[17,18]

Therefore, short and simple questionnaires which capture different aspects of PCC are essential to evaluate patient experiences with hospital care.[19-21] These questionnaires should preferably be developed with extensive involvement of users applying techniques such as interviews, focus groups, and usability tests (cognitive interviewing).[22-24] Additionally, the questionnaires must be useful to guide quality improvement (QI) in clinical practice.[25-27]

In the search for validated patient experience questionnaires that met the aforementioned criteria, Picker Institute questionnaires were selected considering; 1) Picker Institute's longstanding history and extensive research in developing and validating patient experiences questionnaires, 2) the underlying theory of 8 principles of PCC,[21] 3) extensive patient involvement in questionnaire development, and 4) permission to adapt the questionnaires.

The development of Patient Experience Monitor (PEM) contributes to patient experience measurements by integrating the various insights from existing questionnaires, the latest insights regarding literacy, the trend towards shorter questionnaires and the focus on QI. The aims of this study were twofold:

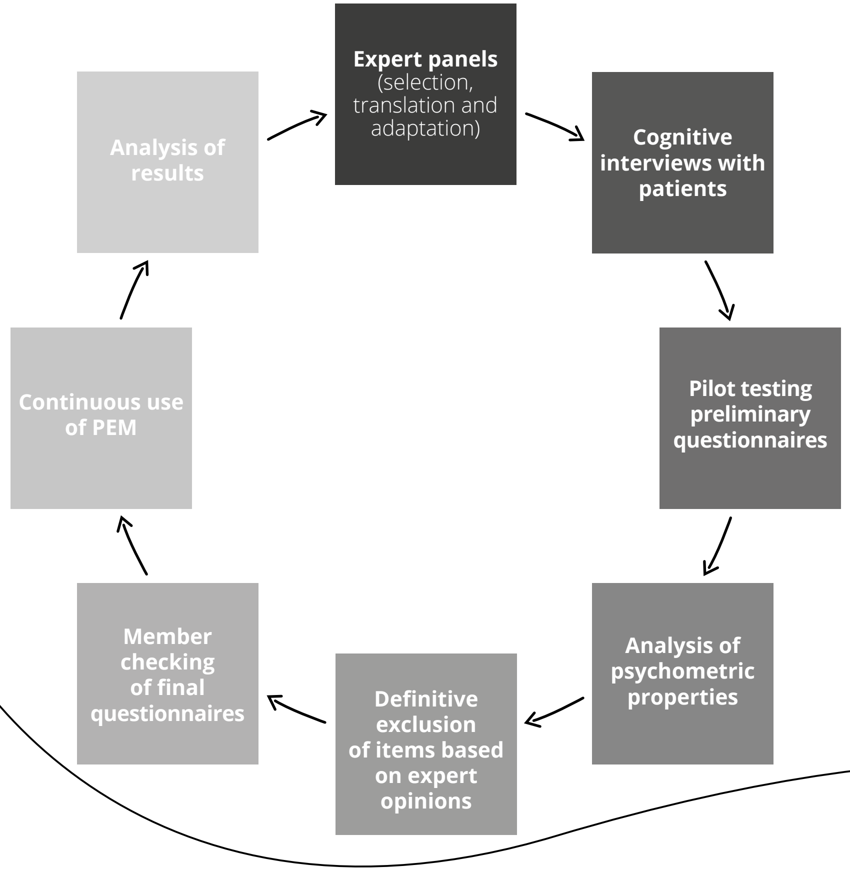
a) To adapt this questionnaire for people with limited health literacy by the use of simple language.
b) To shorten existing validated patient experience questionnaires for a better response rate.

This paper describes the process of adapting two existing patient experience questionnaires of Picker Institute for patients with a wide range of literacy levels in a hospital setting, while enabling the potential for QI in the Netherlands and internationally.

Methods

The following methods were used to construct the new questionnaires: expert panel, cognitive interviews, analysis of psychometric properties and member checking (Figure 1). Each method is described below.

Figure 1 Method of Survey Development



Expert panel

An expert panel of ten members was convened to select existing questionnaires and adapt these to shortened versions and to optimize comprehensibility for a broad range of literacy levels. The panel included the original translator, experts in healthcare, quality managers and staff advisors of various university medical centers, as well as experts with experience in questionnaire development and translation. Furthermore, a staff member of Pharos was involved. Pharos is a Dutch institute that specializes in decreasing healthcare disparities related to language, education level, health skills and cultural background of patients (https://www.pharos.nl/english/). Given that the original Picker questionnaires consist of 67 to 87 items, the expert panel aimed to reduce the questionnaires to a core set of items that represent the eight key domains of PCC as identified by Picker Institute.[21]

Cognitive interviews

Provisional questionnaires, the version compiled by a first reduction of the expert panel, were tested by means of cognitive interviews on a purposive sample (N=28). Participants were informed about the aims of the study and received written information about participating in medical scientific research prior to the start of the study by the principal investigator (CB). All participants (and parents or legal guardians if under 18 years of age) provided written informed consent prior to the interview. The Three-Step Test-Interview procedure (TSTI) was used.[28] The TSTI is an observation-based method for pretesting self-completion questionnaires in three steps; 1) Observation of response behavior and concurrent think aloud verbalization, 2) Follow-up interview for clarifying and completing the interviewers interpretation, and 3) Eliciting experiences and opinions of the interviewees. Relevance of the questions and answers was evaluated, as well as the method of online collection. All participants verified the findings and the suggestions of their own interview as part of a member checking process. The findings and suggestions were completely anonymized and documented by the interviewer.

Data analysis of psychometric properties

In order to test whether the number of items of the provisional questionnaires had to be further reduced, a pilot study was performed in a University Medical Centre in The Netherlands between January and April 2019 at departments that were enthusiastic about the study and were willing to participate. All in- and outpatients of 16 years and older who visited or were hospitalized at the neurology, surgery or ear-nose-throat (ENT) department received within two weeks after discharge by email an invitation with a link to complete one of the provisional questionnaires in an online environment. Patients who were not willing to participate could unsubscribe via a link in the received e-mail. A reminder was sent to non-responders two weeks after the initial invitation. Questionnaires were included for analysis only if at least 50% of multiple-choice items were completed. Questionnaire items were eligible for exclusion if they fulfilled one of the following criteria:

1. Item response: more than 10% missing values, with exemption of routing questions (e.g., "if yes go to question…");
2. Room for improvement: items with more than 90% of responses in the same extreme category (i.e. floor- ceiling effect);
3. Item relevance: items with more than 40% of response "not applicable".

Since the questionnaires were developed with the aim of QI, a theory-driven approach was followed for definitive enrolment of items instead of a data driven approach.[29,30] A data driven approach, such as performing Rasch analyses or principal component analyses followed by reliability analyses for item reduction, better suits questionnaires with many questions per domain. This is not applicable here, as there are only a few questions for each domain, and we want to maintain all eight domains. The theory driven approach means, that the items eligible for exclusion had been carefully reviewed by the expert team and representatives of a patient council before definitive exclusion (member checking). For example, the item was not excluded when it represented an essential component of PCC according to Picker institutes principles or was considered to be of great importance for QI, despite a floor- ceiling effect or low relevance. Of the final selection of items, Spearman correlation coefficients were calculated, correlations >0.70 were flagged as an indication that items yield overlapping information.

Member checking

Member checking is traditionally a technique in qualitative research used to establish the tenet of credibility of data.[31] The results has to be returned to participants to check for accuracy and resonance with their contribution. The final questionnaires were presented to all those involved in the adaptation process (quality managers, staff advisors, healthcare professionals and patients) for evaluation, discussion and approval.

Ethical approval

Ethical approval for the study was given by the Institutional Review Board Erasmus MC Rotterdam in the Netherlands, case number MEC-2018-1714.

Results

PEM Adult Outpatient: Expert panel

To illustrate, the results of the adaptation process of PEM Adult Outpatient are presented. The process and results of the PEM Adult Inpatient followed a similar path (Supplementary Table 1-3, Supplementary Figure 1). As required by Picker Institute, their Survey Adaptation Guide was accurately followed.[32] This implies that every step in the adaptation process that generates a reduction or adjustment of items was presented to Picker Institute for discussion and approval. The questionnaire was first translated from English into Dutch according to the forward-backward procedure. Based on the results of previously used patient experience questionnaires of various university medical centers in the Netherlands, our knowledge on what patients value in healthcare[4] and the suitability of items for QI, the expert panel reached consensus on 22 eligible items out of 87 items of Picker Adult Outpatient (Figure 2). An even representation of Picker Institutes 8 principles of PCC (2-5 items per principle) was taken into account. The pilot study was used to investigate whether the selection should be further reduced. A staff member of Pharos edited the selected items to language level B1, the language level of which patients can express their own opinion and describe experiences, events and expectations (https://europass.cedefop.europa.eu/nl/resources/european-language-levels-cefr).

PEM Adult Outpatient: Cognitive interviews

This provisional questionnaire of 22 items was cognitively tested on a purposive sample of 28 discharged patients for comprehensibility and relevance of the items from a patients point of view. These patients were recruited in a primary care center by their GP or physiotherapist 6 weeks after hospital discharge or visiting an outpatient clinic at the latest. This sample consisted of 13 men and 15 women, of whom eight were aged 16-25, fourteen aged 25-60 and six of them were 60 years and older. Sixteen had a lower education level (≤ lower secondary education) and 12 of them had a higher education level (≥ upper secondary education). On the basis of the interviews, adjustments were made to the text of the introduction and questions and one item (Q22) was removed due to multiple interpretations. Two patients with a higher level of education criticized the simplicity of the language used, but acknowledged that the language chosen was to give priority reaching lower literate people. The vast majority, 26 of the 28 interviewees, did not comment on the simplicity of language used.

PEM Adult Outpatient: Data analysis of psychometric properties

The cognitively tested and modified outpatient questionnaire of 21 items was sent within two weeks after consultation to all neurology, surgery and ear-nose-throat (ENT) outpatients who registered their email and had given permission to use email for communication (N=6806, which is 58.7% of the visiting patients). Of these, 53.3% were men and 46.7% women. Patients who were not willing to participate could unsubscribe via a link in the received e-mail, or simply not respond. The final response rate for this survey was 36.8%. In Table 1 gender, age and education level of the respondents are shown.

Table 1 Characteristics of respondents

	PEM Adult outpatients	
Sample description	**N=2506**	**Valid %**
Gender		
Male	1253	54.4
Female	1050	45.6
Age		
16-20	24	1.0
21-30	94	4.1
31-40	153	6.6
41-50	263	11.4
51-60	550	23.9
61-70	726	31.5
> 70	492	21.4
Educational level		
Early childhood education	35	1.6
Primary school	61	2.8
Lower secondary education	379	16.9
Upper secondary education	790	35.3
Tertiary education	230	10.3
Bachelor's/ Master's or equivalent level	530	23.7
Doctoral or equivalent level	212	9.6

Of the 2506 respondents, 54.4% were men and 45.6% were women. Regarding educational level, 21.3% of all respondents had a low education level (early childhood, primary and lower secondary education), 35.3% an intermediate education level (upper secondary education) while 43.6% had a high education level (equivalent to tertiary education and Bachelor's, Master's or Doctoral level). Of all these respondents, 2384 completed more than 50% of the items and were included for further analysis. Missing values ranged from 0.3% to 5.4% with the exception of the question Q4 "Could other people hear what you were saying to the person at the reception?", where 17.4% of the answers was missing (Table 2). Seven items had a ceiling effect, items with a floor effect were not found. Four items of the questionnaire were of low relevance for a larger group of patients (> 40% category response "not applicable").

Table 2 Statistical characteristics of items

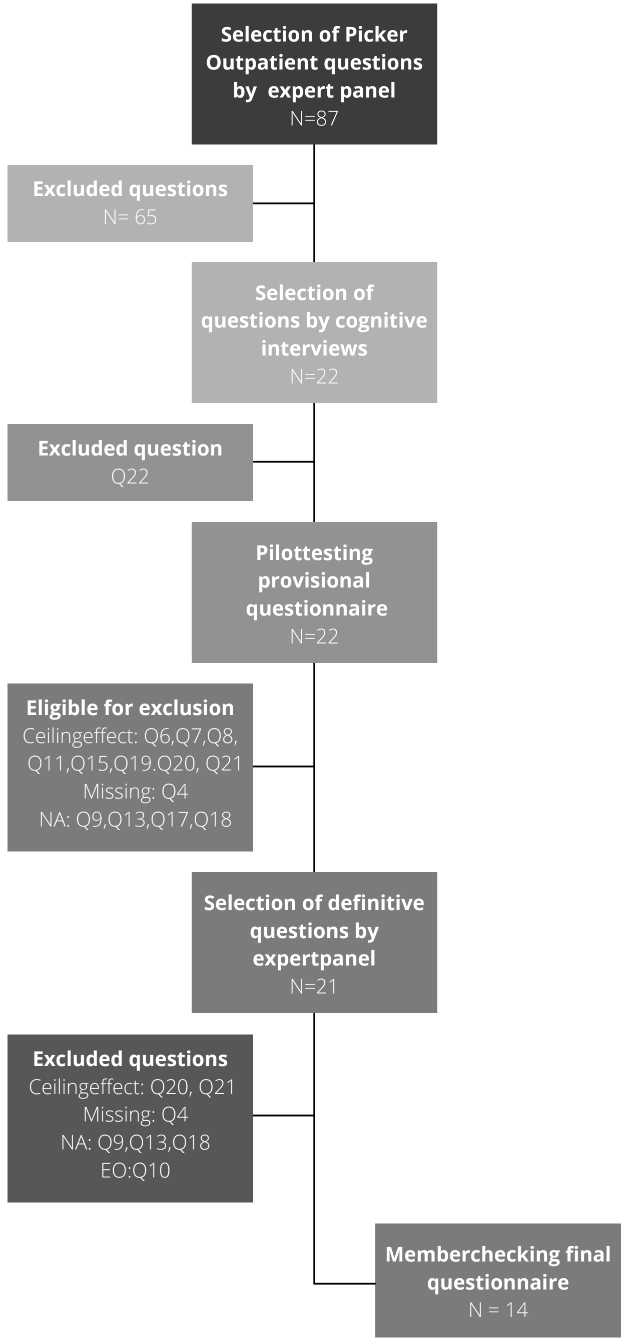
Picker Principle	Questions selected by expert team Adult Outpatient		Ceiling >90% Positive answers	Floor >90% negative answers	Missing >10%	Do not know >10%	NA >40%
FA, ES	Q1	Did you have to wait at the clinic to see the nurse/doctor or was they on time?**	42.8	3.3	0.0	0.8	n/a
ES, CI, FA	Q2	Were you told how long you would have to wait? ("go to")**	22.0	60.1	0.0	1.2	72.8
ES	Q3	Were the staff at the Outpatients Clinic reception friendly?**	85.1	1.1	0.2	0.3	n/a
ES	Q4	Could other people hear what you were saying to the person on reception?	42.4	8.6	17.4*	9.6	n/a
CI	Q5	Did the staff at the Outpatients Clinic tell you what was going to happen to you? ("go to")**	80.9	14.5	1.5	3.1	n/a
CC, ET	Q6	Did the doctors or nurses know what was written in your medical records?**	92.0*	1.0	0.4	1.2	0.5

Picker Principle	Questions selected by expert team Adult Outpatient		Ceiling >90% Positive answers	Floor >90% negative answers	Missing >10%	Do not know >10%	NA >40%
CI, IR, ES	Q7	If you had a question for the doctor did you understand what they told you?**	91.6*	0.6	0.2	n/a	5.4
ET	Q8	Did you trust the doctors? ("go to")**	91.3*	1.2	2.3	0.1	n/a
IR, CI, ES	Q9	If you had a question for one of the other members of staff at the Outpatients Clinic, did you understand what they told you?	89.8	0.5	0.4	0.2	45.3*
ET	Q10	Did you trust the other members of staff at the Outpatients Clinic? ("go to")	87.1	1.3	20.4	9.6	n/a
AN, ET	Q11	Did you have enough time to talk to the doctor or other members of staff about your illness or problem?**	93.1	1.8	2.3	n/a	n/a
CI, CC	Q12	Sometimes at the Outpatient Clinic, members of staff say different things which may confuse you. Did this happen to you?**	79.5	3.4	2.8	n/a	n/a
ES	Q13	Were you able to talk to anyone at the Outpatients Clinic about any worries or fears you had?	76.9	12.1	1.9	n/a	56.9*
IR	Q14	Were you involved in the decisions about your treatment?**	88.1	2.6	1.9	1.7	24.6
IF, IR, CC	Q15	Were your family or someone close to you involved in the decisions about your treatment?**	93.4*	2.3	2.3	n/a	34.9
IR, CI	Q16	Did anyone at the Outpatients Clinic explain to you the pros and cons of the treatment?**	84.4	1.3	2.6	n/a	23.2
CC, CI	Q17	Did a member of staff tell to you about possible side effects that you could have from any new medication?**	67.4	15.4	2.8	n/a	54.9*
CC, CI	Q18	Did anyone at the Outpatients Clinic explain to you about any problems you needed to be aware of when you got home?	77.3	12.5	2.6	n/a	46.0*
CC, CI	Q19	Did anyone speak to you about after care? For example: Should you make a new appointment or should you see your GP?**	92.5*	2.1	2.5	1.2	23.2
AN, ET	Q20	How clean was the Outpatients Clinic?	98.4*	0.0	2.3	1.6	n/a
ES	Q21	Do you feel that the members of staff at the Outpatients Clinic treated you with respect?	92.8*	0.3	2.8	n/a	n/a

FA=Fast Access to reliable healthcare; ET=Effective treatment and trusted professionals; CC=Continuity of care and smooth transitions; IR=Involvement in decisions and respect for preferences, needs and values; CI=Clear information and support for self-care; IF=Involvement of and support for family and friends; ES=Emotional support, empathy and respect; AN=Attention for physical and environmental needs; NA= Not Applicable (it was not necessary/ I don't need to/ I didn't have to/ I didn't spoke to); n/a= not applicable, go to=routing question; *=item eligible for exclusion; **=final selected item

These results have been submitted to the expert panel who, after careful consideration, made a final selection of 14 items (Figure 2).

Figure 2 Flowchart of exluded questions



Q1-21=Questions selected by expert team (Table 2); NA=Not Applicable>40%; EO=Expert Opinion

This selection was based on the statistical characteristics of items (Table 2), an even representation of the 8 principles of PCC, and the advice of users (healthcare professionals and patients). To illustrate; the item Q7 "If you had a question for the doctor did you understand what they told you?" was eligible for exclusion based on a ceiling score of 91.6 %. However, the client council strongly advised to include this item since comprehensibility of healthcare was considered a key prerequisite for patient centered care. They considered understandable information as crucial for the assessment of quality of care in the long term. Item Q15 "Were your family or someone close to you involved in the decisions about your treatment?" was included despite of a 93.4% ceiling score, as it was a serious issue for the expert panel and was considered to be the best representation of the Picker principle "family involvement". A final illustration of how the qualitative weighting of items influenced the final selection was the inclusion of item Q17 "Did a member of staff tell to you about possible side effects that you could have from any new medication?". Even though 54.9% of respondents indicated they had not received new medication, which made the item eligible for exclusion, it was decided to include. Medication is an important topic considering the substantial risk of adverse events through incorrect use of medication. There is considerable room for improvement, only 67.4% of respondents received adequate information about side-effects and 15.4 % of the respondents did not receive any information about side-effects at all.

As a final consideration, the Spearman's inter-item correlation coefficients of the final selection of items were calculated (Table 3). The correlations above the threshold of 0.7 were flagged. This was the case for "Q14 Were you involved in the decisions about your treatment?" and "Q15 Was your family or someone close to you involved in the decisions about your treatment?" with a correlation of 0.708. Despite the strong relation between these items, the expert panel decided not to remove either of the questions due to their various meaning; 1) involvement in decisions and 2) family involvement.

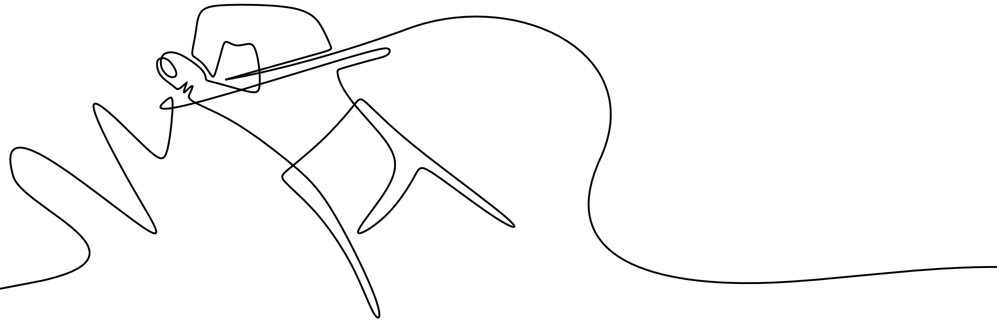


Table 3 Spearman correlation coefficients between selected items

	Q1	Q2	Q3	Q5	Q6	Q7	Q8	Q11	Q12	Q14	Q15	Q16	Q17	Q19
		0,104	0,201	0,169	0,111	0,073	0,123	0,085	0,096	0,097	0,099	0,114	0,113	0,052
Q1	2364		0,165	0,156	0,070	0,075	0,055	0,085	0,101	0,118	0,101	0,115	0,083	0,119
Q2	612	619		0,205	0,235	0,180	0,230	0,232	0,214	0,230	0,207	0,224	0,225	0,195
Q3	1950	497	1967		0,195	0,137	0,173	0,178	0,096	0,247	0,186	0,268	0,237	0,163
Q5	2259	588	1885	2276		0,359	0,386	0,357	0,304	0,416	0,339	0,407	0,223	0,273
Q6	2317	611	1931	2230	2335		0,330	0,315	0,276	0,370	0,249	0,374	0,249	0,225
Q7	2233	582	1868	2154	2217	2251		0,344	0,295	0,403	0,326	0,371	0,294	0,252
Q8	2305	603	1923	2218	2288	2241	2325		0,287	0,392	0,338	0,395	0,297	0,197
Q11	2309	604	1924	2228	2284	2202	2274	2329		0,325	0,258	0,321	0,238	0,216
Q12	2297	602	1918	2216	2272	2187	2260	2293	2317		0,708	0,527	0,369	0,355
Q14	1699	447	1448	1655	1688	1647	1677	1676	1675	1712		0,358	0,237	0,310
Q15	1489	393	1266	1434	1478	1445	1469	1472	1462	1264	1499		0,463	0,294
Q16	1757	463	1502	1696	1739	1699	1735	1732	1735	1479	1310	1770		0,290
Q17	1003	290	876	970	998	977	990	989	994	874	781	951	1009	
Q19	1727	448	1484	1684	1712	1674	1704	1710	1700	1356	1207	1425	871	1742

PEM Adult Outpatient
Note: Correlations are in the right-upper triangle, numbers in the left-lower triangle. Correlations > 0.7 are flagged.

PEM Adult Outpatient: Member checking

The final selection of 14 questions has been evaluated by healthcare professionals and patients (former interviewees) for discussion and were approved. It was discussed whether the final version met the predetermined criteria such as inclusion of each of the 8 principles of PCC, language level B1, a limited length of the questionnaire, the potential to improve quality and whether all advices for adjustments of stakeholders were processed satisfactorily. The final selection was translated back into English and approved by Picker Institute.

Discussion

Patient Experience Monitors (PEMs) were specifically developed for hospital patients with a wide range of literacy levels, while enabling the potential for QI. We want to give the largest possible number of patients the opportunity to share their experiences. A concise questionnaire with accessible language is an important first step. We described the process of adaptation so that colleagues outside the Netherlands could do likewise in their own language.

We aimed to develop questionnaires appropriate for patients with a wide range of literacy levels. Population statistics on educational levels in the Netherlands show that 30.4% has a low education.[33] Although education and literacy are different entities, there is a strong positive relation between them.[34] As such, we reached both lower and higher educated patients, however we should also acknowledge that lower educated patients (21.3%) are still substantially under-represented. Other studies also found that lower educated people represent the largest group of survey non-respondents.[35] However, we also expect this non-response to be related to the method of administration (e-mail). Although the method of administration in the cognitive interview did not cause a problem for lower educated participants, studies on the relationship between health literacy and the use of health information technology shows that lower educated people have a lack of information technology skills.[36] Notably, lower health literate patients are less likely to use information technology which is positively associated with trust in health care.[37] Accordingly, we will further investigate possible response bias to facilitate extra participation of those with a lower education level.

The provisional selection of approximately 21 items was reduced to 14 items by evaluating relevance, ceiling effects or missing answers in the first place. Also, an expert panel followed a theory-driven approach for the definitive enrolment of items. Methodologically, a common approach is to administer a questionnaire and select items using principle component analysis (PCA) and item response theory (IRT).[29,30] With data from Picker Institute original questionnaires we probably could have more easily investigated by Principle Component Analysis or Item Response Theory which item per Picker principle is best to select. However, we did not want to burden patients unnecessarily with the initially long questionnaires of 67 to 87 items. We also expected that these long questionnaires would affect the response rate negatively. Thereby, selecting entirely at statistics obtains items which can be improved on in theory, but may be of little importance for clinical practice (patients or healthcare providers). In practice, a poorly scoring item in statistics can be a key condition for a good experience.

A selected item about privacy was “Could other people hear what you were saying to the person at reception?” This item was removed for final selection based on 17.4% missing values. This could be explained by the fact that the pilot hospital had recently switched to new self-registration desks. This and the aforementioned examples indicate that the location of the pilot study determines which items ultimately prove relevant and that the choice of conducting the pilot at merely three departments of one hospital influences the final results. We also acknowledge that some patients of neurology, surgery and ear-nose-throat (ENT) departments could not fill in the questionnaires due to cognitive problems or other severe diseases which is, among other unit non response factors, a known problem of PREMS.[38] Furthermore, the questionnaires were developed with the input of quality advisors from several university medical centers, the selected questions cover all 8 principles of PCC and represent the patients journey of care, with specific attention for QI. Future studies are required to examine whether the questionnaires are suitable for QI.

Conclusion

Based on Picker Institute Questionnaires, two short form questionnaires were designed, called Patient Experience Monitor (PEM): PEM Adult Inpatient and PEM Adult Outpatient. PEMs are short and valid questionnaires specifically developed to measure patient experiences of hospital patients with a wide range of literacy levels. Acceptance of the questionnaires for both lower and higher educated patients is confirmed by usability tests. The respondents of the pilot study represent both groups. To enable the potential for quality improvement, the developed questionnaires should not be seen as static, but as a dynamic entity and part of a continuous effort to evaluate and improve patient experiences. The set of questions are constantly liable to changes in healthcare and patient expectations. Annual analysis of survey results with respect to (new) needs of users should lead to improvement of the questionnaire by going over the same cycle (Figure 1). Future studies are needed to examine the usability of these new questionnaires for literacy levels and quality improvement.

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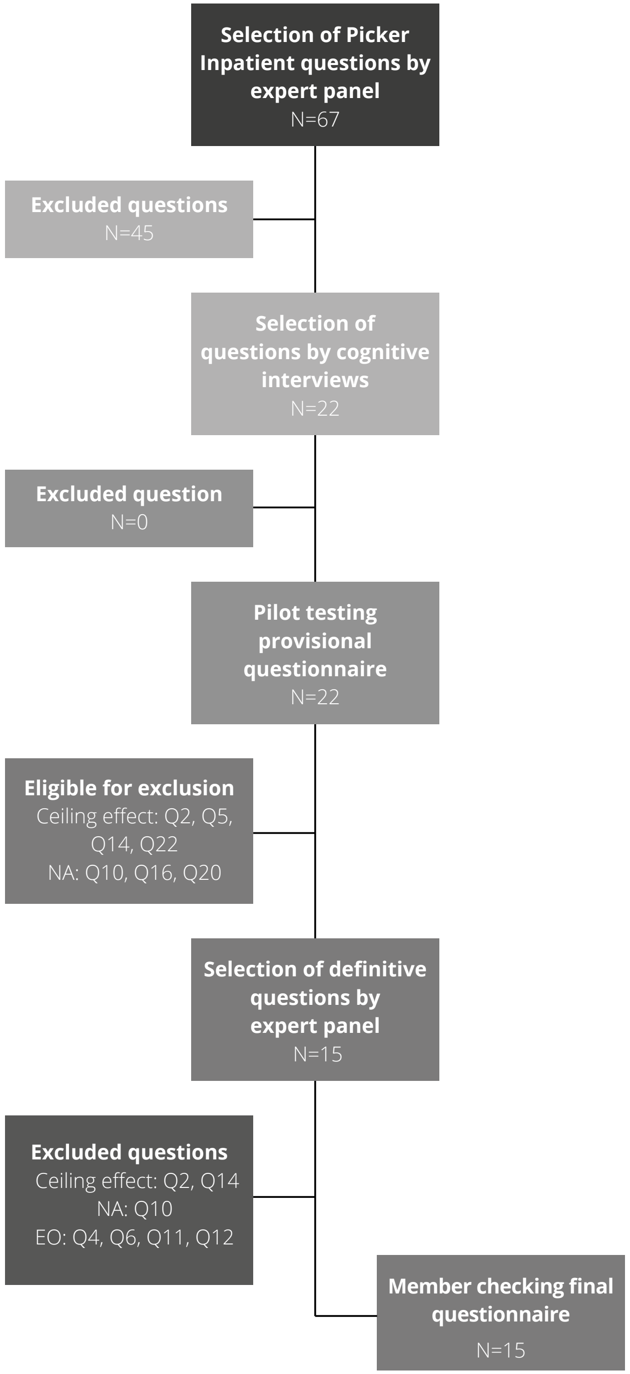
Supplementary material

Supplementary Table 1 Characteristics of respondents

	PEM Adult Inpatient	
Sample description	**N=411**	**Valid %**
Male	219	55.9
Female	173	44.1
Age		
16-20	6	1.5
21-30	17	4.3
31-40	34	8.7
41-50	57	14.5
51-60	100	25.5
61-70	111	28.3
> 70	67	17.1
Educational level		
Early childhood education	1.6	6
Primary school	2.4	9
Lower secondary education	14.8	55
Upper secondary education	35.5	146
Tertiary education	7.3	30
Bachelor's/ Master's or equivalent level	21.7	89
Doctoral or equivalent level	9	37

Supplementary Figure 1 Flowchart of exluded questions



Q1-21=Questions selected by expert team (Table 2); NA=Not Applicable>40%; EO=Expert Opinion

Supplementary Table 2 Statistical characteristics of items

Picker Principle	Questions selected by expert team Adult Outpatient		Ceiling >90% Positive answers	Floor >90% negative answers	Missing >10%	Do not know >10%	NA >40%
FA, ES	Q1	Often people have to go onto a waiting list. What did you think about the time you had to wait?**	53.1	16.2	0.5	n/a	36.3
CI	Q2	Did the hospital staff tell you what was going to happen to you?	90.8*	1.2	1.0	1.5	n/a
CC, ET	Q3	Did the doctors know what was written in your medical records? **	89,3	1.0	1.7	1.0	3.9
IR, CI, ES	Q4	If you had a question for the doctor did you understand what he told you? (“go to”)	87.7	0.8	5.4	0.5	2.9
ET	Q5	Did you trust the doctors? (“go to”) **	91.5*	0.3	5.4	n/a	n/a
IR, CI, ES	Q6	When you had a question for the nurses did you understand what they told you?	88.8	1.3	1.5	n/a	5.1
ET	Q7	Did you trust the nurses? **	81.6	1.7	1.0	n/a	n/a
ET, AN	Q8	Did the nurses have enough time to care for you? **	61.7	8.1	1.0	n/a	n/a
CC, CI	Q9	Sometimes in a hospital, staff will say different things which could leave you feeling confused. Did this happen to you? **	4.9	69.9	1.5	n/a	n/a
ES	Q10	Were you able to talk to anyone at the hospital about your problems or worries?	68.5	12.5	1.7	n/a	53.5*
ES	Q11	When you were talking to the doctors or the nurses could other people hear what you were saying?	74.1	3.7	2.2	4.9	n/a
ET, AN	Q12	How clean was the hospital room you stayed in?	59.3	0.2	1.2	0.7	n/a
ET	Q14	Did the doctors and nurses do everything they could to control any pain you may have had?	94.0*	0.0	2.4	n/a	17
IR, CI	Q15	Did anyone at the hospital explain to you the pros and cons of the treatment? **	84.3	2.3	2.4	n/a	12.4
CC, CI	Q16	Did a member of staff tell to you about possible and side-effects you could have from any new medication? **	69.4	17.7	2.9	n/a	46.2*
CC, IR	Q17	Did the hospital staff involve you in the decision about leaving the hospital/ your discharge? **	75.7	7.9	3.4	1.9	29.7
CC, CI	Q18	Did anyone from the hospital explain to you about any problems you needed to be aware of when you got home? **	76.9	10.8	3.6	n/a	54.9*

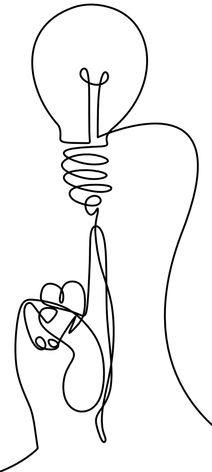
Picker Principle	Questions selected by expert team Adult Outpatient		Ceiling >90% Positive answers	Floor >90% negative answers	Missing >10%	Do not know >10%	NA >40%
IF, CC	Q19	Did someone at the hospital tell your family or someone close everything, so that they could look after you properly? **	74.5	10.9	3.6	1.7	28.0
CC, CI	Q20	Did anyone at the hospital talk to you about aftercare? E.g., aftercare from your GP, physiotherapist, nursing home? **	66.0	18.6	3.6	1.9	48.7*
ES	Q21	Did you feel that the hospital staff treated you with respect? **	87.4	0.8	3.6	n/a	n/a
AN, ES	Q22	*Did you feel safe in hospital? ***	92.1*	1.3	4.4	n/a	n/a

FA=Fast Access to reliable healthcare; ET=Effective treatment and trusted professionals; CC=Continuity of care and smooth transitions; IR=Involvement in decisions and respect for preferences, needs and values; CI=Clear information and support for self-care; IF=Involvement of and support for family and friends; ES=Emotional support, empathy and respect; AN=Attention for physical and environmental needs; NA=Not Applicable (it was not necessary/ I don't need to/ I didn't have to/ I didn't spoke to); n/a=not applicable, go to=routing question; *=item eligible for exclusion; **=final selected item

Supplementary Table 3 Spearman correlation coefficients between final selected items

	Q1	Q3	Q5	Q7	Q8	Q9	Q13	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22
		0,072	0,145	0,151	-0,021	0,083	0,192	0,067	0,029	0,049	0,166	0,265	0,284	0,298	0,204
Q1	256		0,370	0,441	0,072	0,227	0,298	0,370	0,346	0,247	0,409	0,358	0,285	0,370	0,242
Q3	244	378		0,472	0,061	0,365	0,266	0,328	0,225	0,342	0,302	0,352	0,289	0,395	0,276
Q5	256	378	399		0,097	0,277	0,611	0,536	0,226	0,379	0,447	0,623	0,527	0,355	0,214
Q7	120	175	183	183		0,089	0,027	0,030	0,048	0,160	0,005	0,039	0,001	0,093	0,117
Q8	242	357	377	173	377		0,178	0,182	0,163	0,199	0,189	0,138	0,023	0,298	0,225
Q9	254	376	397	183	377	397		0,423	0,194	0,332	0,268	0,354	0,232	0,290	0,227
Q13	186	274	288	147	276	287	288		0,275	0,172	0,393	0,306	0,424	0,300	0,226
Q15	235	333	349	167	331	347	267	349		0,300	0,421	0,383	0,336	0,189	0,141
Q16	126	203	208	119	200	208	161	196	208		0,389	0,334	0,317	0,167	0,119
Q17	174	258	266	129	256	266	208	244	154	266		0,633	0,522	0,313	0,165
Q18	232	324	341	158	321	339	254	308	198	242	341		0,648	0,248	0,224
Q19	195	262	273	132	257	272	205	254	171	201	260	273		0,200	0,141
Q20	113	182	187	98	179	187	137	168	127	149	176	164	187		0,378
Q21	252	371	392	178	371	390	285	345	207	265	340	273	187	392	
Q22	250	369	389	177	368	387	283	342	206	263	337	270	186	389	389

PEM Adult Inpatient
Note: Correlations are in the right-upper triangle, numbers in the left-lower triangle



Chapter

6

Patient Experiences: A Systematic Review of Quality Improvement Interventions in a hospital setting

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Abstract

Purpose: In the era of value based healthcare we strive for the most optimal outcomes and experiences from the perspective of the patient. So, patient experiences have become a key quality indicator for healthcare. While these are supposed to drive quality improvement (QI), their use and effectiveness for this purpose has been questioned. The aim of this systematic review was to provide insight into QI interventions used in a hospital setting and their effects on improving patient experiences, and possible barriers and promoters for QI work.

Methods: Prisma guidelines were used to design this review. International academic literature was searched in Embase, Medline OvidSP, Web of Science, Cochrane Central, Pubmed Publisher, Scopus, PsycInfo and Google Scholar. 3289 studies were retrieved and independently screened by the first two authors for eligibility and methodological quality. Data was extracted on the study purpose, setting, design, targeted patient experience domains, QI strategies, results of QI, barriers and promotors for QI.

Results: Twenty-one pre-post intervention studies were included for review. The methodological quality of the included studies was assessed using a Critical Appraisal Skills Programme (CASP) Tool. QI strategies used were staff education, patient education, audit and feedback, clinician reminders, organizational change and policy change. Twenty studies reported improvement in patient experience, 14 studies of 21 included studies reported statistical significance. Most studies (n=17) reported data-related barriers (eg, questionnaire quality), professional and/or organizational barriers (eg, skepticism among staff) and 14 studies mentioned specific promoters (eg, engaging staff and patients) for QI.

Conclusions: Several patient experience domains are targeted for QI using diverse strategies and methodological approaches. Most studies reported at least one improvement and also barriers and promoters that may influence QI work. Future research should address these barriers and promoters in order to enhance methodological quality and improve patient experiences.

Introduction

In the era of value based healthcare we strive for the most optimal outcomes and experiences from the perspective of the patient. Therefore, patient experience has become a key quality indicator for healthcare and is positively associated with patient safety and clinical effectiveness.[1] Measuring and analyzing experiences is seen to support improvement in healthcare quality governance, public accountability and patient choice.[2-5] Through the years a variety of patient experience measures have been developed and used in healthcare, among which are questionnaires, focus groups and interviews. While such tools are supposed to drive quality improvement (QI), their use and effectiveness for this purpose has been questioned.[6,7] The lack of QI may be linked to methodological barriers (eg, using a survey with poor psychometric properties, infrequent data-collection, ineffective monitoring), hampering the assessment of effectiveness. Also the lack of local ownership for QI, limited training and education of staff for QI as well as the absence of an organizational culture for change has a negative effect on the improvement of patient experiences.[8,9] Moreover, patient experiences cover diverse domains which all require appropriate measurement and different quality improvement initiatives.[10]

Previous systematic reviews examining one or more aspect of QI initiatives confirms the aforementioned barriers and all conclude that the optimal approach for using experience data effectively is lacking.[11-13] The aim of this systematic review, compared to other reviews, was to broaden our scope to national as well as local patient experience measures in a hospital setting and gain more insight into the effectiveness of diverse QI initiatives and their influencing factors. The following research questions were addressed:

1. Which QI strategies are being used to improve patient experiences?
2. What is the effectiveness of QI interventions to improve patient experiences?
3. What are the barriers and promoters of QI interventions aimed at improving patient experiences?

Methods

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were used to design this review.[14]

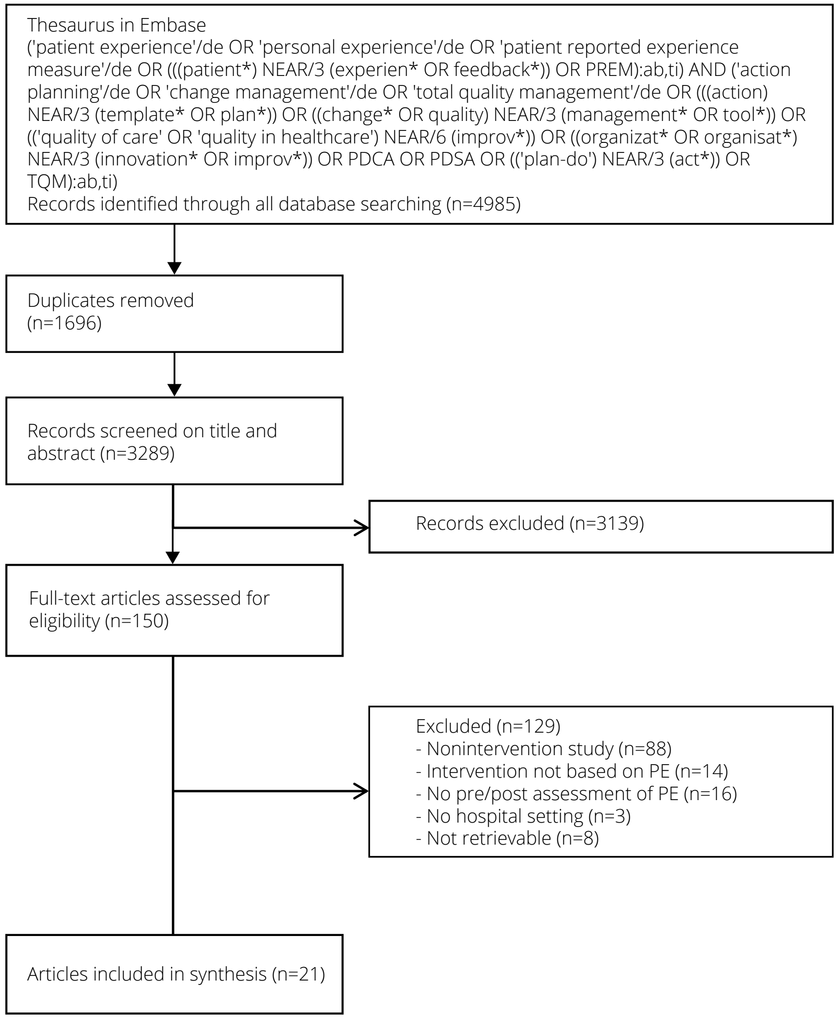
Scope of the review

Patient experiences were defined as; 'the sum of all interactions, shaped by the organization's culture, that influence patient perceptions, across the continuum of care'.[15] We limited our scope to patient experiences related to Picker's eight domains of Person Centered Care; 1) Accessibility, 2) Effective treatment and trusted professionals, 3) Continuity of care and transitions, 4) Involvement in decisions and respect for preferences, needs and values 5) Comprehensible information and support for self-care, 6) Involvement of and support for family and friends, 7) Emotional support, empathy and respect, and 8) Attention for physical and environmental needs.[16] Studies that were limited to evaluating patient satisfaction, rather than patient experience, were beyond the scope of this review. Patients generally tend to overrate their satisfaction, for example due to gratitude bias.[17] Therefore, the validity and usefulness of satisfaction data is questionable.[18]

Information sources and search parameters

The following databases were searched on September 29th 2017: Embase, Medline OvidSP, Web of Science, Cochrane Central, Pubmed Publisher, Scopus, PsycInfo and Google Scholar.Search terms were derived from previous studies[11,19] and our research questions. The thesaurus in Embase which formed the basis for the search strategies for the other electronic databases is shown in Figure 1.

Figure 1 Flowchart Literature Search



Eligibility criteria

Included studies met the following criteria: 1) QI interventions that targets patient experiences; 2) patients' experiences are examined pre- and post-intervention; 3) hospital setting; 4) written in English; 5) published after 2006. Nonintervention studies and editorials, conference papers, reviews, books, interviews or columns were excluded as well as studies that could not be retrieved in full-text.

Data extraction

Two authors (CB and HB) independently screened titles and abstracts for inclusion. Eligible studies were evaluated in full-text by both authors. A third author (LdJV) was consulted when agreement was not reached. For all eligible studies, details about study design, patient experience topic, measurements, sample size, interventions and outcomes were extracted.

Data synthesis and analysis

Due to the variation of the used methodology, interventions, topics, heterogeneity of data and method of reporting outcomes, we performed a narrative synthesis of all relevant themes within and across the studies.

Risk of bias

The methodological quality of the included studies was assessed independently by the same researchers using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist.[20] The checklist was adapted using two questions in order to assess and compare all eligible studies with diverse methodology. The question "Is a qualitative methodology appropriate?" was adapted into "Is a qualitative/quantitative methodology appropriate?". For quantitative studies, the question "Was the data analysis sufficiently rigorous?" was judged by considering size of the confidence intervals and by examining whether the following variables were considered: confounding factors, blinding of providers and response rate. Studies that obtained negative ratings for at least five out of ten items (ie, 'no', 'can't tell' or 'unclear') were excluded from this review.

Results

In Figure 1, a flow diagram of the search process is presented. After removal of duplicates, a total of 3289 records were identified. Of these, 3139 studies were excluded based on title and abstract. Of the remaining 150 full-text articles 21 studies were in agreement with the inclusion criteria and were included for review.

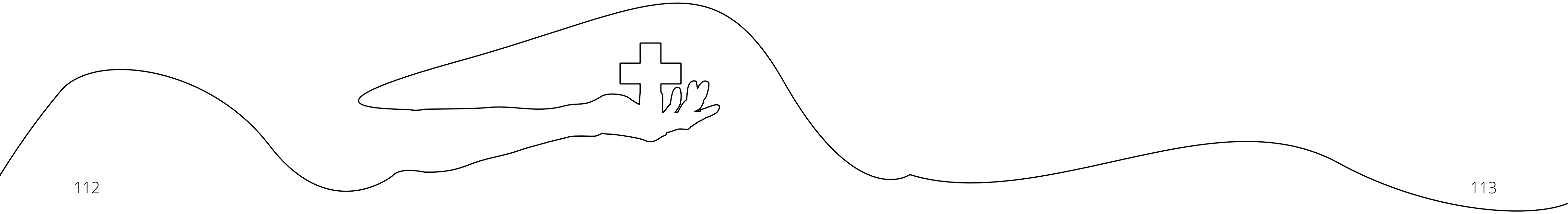
Characteristics of included studies

The search resulted in 15 pre- post intervention studies, two qualitative studies,[21,22] three RCT's,[23-25] and a longitudinal study.[26] One study was performed in Tanzania[24] and the other studies in either Europe, the United States of America or Canada. The majority of studies (n=15) included patients from a specific department (eg, neurosurgery). One study focused on the transition of hospital to primary care in a radical prostatectomy pathway.[27] In 12 studies, patient experiences were assessed using an existing survey (eg, Hospital Consumer Assessment of Healthcare Providers and Systems, HCAHPS) and seven studies used a self-developed survey. The remaining two studies used informal interviews[21] or a combination of methods.[22] The study characteristics are summarized in Table 1.

Table 1 Study Characteristics

Author/ Year	Setting	Design and Size	PE assessment method(s) and PE topic(s) to be improved
Ahrens et al, 2013[39]	Neuro-medical surgery, USA	Pre-post design N=60 pre vs 61 post	Survey (H-CAHPS) Medication side-effects
Bellamkonda et al, 2016[32]	Emergency department, USA	Pre-post design N=193 pre vs 45 post	Survey (Point-of-service cards) Provider compassion
Bookout et al, 2016[28]	Cardiac telemetry, USA	Pre-post design N= N/R	Survey (H-CAHPS) Pain management
Davies et al, 2007[37]	N/A, UK	Pre-post design N= N/R	Survey (Modified CAHPS) Overall patient experiences
Indovina et al, 2015[23]	General internal medicine, USA	RCT N=35 pre vs 30 post	Survey (H-CAHPS) Provider specific experiences
Jayasinha et al, 2016[33]	Pediatrics, USA	Pre-post design N=94 pre vs N/R post	Survey (self-developed) Cycle time
Jiang et al, 2016[38]	Otolaryngology surgery, USA	Pre-post design N=17 pre vs 10 post	Survey (S-CAHPS) Enough time, involvement and respect
Kamiya et al, 2017[24]	N/A, TZ	RCT N=1101 pre vs 1070 post	Survey (self-developed) Communication, confidence and trust
Kane et al, 2015[30]	Emergency department, USA	Pre-post design N= N/R	Survey (Press Ganey survey) Crowding
Khan et al, 2014[34]	Neurosurgery, UK	Pre-post design N=150 pre vs 150 post	Survey (self-developed) Communication
Maqbool et al, 2016[35]	Orthopedics, plastics, CA	Pre-post design N=42 pre vs 20-25 post	Survey (self-developed) Stress levels related to waiting
Nieboer et al, 2014[26]	N/A, NL	Longitudinal study N=140 pre vs 177 post	Survey (Mind the GAP scale) Transitional care delivery
Norgaard et al, 2012[40]	Orthopedics, DK	Pre-post design N=1279 pre vs 1854 post	Survey (ISRF=Interpersonal skills rating form) Communication
Norton et al, 2014[31]	N/A, UK	Pre-post design N=749 pre vs 783 post	Survey (self-developed), interviews Sleep disturbance
Pratt et al, 2011[21]	Pediatric intensive care, UK	Qualitative study N=4 families pre vs 8 parents post	Informal interviews Admission to health care
Reeves et al, 2013[25]	N/A, UK	RCT N=987 pre vs 648 post	Survey (NHS Adult inpatient questionnaire) Nursing care
Roberts, 2013[41]	Physiotherapy, UK	Pre-post design N=100 pre vs 349 post	Survey (CSP's patient feedback questionnaire) Overall patient experience
Ugarte, 2015[22]	N/A, UK	Qualitative study N=76 pre vs 106 post	Narrative stories, survey (FFT), interviews Waiting time
Van Houdt et al, 2013[27]	Radical prostatectomy pathway, BE	Pre-post design N=46 pre vs 46 post	Survey (self-developed) Coordination between caregivers
Waldhausen et al, 2009[29]	Surgery, USA	Pre-post design N= N/R	Survey (Picker Questionnaire) Waiting and value added time
Wilson et al, 2017[42]	Medical oncology, surgery, USA	Pre-post design N= N/R pre vs 27 post Interviews N=30 pre vs 30 post	Survey (H-CAHPS), interviews Hospital environment noise at night

BE= Belgium; CA=Canada; CSP=The Chartered Society of Physiotherapy; DK=Denmark; FFT= Family and Friends Test; H-CAHPS= Hospital Consumer Assessment of Healthcare Providers and Systems; NHS=National Health Service; N/A=Not applicable; NL=The Netherlands; PE= Patient experiences; S-CAHPS= Consumer Assessment of Healthcare Providers and Systems Surgical Care Survey; TZ=Tanzania; UK= United Kingdom; USA= United States of America



Methodological quality

For all the differences of methodological design and quality, none of the 21 studies obtained more than five negative ratings thus were all included (Table 2).

Table 2 CASP Quality Assessment of Included Papers

First author	1	2	3	4	5	6	7	8	9	10
Ahrens[39]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Valuable
Bellamkonda[32]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Unclear
Bookout[28]	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	No	No	Valuable
Davies[37]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Valuable
Indovina[23]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Valuable
Jayasinha[33]	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Unclear
Jiang[38]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Valuable
Kamiya[24]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Valuable
Kane[30]	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	No	Yes	Valuable
Khan[34]	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	No	No	Valuable
Maqbool[35]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	No	Valuable
Nieboer[26]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Valuable
Norgaard[40]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Valuable
Norton[31]	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Valuable
Pratt[21]	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes	No	Unclear
Reeves[25]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	No	Valuable
Roberts[41]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Valuable
Ugarte[22]	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Can't tell	Yes	Valuable
Van Houdt[27]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Waldhausen[29]	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Can't tell	Yes	Yes	Valuable
Wilson[42]	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Valuable

1) Was there a clear statement of the aims of the research? 2) Is a qualitative/ quantitative 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?

All studies clearly described the aims of their research, used appropriate methodology and research design, and collected data in a way that addressed the research question. However, in six studies it could not be determined whether the recruitment strategy was appropriate to the aims of the research.[21,22,28-31] Two qualitative studies[21,22] did not report on the relationship between researcher and participants and for 14 out of 19 quantitative studies patients remained anonymous during the entire study. Six studies did not report whether they had taken ethical issues into consideration. The rigor of data-analyses was rated insufficient in 14 studies mostly because they didn't report statistical significance of pre-post changes in patient experience scores or multiple comparisons were made without correcting for multiple testing. The latter increases the chance of false positives. Seven studies did not clearly describe their findings in relation to other studies or current practice.[21,25,28,32-35] Lastly, three studies were rated 'unclear' because the authors did not consider the findings in relation to current practice or policy or they did not identify new areas for research.[21,32,33]

QI interventions

Various QI strategies were applied (Table 3). These can be categorized into staff education, patient education, audit and feedback, clinician reminders, organizational change, promotion of self-management and policy change.[36] The most common strategies are organizational change[21,22,24,26-35,37,38] and staff education.[23-25,29-32,34,37,39-42] These strategies all relate to changing ward procedures and staff behavior. Most studies applied multiple QI strategies[21,23-26,29-32,34,37-39,41,42] while other studies used only one of the aforementioned QI strategies.[22,27,28,33,35,40] Eleven studies reported to use a specific change management approach or tool. These include Lean or Lean Six Sigma,[24,29,30,32,33,38] Plan-Do-Study-Act,[22,34,35] Kotter's Model of Change,[42] and a 30-step-scenario.[27] One study used The CAHPS improvement guide.[37]

Table 3 Interventions and Results

First author	PE topic: Outcome measure(s)	Main QI method and intervention (theoretical model, tool)	No of statistically significant pre/ post comparisons; significant results in words
Ahrens[39]	Medication side effects: understanding the description of medication	Patient education: information brochure/website; Staff education: communication skills; Clinician reminders: repeated communications through work- and e- mail	N/R
Bellamkonda[32]	Provider compassion: receiving compassionate care	Organization change: survey cards and sending a follow up letter; Staff education: communication skills of shared decision making; Patient education: giving information by staff (Lean, Kano)	1/1; Improvement in perceived concern and sensitivity
Bookout[28]	Pain management: experienced pain management; overall patient experience	Organization change: implementation of a patient and family advisory council and comfort carts	N/R
Davies[37]	Overall patient experiences: kept informed of a clinic wait; taken to exam room within 15 min; schedule appointment when needed; treated with courtesy and respect by staff; received follow up of test results; doctor is informed and up-to-date; rating of doctor's knowledge of medical history; patients see their personal doctor; understandable explanation by doctor; understanding/ satisfaction with FU-plan	Organization change: redesigning processes and better information; Staff education: communication skills; Audit and feedback: patient and staff evaluations and focus groups (The CAHPS improvement guide)	1/15; More patients were taken to the exam room within 15 minutes
Indovina[23]	Provider specific experiences: overall hospital rating; courtesy/respect; clear communication; listening	Staff education: communication skills; Audit and feedback: real time patient feedback	1/4;The overall hospital rating was higher in the intervention group than in the control group
Jayasinha[33]	Cycle-time: overall cycle time; friendliness of staff, nurses and front desk	Organization change: relocation of staff and revise unnecessary processes (Lean Six Sigma)	N/R
Jiang[38]	Overall patient experience; did the provider spend enough time with you; did the provider encourage you to ask questions; did the provider show respect for what you had to say	Organization change: new procedure of scheduling post-operative appointments; Clinician reminders: a list of standardized questions in each clinic room? (Lean, A3)	4/6; 2 weeks post intervention: improvement of provider spend time with the patient; encourage to ask questions; show respect for what the patient had to say
Kamiya[24]	Communication: enough time to discuss; reason for treatment; listen; get answers; confidence and trust; reason of test; how to take medication; purpose of medication; side effect	Organization change: redesigning workspaces and reorganize processes and procedures; Staff education: training of the 5S (Lean, 5S)	1/10; Improvement in understandable explanation by health worker about test results
Kane[30]	Crowding: likelihood to recommend (percentile); waiting time to see doctor (percentile); informed about delays (percentile)	Staff education: rapid process improvement workshop; Organization change: 5S workshop and value stream mapping; Audit and feedback: data sharing with visibility walls (Lean, 5S)	N/R

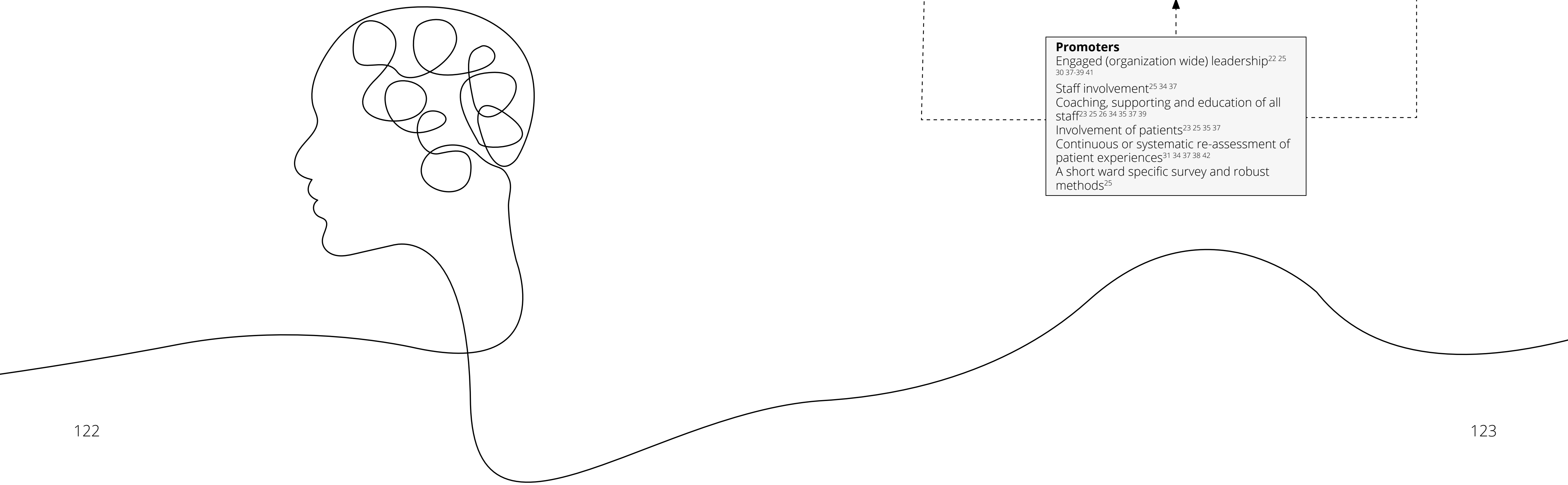
First author	PE topic: Outcome measure(s)	Main QI method and intervention (theoretical model, tool)	No of statistically significant pre/ post comparisons; significant results in words
Khan[34]	Communication: mean experience with surgeons/ junior doctors/ nurses/ hospital service	Organization change: optimizing staff collaboration Staff education: communication skills (Plan Do Study Act)	2/4; Improved experience with junior doctors and nurses
Maqbool[35]	Waiting experience: Stressful waiting process	Organization change: floor signage and navigation guide (Plan Do Study Act)	1/1;Reduction in patient stress levels
Nieboer[26]	Transitional care delivery: staff knows how to talk and listen to teenagers; treats as an individual and understands needs; staff understands realities of being a teenager; providers work well together; interested in me as a person, not just the illness; make own decisions about health care options; opportunities to be seen in the clinic alone; provides info to other involved professionals; decide who is in consultation/ examination room; helps prepare for move to adult services; helps plan for future; providers arrange joint appointments hours; helps improve independence with action plan; does not waste my time at the clinic; staff to talk about sensitive or difficult issues; staff member coordinating my transitional care	Patient education: group education; Promotion of self-management: the completion of an individual transition plan; Organization change: optimizing caregiver consultation; Policy Change; joint policies to align procedures and treatment; Clinician reminders: formats and instruments for intervention (Breakthrough Series improvement and implementation strategy)	2/16;Improved provision of opportunities for adolescents to visit the clinic alone and to decide who should be present during consultations
Norgaard[40]	Communication: doctor/ nurse/ nursing assistant prepared for interview; understandable language doctor/ nurse/ nursing assistant; opportunity explain problem to doctor/ nurse/ nursing assistant; doctor/ nurse/ nursing assistant explain examination/ treatment; doctor/ nurse/nursing assistant explain future plans; satisfied with information from doctor/ nurse/ nursing assistant; coherent information from doctors/ nurse/ nursing assistant; overall information received coherent; experience kindness and obligingness; doctors/ nurse/ nursing assistant enough time; involved in care and treatment	Staff education: communication skills	15/19; Improved preparation for interview of nurses/ nursing assistants; understandable language of doctor/ nurse/ nursing assistant; opportunity to explain problems to nurse/ nursing assistant; explanation of examination/ treatment and future plans by nurse/ nursing assistant; satisfaction with information from doctor/ nurse/ nursing assistant; coherent information from doctors/ nurse/ nursing assistant; coherent received overall information; experience of kindness and obligingness; time with doctors/ nurse/ nursing assistant/ time and involvement in care and treatment
Norton[31]	Sleep disturbance: patient rating of sleep	Audit and feedback: ward specific patient feedback Staff education: ward specific action plan; Organization change: window blinds instalment and reduce noise; Clinician reminders: text notifications by posters and telephone	1/1; Improved ratings of sleep

First author	PE topic: Outcome measure(s)	Main QI method and intervention (theoretical model, tool)	No of statistically significant pre/ post comparisons; significant results in words
Pratt[21]	Admission to health care: experiences of parents about the use of a structured checklist to ensure a successful admission	Clinician reminders: new admission checklist; Organization change: a pre-admission key-member of staff	N/A
Reeves[25]	Nursing care: basic feedback or control vs. feedback plus	Audit and feedback: ward specific patient feedback; Staff education: ward specific action plan	1/1; Nursing care is improved more for Feedback Plus than Basic Feedback or Control
Roberts[41]	Overall patient experience of physiotherapy care: 37 items of patient experiences from initial contact to discharge	Audit and feedback: ward specific patient feedback; Staff education: ward specific action plan; Clinician reminders: item on the agenda of a departmental meeting	8/37; Improved choices of appointment times; addressment by the name of choice; change to say what was on the mind; listening to the patient; choice of options for treatment; information of possible achievements; satisfaction with care; involvement in deciding about treatment plan
Ugarte[22]	Waiting time: overall patient experience of waiting time; time spend in the clinic	Organization change: new appointment scheduling profile (Plan Do Study Act)	N/R, N/A
Van Houdt[27]	Coordination between caregivers: specialist/ GP familiar with recent medical history; GP aware of results of surgery; GP aware of recommended treatment; GP had information to make treatment decision; received info you wanted about condition/ treatment; contradictory info in hospital; contradictory info from caregivers at home; contradictory info between caregivers; you knew who to ask if anxious or worried; you knew who to contact if you experienced problems; received a clear/ understandable response to questions; you knew what the next step in your care would be; home care staff worked well together; home care staff made good agreements; caregivers aware of special conditions/ needs	Organization change: Implementation of a care pathway (30-step-scenario)	0/16
Waldhausen[29]	Waiting and value added time: overall patient experience of value-added time with provider	Staff education: rapid process improvement workshop; Organization change: standardization of exam rooms and revise unnecessary processes (Lean, 5S)	1/1; Improved overall patient experience
Wilson[42]	Hospital environment noise at night	Staff education: purposeful rounding to inform patients and the use of a flashlight; Clinician reminders: visual aids for staff (Kotter's model of change)	N/R

N/R=Not reported; N/A= Not applicable

QI outcomes

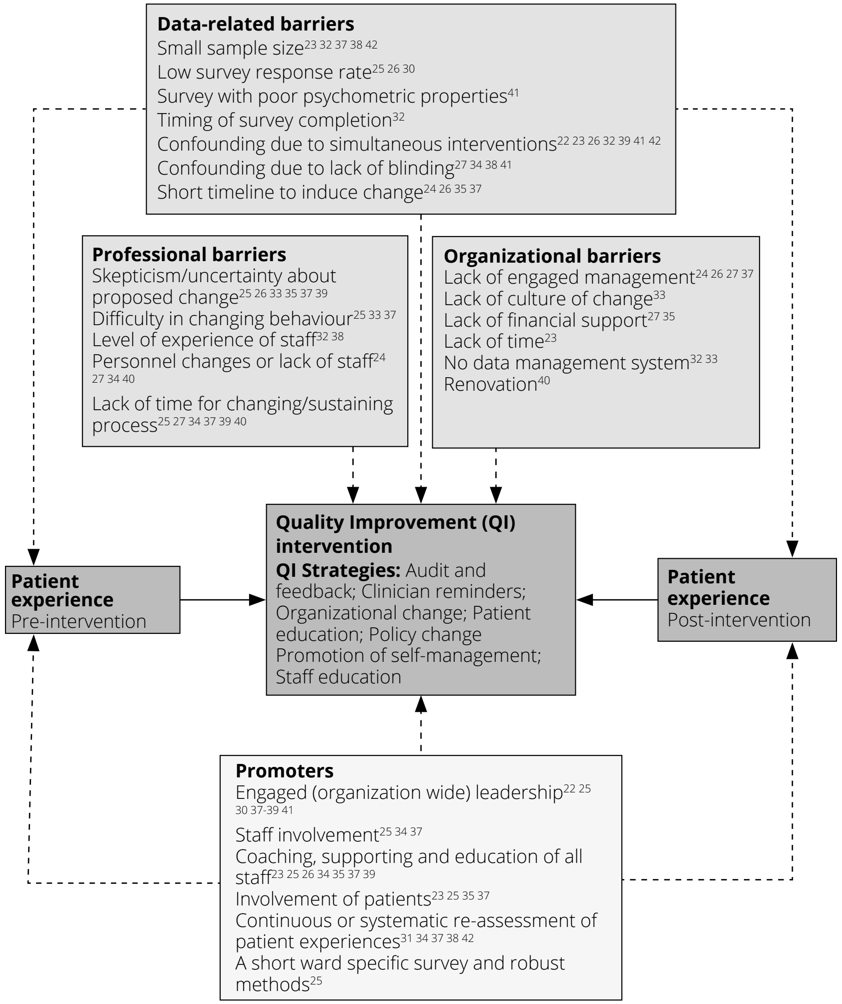
With exception of one study,[27] all studies reported at least one improved patient experience score following intervention. A dichotomy can be approximately found; 6 studies focused on improving the interaction of staff with patients (eg communication, compassion, respect)[23,24,32,34,38,40] and 10 studies focused on improving processes (eg waiting time, noise disturbance, pain management).[21,22,27-31,35,39,42] Five studies had objectives in both areas.[25,26,33,37,41] Fourteen studies examined whether statistically significant change had occurred following intervention. In these 14 studies, 106 pre-post comparisons were made of which 38 pre-post improvements were labelled statistically significant by the researchers. Six of these studies targeted on staff-patient interaction[23,24,32,34,38,40] and four studies on improving processes.[27,29,31,35] Within the studies focusing on improving interactions, 55% of the pre- post comparisons significantly improved, while this was 16% within studies of improving processes and 17% within studies who wanted to improve on both levels. Noteworthy is the fact that studies who in advance targeted on the improvement of one outcome measure, such as improving waiting experience,35 compassionate care,[32] ratings or sleep,[31] nursing care,[25] or overall patient experience[29] were most successful.



Barriers and Promoters

Eighteen studies mentioned specific barriers for QI (Figure 2).[22-27,31-35,37-42]

Figure 2 QI Initiative



These can be categorized into data-related, professional and organizational barriers.[8] Commonly reported data-related barriers were the risk of bias due to a small sample size[23,32,37,38,42] or a low response rate[25,26,40] and confounding by simultaneously applied interventions[22,23,26,32,39,41,42] or a lack of blinded providers.[27,34,38,41] Furthermore, four studies mentioned that their QI intervention may have been too short to induce significant change.[24,26,35,37] Skepticism amongst staff about the necessity or usefulness of the proposed change was the most frequently reported professional barrier.[25,26,33,35,37,39] Also, staff changes, especially at management level, were held responsible for not achieving objectives[24,27,34,40] along with the lack of time required for a successful implementation.[25,27,34,37,39,40] The organizational barriers mentioned were mostly related to lack of engaged management for QI[24,26,27,37] or no culture of change.[33]

Fourteen studies mentioned specific promoters for QI (Figure 2).[22-26,31,34,35,37-42] Several studies indicate that a QI intervention only succeeds if the organization supports system change and approaches this through engaged leadership.[22,25,30,37-41] Staff must be involved in data collection and be given help and insight into the interpretation of departmental patient experience scores.[25,34,37] It is important to support staff by means of coaching, provision of information, education and multi-disciplinary collaboration.[23,25,26,34,35,37,39] Another way that may facilitate QI is to involve patients in designing QI interventions.[23,25,35,37] Finally, frequent or continuous assessment of patient experiences has been mentioned as an important element to maintain a culture of change in healthcare.[31,34,37,38,42]

Discussion

The aim of this systematic review was to broaden our scope to national as well as local patient experience measures and gain more insight into the effectiveness of diverse QI initiatives and their influencing factors in a hospital setting. Although all studies reported positive results, they showed large variability in their methodology of QI initiatives which hamper the comparison of results. However, similarities were found in experienced barriers and the proposed promoters for QI.

QI strategies used to improve patient experiences

Most studies applied a combination of QI strategies. Organization change was one of the most frequently used QI strategy, probably because it encompasses a wide range of topics; from physical changes to the hospital surrounding, to changes in staff. Another frequently used QI strategy is staff education. About half of the included studies educated staff as part of their QI intervention. The other half reported resistance among staff,[25,26,35] discussed staff changes as a barrier for QI success[27,32,38] or mentioned not having a culture that supports QI.[33] Besides involving staff, it may also be valuable to involve patients in QI efforts. Five studies involved patients in designing QI interventions by patient focus groups or participation in a patient and facility advisory council and may well offer an additional strategy for QI.[21,28,31,32,37]
To reach its full potential, it is however important that staff members recognize and value patient involvement.[23,25,35,37,43,44]

Effectiveness of QI interventions to improve patient experiences

It is noteworthy that studies which targeted on improving interaction of staff with the patient seem more successful than studies who targeted on improving processes. Furthermore, studies which targeted the improvement of 1 outcome measure in advance, were all successful.[29,31,32,35,45] Within the studies with multiple outcome measures,[23,24,26,27,34,37,38,40,41] it often remained unclear whether they actually intended to improve all outcomes, this could be an explanation for the lack of significant change. Other explanations can be found in the mentioned data-related, professional and organizational barriers (Figure 2). Obviously, the type of study design is also an important determinant of the results and their interpretation. Three of the studies were Randomized Controlled Trials (RCTs).[23-25] These studies were successful in improving patient-provider communication. An obvious advantage of an RCT is the possibility to assign differences in pre- to post scores to the effects of the QI intervention. However, in clinical practice an RCT is not always feasible for practical and methodological reasons (eg, ethical issues and costs). The 11 studies reporting the use of a specific change management approach or tool (eg Lean or Lean Six Sigma, Plan-Do-Study-Act) had no better results in terms of methodology or significance. Seven studies reported improved patient experiences but did not examine whether this improvement was statistically significant,[21,22,28,30,33,39,42] for example because this was beyond the scope of their research question. Data had served as a communication tool to establish the need for change[33] or to provide insight into the development or operation of a QI strategy.[22]

Barriers and Promoters for QI

Almost all studies reported on specific barriers or promoters for QI and a relationship is assumed with (a lack of) significant results. For instance, four of the studies did not adequately report on the number of patients included or included a small sample size.[28,30,39,42] The risk of a small sample size is that changes in score results reflect random fluctuations rather than actual improvement. Regarding professional and organizational barriers, the findings are in line with previous studies among healthcare professionals and managers[8,9,46] and frequently reported barriers for QI in other healthcare settings such as mental healthcare.[47,48] This highlights the importance of designing and implementing strategies to involve and educate staff.[9,12,49] Physician engagement may for instance be enhanced by developing clear and efficient communication channels with physicians by building trust, understanding and identifying or developing physician leaders.[50]

Promoters of QI interventions were focused around engagement of patients, staff, management and culture. This is in line with previous systematic reviews on the use of patient experiences for QI[11,12] and qualitative studies on promoters and barriers for improving patient experiences in healthcare.[8,51] A barrier that was not identified in the current review was changing employees' mind-set from 'provider-focused' to 'patient-focused', which is an important aspect of patient-centered care.[8,51]

Strengths and Limitations

A strength of this review is that outcomes, barriers and promoters for QI were derived from the studies included as a valuable source for further QI work. Also, the findings of previous reviews[11-13] were extended by this, looking beyond national patient experience surveys and gaining insight into the effectiveness of QI. In clinical practice, it is usually the case that departments obtain national as well as local patient feedback using a variety of measures (eg, surveys, focus groups). The inclusion of a wide variety of patient experience measures can also be considered a limitation of the current review. The many differences between studies (eg, study design, type of patient experience measures) hamper the interpretation of results. The studies that did meet inclusion criteria were evaluated for their methodological quality using the CASP Qualitative Checklist. As its name already implies, this checklist was developed for qualitative studies and was therefore less appropriate for quantitative studies.

Implication for future policy and research

Knowledge on barriers and promoters provides a valuable source of information that can be used to guide future QI initiatives. Addressing data-related, professional and organizational barriers may positively influence the effectiveness of QI interventions that target patient experiences. Ideally, healthcare organizations or hospital departments develop structured plans on how to use patient feedback for QI and methods to engage clinicians in this process. In current practice, such plans are often lacking.[19,52] Also, it is encouraged to include a follow-up assessment to examine changes in patient experience following QI intervention. This is important, as a change is an improvement only when the patient experiences it as such. Large-scale RCT's are needed to determine whether improvements are actually the direct result of a QI intervention and also to compare the effectiveness of different QI strategies. Another potentially valuable direction for future research is to examine the extent to which patients could and should be involved in designing QI interventions. Just as experiences may differ between patients and staff, this could also be the case with their perceptions on future healthcare.

Conclusion

Despite the heterogeneity of methodology and methodological quality of studies reviewed, many lessons can be learned. A wide range of patient experience domains were targeted for QI, but outcome measures focused on improving communication and interaction were more successful than outcome measures focused on changing processes. Alongside this, studies with a small number of outcome measures were most effective, organizational change and staff education were the most frequently used QI strategies in those cases. While most studies report positive outcomes, they also report on significant barriers and promoters that can influence QI work, not least a sound design of research. Furthermore, engagement of patients and all stakeholders at both departmental and management level is commonly recommended for successful QI. Future research should address barriers and promoters in order to enhance methodological quality and study outcomes.

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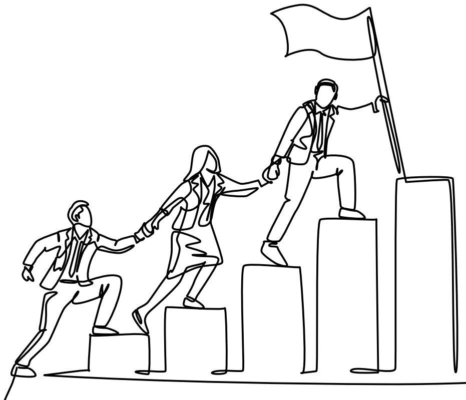
Chapter

7

Discussion



What is the importance of patient values

While observing the evolution of healthcare in recent years, we can conclude that patient centered care is at the front. There is an ongoing paradigm shift in which we realize that there is a call for more balance between science, clinical expertise, and patient values.[1-6] The absence of this balance in daily practice seems attributable, among other things, to an under-conceptualization or interpretation of PV.[7-11] The lack of common conceptualization of PV is an important topic to consider as a conceptual flaw that may have negative consequences for the quality of care and hinders the provision of patient centered care. This thesis contributes to the conceptualization of PV by empirical research at first. The second part of the thesis gives insight in the additional benefit of PV (how patients experience their care) to improve care.

What is the concept of patient values

Our search started with the exploration of existing literature of what patients value, expressed by themselves and in their own words. Based on this review we aimed to design a taxonomy of patient values (**chapter 2**). We noticed that of 3256 identified studies, only 22 met the qualitative criteria. However, by gathering all the expressions c.q. determinants of PV of the included studies we were able to recognize a pattern. The determinants could be assigned to three categories; 1) values related to the patient and his personal context, 2) values related to the characteristics of the professional, and 3) values related to the interaction between the patient and the professional. Subsequently, we identified within the main categories a consistency of determinants that led to seven key elements; 1) uniqueness, 2) autonomy, 3) compassion, 4) professionalism, 5) responsiveness, 6) partnership and 7) empowerment. In this categorization, we could not avoid a certain overlap, though content analysis resulted in an allocation to the dominant category. The results amplify existing literature of the synthesis of PV, preferences, needs and experiences among patients in diverse care settings and with healthcare problems.[12-15] We contribute by creating a framework with a possibility for identification and objectification.

To assess the outcomes of literature search in daily practice and to further improve the taxonomy of PV in healthcare, a qualitative study onto PV was carried out by interviewing physiotherapy patients with musculoskeletal pain in primary care (**chapter 3**). We opted this context by the fact that PV emerge in contexts where health problems are complex and the need arises for a good professional-patient relationship. Physical therapy practice can be characterized as such a place where patients dealing with complex pain problems meet their health practitioner and often have very personal interactions with them. Historically however, physical therapy is known as a profession with a strong biomedical focus and in which a patient-centered approach is not always common ground.[16,17] This study resulted in a refining of the preliminary taxonomy where the values of the professional in particular were made more stringent. The element 'professionalism' is refined by the partitioning into 'conscientious professional' and 'technically skilled professional' and by renaming the elements compassion and responsiveness towards the compassionate professional and the responsive professional. Data analyses revealed the importance of a committed and responsible execution of treatment and care by adapting to the patients' needs and circumstances. The results are in line with earlier research where patients with chronic musculoskeletal pain are often dissatisfied about the quality of the care they receive.[18,19] Important aspects of dissatisfaction are the feeling of not being heard, understood or even not being taken seriously.20,21 Our analysis demonstrates that a balance must been sought between objective diagnostic skills or treatment and subjective skills as paying attention and listen sincerely. This study was a first exploration with a relatively small group and thereby, whether physiotherapy practice is fully representative for the sharpening this taxonomy is unknown. Nevertheless, this study emphasizes the need for discussing patient values in the clinical encounter and guidelines as a counterweight against an overreliance on scientific evidence as the cornerstone of clinical practice.[4,22,23]

As a third perspective on patient values, a second qualitative study gained a deeper understanding of the beliefs of caregivers about PV (chapter 4). We chose to interview a selection of 23 physiotherapists about PV in physiotherapy practice and created the possibility to compare the outcomes with those of patients (**chapter 4**). Next to the exploration for the meaning of PV for physiotherapists in daily practice, we were also interested in how physiotherapists take PV into account in daily practice and the thereby experienced barriers and facilitators. It enriches our insight of the dynamics of values and possible grounds for conflicts or dissatisfaction between the patients' and the professionals' values.

PV appears to play a major role for professional caregivers, but it becomes apparent that it's a mainly unconscious process. The description of PV is often by practical examples. Automatically aligning with the patient and his expectations as fellow human beings, being responsive, turns out to be central in this process and confirm existing research.[13,14,24] At the same time, alignment is the most commonly mentioned barrier in the physiotherapeutic encounter.

The examples given often show the tension between taking PV into account and safeguarding professional values. The outcomes endorse that the integration of the different kinds of 'knowledge' (scientific evidence versus moral values) don't easily merge and sometimes leads to clinical dilemmas.[25] Situations were described as how insufficient or mistaken alignment leads to uncomfortable situations, difficult conversations or even discontent.

How to improve healthcare using patient values

Once we provided ourselves with the understanding of PV, the possibility arose to objectify them in clinical practice and to use them for the improvement of PCC. Patient experiences are appropriate objectifiable derivatives of PV and a way to get a sense of the impact of care on the patient's life and well-being.[14,26-30] A good experience correspond with the underlying values and is positively associated with patient safety and clinical effectiveness.[31] Commissioned by the Netherlands Federation of University Medical Centers and in collaboration with Picker Institute Europe we developed large scale patient reported experience questionnaires for hospital care (PREM) which reflect the following; 1) items that matter the most to the patient, 2) understandable for all patients, also those with limited health literacy, 3) less items for a better response rate and 4) the incorporation of the patient journey as a whole (**chapter 5**). We choose to collaborate with Picker Institute Europe by their extensive work of development in patient experience measurements and shortened their existing validated patient experience questionnaires.

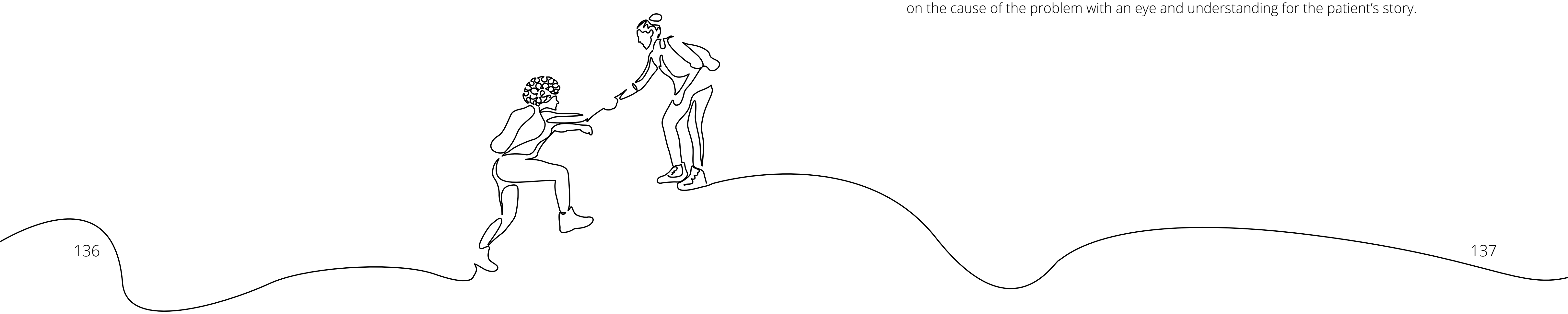
Despite more common quantitative approaches, such as principle component analysis (PCA) or item response theory (IRT),[32,33] mixed methods were used to adapt Picker Institute patient experience questionnaires: the selection of items and adaptation towards language level B1 by expert panels, usability tests with patients, analysis of psychometric properties and member checking. A theory-driven approach was followed for definitive enrolment of items, meaning that the items eligible for exclusion had been carefully reviewed by the expert team and representatives of a patient council before definitive exclusion. The rationale for using mixed methods and a theory-driven approach was that we did not want to burden patients unnecessarily with the initially long questionnaires of 67 to 87 items. Additionally, selecting entirely at statistics obtained items which can be improved on in theory may be of little importance for clinical practice (patients or healthcare providers).[33] This process led to two short-form questionnaires of 14-15 items, called Patient Experience Monitor (PEM) Adult Inpatient and PEM Adult Outpatient.

Next it is important to know how to use the outcomes of PREMs to improve care because their use and effectiveness for this purpose has been questioned.[34,35] We searched existing research for PREM-based quality improvement (QI) strategies which were used to improve patient experience. We studied their effectiveness for QI and the experienced barriers and promoters of these QI interventions (**chapter 6**). Despite the heterogeneity of methodology and methodological quality of studies reviewed, lessons could be learned. To improve healthcare successfully based on PREMs there must be a sound research design and a focus on one outcome measure. Further, a culture of change and engaged leadership is needed within an organization, sceptic professionals about the necessity or usefulness of the proposed change are the most mentioned barriers. And supporting our main question, experience measures focused on improving communication and interaction were more successful than experience measures focused on changing processes.

Embracing PV

The aim of this thesis was to explore the concept of PV, the role PV play in healthcare and how patient experiences, as derivate of PV, can contribute to quality of care. We explored multiple perspectives of PV, used various research methods and been in diverse settings. Overall, the outcomes of our studies revolves around the taxonomy of PV with the main focus on paying attention and listening to the patients narrative and being responsive. We can conclude that balancing between science, protocols, clinical expertise, and patient values is a struggle every so often.

This thesis contributes to the clarification of the concept of values in healthcare and in finding a balance and mutual reinforcement of implicit and explicit knowledge. We actually see that PV does not stand next to scientific evidence and clinical expertise of the professional, as outlined in EBP, but PV *embraces* scientific evidence and clinical expertise. The patients desire a professional who draws on the latest scientific evidence, and uses his clinical experiences in the clinical encounter. And in that specific encounter he must be responsive and attentive to the patient as an fellow human being. So PV isn't just good listening and shared decision making, it's even a bigger picture. It presupposes a co-production of patient and professional with room for input of the professionals' knowledge, skills and experiences, but also for the patients' narrative; their story, their experiences, their values, their preferences and needs.



Reflections on PV

PV do not turn out to be static quantities, they appear to be dependent by context. When healthcare problems are uncomplicated, or the remedy is straightforward, one may suffice with prescribing medication, an intervention or clear information (of course tailored to the patient). However, many problems in today's healthcare are not simple and straightforward, but often chronic and complex. For example; The Netherlands is ageing whereby osteoarthritis, dementia and multimorbidity increasingly playing a role. Chronic conditions such as cancer, cardiovascular problems and type 2 diabetes account for 20% of the disease burden and are largely caused by behavior; 1) smoking, 2) alcohol consumption, 3) too little exercise and 4) unhealthy diet.[36] In these cases the professional actually stands empty-handed in a biomedical sense when it comes to solving the problem, he can only lapse into controlling symptoms. All kind of factors in behavior, lifestyle and social environment play an important role in the origin of these health problems, which actually require an active role of the patient, but where low health literacy often play a major role. These are the exact cases where professionals are asked, together with the patient, to extensively explore the unique, individual situation and think along with the patient how to intervene

.

Obviously, attention is paid how to prevent this challenging situation in healthcare. The National Prevention Agreement, drawn up by the Ministry of Health, Welfare and Sports in coalition with engaged social parties and entrepreneurs, focuses on countering smoking behavior, overweight and problematic use of alcohol.[37] The ambitions regarding the current situation in Dutch society represent a major challenge for all those involved, prevention must play an important role. A valuable development in this light is the concept of 'positive health', which bridges the gap between healthcare and the social and personal domain.[38] Positive health proposes a broad perception of health in which health is no longer seen as the absence or presence of disease, but as the ability of people to deal with the physical, emotional and social challenges of life and to take control as much as possible.[39] This body of thought is increasingly gaining a place in healthcare, especially around lifestyle improvement and interventions.[40,41] The focus here should be on determine the exact reason(s) for unhealthy behavior, in clinical practice it appears that these are often found in psychosocial problems or a lack of meaningfulness. Just telling patients that they should exercise more or go on a diet is too short-sighted. The patients must be surrounded by a broad spectrum of care providers, whom focus, from their expertise, on the cause of the problem with an eye and understanding for the patient's story.

Shared decision making[42-44], coproduction[45] and patient and family engaged care[24,46] are concepts and developments that are aiming to make these analyses and decisions together with the patient. And here the taxonomy of PV should come into the picture, because these places require a comprehensive analysis of the patient's narrative and values, and guide the path we should take together. This should not only be an intuitive and empathetic process, it requires professional reflection and dialogue. The taxonomy provides a direction of which elements need to be addressed.

Perspectives on a Future with PV

Scientifically we contributed by a taxonomy and confirmation of PV, the development of hospital in- and outpatient PREMs and suggestions for quality improvement initiatives. We want to deliver an input on quality improvement in clinical guidelines, policy, and everyday healthcare by creating more awareness of PV, its conceptualization and objectivation.

More empirical study is needed to further validate and develop our work. This includes empirical research into the actual behavior and interaction between the patient and the professional in the consultation room, but also the development of the taxonomy by examining multiple settings for its applicability.

Further, it is important to inform all involved sectors in the concept of PV and its consequences for clinical practice and education. A first direction is how the knowledge and awareness of PV can be learned during education. Becoming a responsive professional with a sensitivity for human differences as a prerequisite for partnership may require specific educational strategies and training. Until now it seems that therapists mainly take a somewhat holistic, intuitive approach, but that does not absolve them from rationality and systematic reflections. It is important to share the gained explicit knowledge about PV in education in order to make actions more transparent and transferable.

The enhanced scientific insight into PV presupposes a mode of operation in healthcare and education that must consist of advanced knowledge and insight into the paradigm shift towards patient centered care or a better balance in EBP. Additional research is needed on how to find a more equal balance between explicit knowledge such as scientific evidence, and implicit tacit knowledge. This could include adjusting guidelines and protocols and as a result from that, the method of documentation. As example, a change in structure of electronic patient files could lead to awareness of this better balance; less generic quantitative data, more individual qualitative data.

To enable the potential of PV for quality improvement by measurement of patient experiences, the developed PREMs should not be seen as static, but as a dynamic entity and part of a continuous effort to evaluate and improve patient experiences. The set of questions are constantly liable to changes in healthcare and patient expectations. Annual or even continuous analysis of survey results with respect to (new) needs of users should lead to improvement of the questionnaire by going over the same cycle (Chapter 5, Figure 1). Future studies are needed to examine the usability of these new questionnaires for diverse literacy levels. To use the outcomes of PREMs for QI, research should address barriers and promoters in order to enhance methodological quality and study outcomes.

At last, the concept of PCC and the ideas' of involving patients in their care is hardly original, it dates back to the end of the 20th century. Still, the implementation of the concept is less then optimal. Organizational and logistical elements seems to hinder patient centeredness in daily practice such as work pressure, not enough time for such patient-doctor communication, insufficient accessibility of patient records for involved caregivers or institutions or the way financial support is organized. As long as the financing of care is linked to performance and is illness-driven instead of quality and patient-driven, the conditions for a change won't be optimal. So a real challenge is to study whether if these organizational barriers can be addressed it will actually lead to better care, fewer complaints or complications and even possible reduction of costs.

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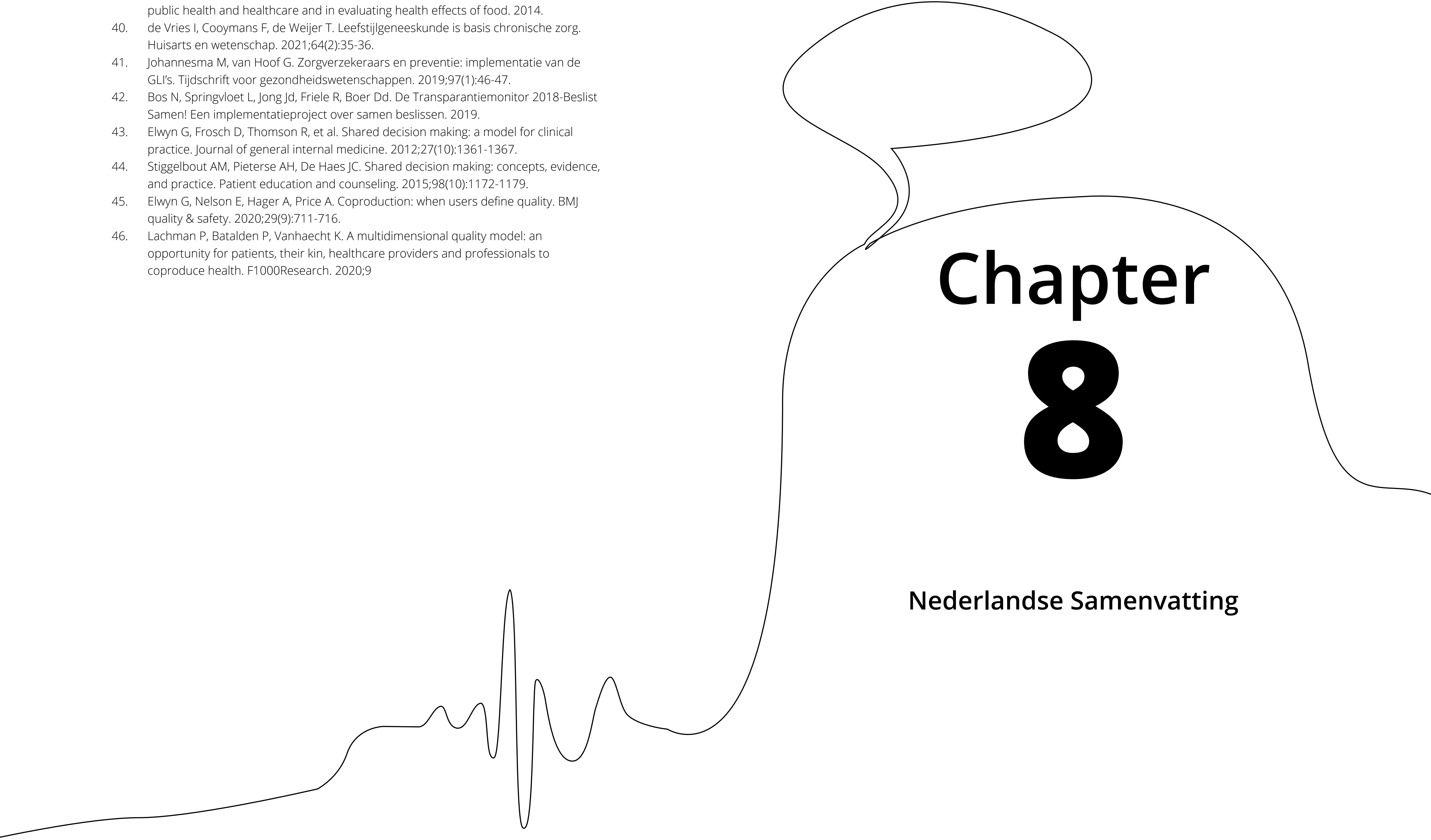


Chapter 8

Nederlandse Samenvatting

Inleiding

Zorgprofessionals streven elke dag naar het bieden van de best mogelijke zorg en hulp aan patiënten. Hierin balanceren zij tussen twee werelden; 1) de wereld van de ongekend snelle ontwikkeling van technologie, medische kennis en mogelijkheden en 2) de waarden, voorkeuren, behoeften en de unieke leefwereld van de patiënt. De spreekkamer is de plek waar de samensmelting van deze verschillende werelden moet samenkomen, maar dat gebeurt niet altijd als vanzelfsprekend.

In concepten als 'evidence-based practice', 'value-based medicine en 'patient-centered care' wordt gesteld dat patiëntwaarden (patient values) de kern vormen van kwaliteitszorg. Ze onderstrepen het belang van de patiënt door elementen als de patient serieus nemen, een gevoel van veiligheid en vertrouwen bij de patiënt te creëren en de patient betrekken bij besluitvorming. Echter, de focus in de zorg is vooralsnog meer wetenschappelijk, biomedisch en ziektegericht dan patiëntgericht. De biomedische stroming is een criterium geworden voor kwaliteit en financiering en domineert de meeste audits en klinische richtlijnen. Tegelijk komt er toenemende kritiek op deze benadering omdat in de bijbehorende richtlijnen en protocollen de relevantie voor de individuele patiënt achterblijft. Dit zou toegeschreven kunnen worden aan het feit dat het begrip van patiëntwaarden op dit ogenblik incompleet, te abstract en onderbelicht is. Veelvuldig gerapporteerde klachten of incidenten in de zorg zouden mede verklaard kunnen worden vanuit deze onder-conceptualisering, het blijkt dat complicaties vaak worden veroorzaakt door een onderschatting van het probleem of een gebrek aan goede informatie en communicatie. Het lijkt duidelijk dat meer patiëntgerichte zorg, met een focus op communicatie en een perspectief waarin de patiënt partner is, bij zou kunnen dragen aan de kwaliteit van zorg.

Onderzoeksvragen en bevindingen

Het doel van dit proefschrift is om te verhelderen wat patiëntwaarden zijn en hoe we deze waarden kunnen gebruiken in de dagelijkse praktijk. De eerste stap in het onderzoek was het verhelderen en conceptualiseren van het begrip patiëntwaarden. **Hoofdstuk 2** beschrijft een literatuurstudie waarin we een overzicht construeerden van de bestaande inzichten in patiëntwaarden vanuit het perspectief van de patiënt zelf. Deze studie keek naar kwalitatieve onderzoeken waarin patiënten zelf hebben aangegeven wat zij waarderen in de zorg en in zorgverleners. Op basis van deze studie is een taxonomie ontwikkeld; een structuur die het mogelijk maakt om de patiëntwaarden gemakkelijk te herkennen, te bespreken en er rekening mee te houden. We herkenden binnen de patiëntwaarden drie thema's: 1) waarden met betrekking tot het leven, de filosofie en zingeving van de patiënt; 2) waarden die verband houden met de persoon en het gedrag van de hulpverlener; en 3) waarden met betrekking tot de interactie tussen de patiënt en de hulpverlener. Vervolgens zijn er binnen de hoofdcategorieën zeven elementen geïdentificeerd; 1) uniciteit, 2) autonomie, 3) compassie, 4) professionaliteit, 5) responsiviteit, 6) samenwerken en 7) empowerment.

Hoofdstuk 3 beschrijft de tweede stap in het inzichtelijk maken van patiëntwaarden. Deze kwalitatieve studie zocht naar hoe de waarden en verwachtingen van de patiënt tijdens klinische ontmoetingen vorm krijgen. Ik interviewde fysiotherapiepatiënten met langdurige of terugkerende musculoskeletale pijn over wat zij waardeerden in het contact met de hulpverlener. Het doel was om de eerdere inzichten uit de literatuurstudie meer betekenis te geven.

Door de interviews werd het element 'professionaliteit' van de taxonomie verfijnd middels de onderverdeling in de 'gewetensvolle professional' en de 'technisch bekwame professional'. De elementen compassie en responsiviteit werden hernoemd naar de 'inlevende professional' en de 'responsieve professional'. Uit de data-analyse bleek het belang van een betrokken en verantwoorde uitvoering van de behandeling en onderzoek door goed af te stemmen op de behoeften en omstandigheden van de patiënt. Er blijkt dat er continu een juiste balans moet worden gezocht tussen objectieve diagnostiek en behandeling en subjectieve vaardigheden zoals aandachtig zijn en oprecht luisteren.

Als een derde perspectief beschrijft **hoofdstuk 4** een kwalitatieve studie naar de gedachten en ideeën van hulpverleners over patiëntwaarden in de fysiotherapiepraktijk. Het verrijkt ons inzicht in de dynamiek van patiëntwaarden, het speelveld tussen de patiëntwaarden en de professionele waarden en wellicht zou het mogelijke gronden voor conflicten of onvrede kunnen blootleggen.

Het blijkt dat patiëntwaarden een grote rol spelen in de behandelkamer, maar dat dit vooral een onbewust proces is. De beschrijving van patiëntwaarden door hulpverleners is niet concreet en gebeurt middels praktijkvoorbeelden. Het als medemens automatisch afstemmen op de patiënt en zijn verwachtingen, responsief zijn, staat in dit proces centraal maar blijkt ook de meest genoemde barrière in de fysiotherapeutische ontmoeting. De beschreven voorbeelden laten het spanningsveld zien tussen het rekening houden met patiëntwaarden en het bewaken van de eigen professionele grenzen. De uitkomsten bevestigen dat de integratie van de verschillende soorten 'kennis' (wetenschappelijk bewijs versus morele waarden) niet gemakkelijk samengaan en soms tot klinische dilemma's leidt.

Nadat het concept patiëntwaarden is verhelderd vanuit verschillende invalshoeken geeft dit proefschrift inzicht hoe patiëntwaarden gebruikt kunnen worden voor kwaliteitsdoeleinden. De ervaringen van de patiënt met de ontvangen zorg kunnen worden gezien als objectiveerbare afgeleiden van hun waarden. De goede ervaring ontstaat als ze aansluit op de onderliggende waarden van de patiënt en is positief geassocieerd met patiëntveiligheid en klinische effectiviteit. Dit maakt patiëntervaringen geschikt voor de verbetering van patiëntgerichte zorg.

Hoofdstuk 5 beschrijft de ontwikkeling en validering van twee patiëntervaringsmeetinstrumenten (PREMs) voor ziekenhuiszorg. Deze vragenlijsten weerspiegelen; 1) de zorgitems die het belangrijkst zijn voor de patiënt, 2) begrijpelijkheid voor alle patiënten, ook voor patiënten met beperkte gezondheidsvaardigheden, 3) een beperkt aantal items ten gunste van een betere respons en 4) de integratie van de hele patiëntreis in het ziekenhuis. Er is gekozen om samen te werken met Picker Institute Europe vanwege hun uitgebreide ervaring op het gebied van het ontwikkelen van meetinstrumenten voor patiëntervaringen. Hun bestaande vragenlijsten zijn aangepast aan de hand van de vier eerder genoemde criteria middels een 'mixed-method' adaptatie protocol van Picker Institute. Dit betekende dat expertpanels geschikte vragen hebben geselecteerd en de taal hebben aangepast naar taalniveau B1. Vervolgens is de selectie getest door patiënten en heeft er een kwantitatieve data analyse van psychometrische eigenschappen plaatsgevonden. Voor de definitieve inclusie van vragen is een theorie-gestuurde aanpak gevolgd, wat onder andere inhoudt dat de items zorgvuldig zijn beoordeeld door het expertteam en vertegenwoordigers van een patiënten raad. De reden voor deze wat ongebruikelijke benadering om vragenlijsten in te korten was dat we patiënten niet onnodig wilden belasten met de aanvankelijk lange vragenlijsten van 67 tot 87 items. Maar daarnaast zien we vaak in de praktijk dat volledig op statistiek verkregen items in theorie verbeterd kunnen worden, maar soms van weinig belang zijn voor de klinische praktijk (patiënten of zorgverleners). Dit hele proces leidde tot twee korte vragenlijsten van 14-15 items, de Patient Experience Monitor (PEM) Adult Inpatient en PEM Adult Outpatient.

Na het meten van ervaringen is het vooral belangrijk om te weten hoe de uitkomsten van PREMs kunnen worden gebruikt om de zorg te verbeteren. **Hoofdstuk 6** beschrijft een literatuurstudie waar er in bestaand onderzoek is gezocht naar op PREM gebaseerde strategieën om de patiëntervaring te verbeteren. We bestudeerden hun effectiviteit voor het verbeteren van kwaliteit en de ervaren barrières en promotors van deze interventies. Ondanks de heterogeniteit van de methodologie en de methodologische kwaliteit van de onderzochte strategieën, heeft deze studie belangrijke aandachtspunten opgeleverd. Om de zorg succesvol te verbeteren op basis van PREMs moet er een gedegen onderzoeksopzet zijn en de focus op bij voorkeur één uitkomstmaat. Verder is een cultuur van verandering en betrokken leiderschap nodig binnen een organisatie, sceptische professionals over de noodzaak of het nut van de voorgestelde verandering zijn de meest genoemde barrières. En ter ondersteuning van onze hoofdvraag, verbeterinitiatieven gericht op het verbeteren van communicatie en interactie waren succesvoller dan verbeterinitiatieven gericht op het veranderen van processen.

Discussie

Het doel van dit proefschrift was om het concept van patiëntwaarden te onderzoeken, de rol die patiëntwaarden spelen in de gezondheidszorg en hoe patiëntervaringen, als afgeleide van patiëntwaarden, kunnen bijdragen aan de kwaliteit van zorg. We hebben meerdere perspectieven van patiëntwaarden verkend, verschillende onderzoeksmethoden gebruikt en verschillende settingen onderzocht. Over het algemeen draaien de resultaten van de onderzoeken om de taxonomie van patiëntwaarden, met de nadruk op aandacht en luisteren naar het verhaal van de patiënt en responsief zijn. We concluderen dat het balanceren tussen wetenschap, protocollen, klinische expertise en patiëntwaarden niet eenvoudig is en om gerichte aandacht en doorgaande reflectie vraagt.

Dit proefschrift draagt bij aan de verheldering van het begrip 'waarden' in de zorg en aan het vinden van een balans en wederzijdse onderbouwing van impliciete en expliciete kennis. We zien dat patiëntwaarden feitelijk niet gelijkwaardig naast wetenschappelijk bewijs en klinische expertise van de professional staat, zoals beschreven in EBP, maar dat patiëntwaarden juist wetenschappelijk bewijs en klinische expertise *omarmen*. De patiënten verwachten een professional die gebruik maakt van de nieuwste wetenschappelijke inzichten en zijn klinische ervaring gebruikt in het consult. En in die specifieke ontmoeting zal hij als medemens ontvankelijk en aandachtig moeten zijn voor de leefwereld van de patiënt. Het gaat dus niet alleen om goed luisteren of samen beslissen, het is een groter geheel. Het veronderstelt een coproductie van patiënt en professional met ruimte voor inbreng van kennis, vaardigheden en ervaringen van de professional, maar ook voor de patiënt; zijn verhaal, ervaringen, waarden, voorkeuren en behoeften.

Patiëntwaarden blijken geen statische grootheden te zijn, ze zijn contextafhankelijk. Wanneer gezondheidsproblemen ongecompliceerd zijn, of de behandeling eenvoudig is, volstaat voorschrijven van medicatie, een interventie of duidelijke voorlichting (uiteraard toegesneden op de patiënt). Echter veel problemen in de hedendaagse gezondheidszorg zijn niet eenvoudig en duidelijk, maar chronisch en complex. Allerlei factoren in gedrag, leefstijl en sociale omgeving spelen een belangrijke rol bij het ontstaan van deze gezondheidsproblemen. Dit vraagt om een actieve rol van de patiënt, echter lage gezondheidsvaardigheden spelen vaak een grote rol. Dit zijn precies de gevallen waarin professionals wordt gevraagd om samen met de patiënt de unieke, individuele situatie uitgebreid te verkennen en met de patiënt mee te denken hoe te handelen.

Een waardevolle ontwikkeling in dit licht is het begrip ‘positieve gezondheid’, dat een brug slaat tussen de zorg en het sociale en persoonlijke domein. Positieve gezondheid stelt een brede perceptie van gezondheid voor waarbij gezondheid niet langer wordt gezien als de aan- of afwezigheid van ziekte, maar als het vermogen van mensen om met de fysieke, emotionele en sociale uitdagingen van het leven om te gaan en zoveel als mogelijk regie te nemen. Echter, alleen patiënten vertellen dat ze bijvoorbeeld meer moeten bewegen of op dieet moeten, is te kortzichtig. De patiënten moeten omringd worden door zorgverleners, die vanuit hun expertise met oog en begrip voor het verhaal van de patiënt focussen op de oorzaak van de gezondheidsproblematiek.

De toekomst

Er is meer onderzoek nodig om ons werk verder te valideren en te ontwikkelen. Denk hierbij aan empirisch onderzoek naar het feitelijke gedrag en de interactie tussen patiënt en professional in de spreekkamer, maar ook aan de ontwikkeling van de taxonomie door deze op andere plaatsen in de zorg te onderzoeken op zijn toepasbaarheid.

Verder is het belangrijk om alle betrokken sectoren te informeren over het concept van patiëntwaarden en de gevolgen daarvan voor de klinische praktijk en het onderwijs. Een eerste richting is hoe de kennis en bewustzijn van patiëntwaarden tijdens het onderwijs aangeleerd kan worden. Om een responsieve professional te worden met een gevoeligheid voor menselijke verschillen als voorwaarde voor samenwerking, zijn specifieke educatieve strategieën en training nodig.

De verbeterde wetenschappelijke inzichten in patiëntwaarden veronderstellen een werkwijze in zorg en onderwijs die moet bestaan uit een paradigmaverschuiving naar patiëntgerichte zorg en een betere balans in EBP. Er is aanvullend onderzoek nodig om te zien hoe een beter evenwicht te bereiken is tussen expliciete kennis, zoals wetenschappelijk bewijs, en impliciete kennis. Hierbij valt te denken aan het aanpassen van richtlijnen en protocollen en mogelijk als gevolg daarvan de wijze van documenteren.

Om het potentieel van patiëntwaarden voor kwaliteitsverbetering door het meten van patiëntervaringen mogelijk te maken, moeten de ontwikkelde PREMs niet worden gezien als statisch, maar als een dynamische entiteit en een onderdeel van een continue inspanning om patiëntervaringen te evalueren en te verbeteren. De reeks vragen is voortdurend onderhevig aan veranderingen in de zorg en de verwachtingen van de patiënt. Jaarlijkse of zelfs continue analyse van enquêteresultaten met betrekking tot (nieuwe) behoeften van de diverse betrokken gebruikers moet leiden tot verbetering van de vragenlijst door dezelfde ontwikkelingscyclus te doorlopen. Toekomstige studies zijn nodig om de bruikbaarheid van deze nieuwe vragenlijsten voor verschillende geletterdheidsniveaus te onderzoeken. Om de resultaten van PREMs voor kwaliteitsverbetering te gebruiken, moeten er rekening gehouden worden met de gevonden barrières en promotors voor de implementatie van verbeterinitiatieven. Hierdoor kan de methodologische kwaliteit en onderzoeksresultaten van toekomstige kwaliteitsverbeteringsstudies verbeteren.

Tot slot, het concept van patiëntgerichtheid en de ideeën om patiënten bij hun zorg te betrekken, is niet nieuw, het dateert uit het einde van de 20e eeuw. Toch is de implementatie van patiëntgerichtheid nog steeds onvoldoende. Organisatorische en logistieke elementen lijken patiëntgerichtheid in de dagelijkse praktijk in de weg te staan, zoals werkdruk, te weinig tijd voor dergelijke patiënt-arts communicatie, onvoldoende toegankelijkheid van patiëntendossiers voor alle betrokken zorgverleners of instellingen en de manier waarop financiële vergoeding is vormgegeven. Zolang de financiering van zorg prestatie gebonden en ziekte-gedreven is en te weinig kwaliteit en patiënt-gedreven, zijn de voorwaarden voor verandering niet optimaal. Een echte uitdaging is om te onderzoeken of het aanpakken van organisatorische barrières daadwerkelijk leidt tot betere zorg, minder klachten of complicaties en mogelijk zelfs tot kostenreductie.

Chapter 9

Summary

Introduction

Healthcare professionals strive every day to deliver the best possible care for their patients. To achieve this ambition successfully, they have to balance between two worlds; 1) the rapidly evolving world of medical knowledge and technological possibilities, and 2) the individual values, preferences and needs of patients. The blending of these two worlds in daily practice appears to be difficult and not straightforward. Where concepts such as Evidence Based Practice (EBP) attributes an equal role to scientific evidence, the clinical expertise of the professional and the patients' values, the focus of quality in care and research is still mainly scientific, biomedical and illness-oriented rather than patient-centered. This biomedical course has become a criterion for quality and funding and dominates most audits and clinical guidelines. At the same time, this approach is increasingly criticized because these guidelines and protocols the relevance of the individual patient is lagging behind. However, the concepts of values, preferences and needs turned out to be moderately defined and utilized. It seems that these concepts are under-researched or used interchangeably, which could certainly hinder the provision of patient centered care. Frequently reported complaints or incidents in healthcare could partly be explained by this under-conceptualization. It turns out that complications are often caused by an underestimation of the problem or a lack of proper information and communication. It seems clear that being more patient centered, with a focus on communication and seeing the patient as a partner could contribute to quality of care.

Aims and findings

The aim of this thesis is to explore the concept of PV, the role PV play in healthcare and how PV can contribute to quality of care. At first, we aimed to clarify and conceptualize the concept of patient values. **Chapter 2** describes the outcomes of a systematic review which was conducted to create an overview of the insights of PV from the perspective of patients themselves. This study reviews qualitative studies in which patients express what they value in healthcare and the healthcare provider. Based on this body of literature a preliminary taxonomy is designed; a structure that makes it possible to recognize, deepen, discuss and take PV into account. The found determinants could be assigned to three categories; 1) values related to the patient and his personal context, 2) values related to the characteristics of the professional, and 3) values related to the interaction between the patient and the professional. Subsequently, we identified within the main categories a consistency of determinants that led to seven key elements; 1) uniqueness, 2)autonomy, 3) compassion, 4) professionalism, 5) responsiveness, 6) partnership and 7) empowerment.

Secondly, to assess the outcomes of literature search in daily practice and to further improve the taxonomy of PV in healthcare, a qualitative study onto PV was carried out by interviewing physiotherapy patients with musculoskeletal pain in primary care (**chapter 3**).

This study resulted in a refining of the preliminary taxonomy where the values of the professional in particular were made more stringent. The element 'professionalism' is refined by the partitioning into 'conscientious professional' and 'technically skilled professional' and by renaming the elements compassion and responsiveness towards the compassionate professional and the responsive professional. Data analyses revealed the importance of a committed and responsible execution of treatment and care by adapting to the patients' needs and circumstances. A balance must been sought continuously between objective diagnostic skills or treatment and subjective skills as paying attention and listen sincerely.

As a third perspective on patient values, a second qualitative study gained a deeper understanding of the beliefs of physiotherapists about PV (**chapter 4**). It enriches our insight of the dynamics of values and possible grounds for conflicts or dissatisfaction between the patients' and the professionals' values.

PV appears to play a major role for professional caregivers, but it becomes apparent that it's a mainly unconscious process. The description of PV is often by practical examples. Automatically aligning with the patient and his expectations as fellow human beings, being responsive, turns out to be central in this process and confirm existing research. At the same time, alignment is the most commonly mentioned barrier in the physiotherapeutic encounter. The examples given often show the tension between taking PV into account and safeguarding professional values. The outcomes endorse that the integration of the different kinds of 'knowledge' (scientific evidence vs. moral values) don't easily merge and sometimes leads to clinical dilemmas.

Once we provided ourselves with the understanding of PV, the possibility arose to objectify them in clinical practice and to use them for the improvement of PCC. Patient experiences are appropriate objectifiable derivatives of PV and a way to get a sense of the impact of care on the patient's life and well-being. A good experience correspond with the underlying values and is positively associated with patient safety and clinical effectiveness.

Chapter 5 describes the development and validation of large scale patient reported experience questionnaires for hospital care (PREM) which reflect the following; 1) items that matter the most to the patient, 2) understandable for all patients, also those with limited health literacy, 3) less items for a better response rate and 4) the incorporation of the patient journey as a whole. We choose to collaborate with Picker Institute Europe by their extensive work of development in patient experience measurements and shortened their existing validated patient experience questionnaires.

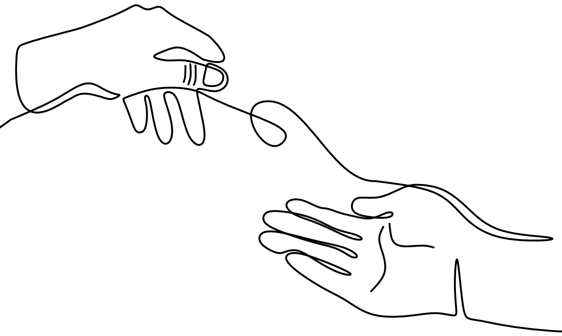
Despite more common quantitative approaches, mixed methods were used to adapt Picker Institute patient experience questionnaires: the selection of items and adaptation towards language level B1 by expert panels, usability tests with patients, analysis of psychometric properties and member checking. A theory-driven approach was followed for definitive enrolment of items, meaning that the items eligible for exclusion had been carefully reviewed by the expert team and representatives of a patient council before definitive exclusion. The rationale for using mixed methods and a theory-driven approach was that we did not want to burden patients unnecessarily with the initially long questionnaires of 67 to 87 items. Additionally, selecting entirely at statistics obtained items which can be improved on in theory may be of little importance for clinical practice (patients or healthcare providers). This process led to two short-form questionnaires of 14-15 items, called Patient Experience Monitor (PEM) Adult Inpatient and PEM Adult Outpatient.

Next it is important to know how to use the outcomes of PREMs to improve care. **Chapter 6** describes the search of existing research for PREM-based quality improvement (QI) strategies which were used to improve patient experience. We studied their effectiveness for QI and the experienced barriers and promoters of these QI interventions. Despite the heterogeneity of methodology and methodological quality of studies reviewed, lessons could be learned. To improve healthcare successfully based on PREMs there must be a sound research design and a focus on one outcome measure. Further, a culture of change and engaged leadership is needed within an organization, sceptic professionals about the necessity or usefulness of the proposed change are the most mentioned barriers. And supporting our main question, experience measures focused on improving communication and interaction were more successful than experience measures focused on changing processes.

Discussion

The aim of this thesis was to explore the concept of PV, the role PV play in healthcare and how patient experiences, as derivate of PV, can contribute to quality of care. We explored multiple perspectives of PV, used various research methods and been in diverse settings. Overall, the outcomes of our studies revolves around the taxonomy of PV with the main focus on paying attention and listening to the patients narrative and being responsive. We can conclude that balancing between science, protocols, clinical expertise, and patient values is a struggle every so often and asks for real attention an ongoing refection.

This thesis contributes to the clarification of the concept of values in healthcare and in finding a balance and mutual reinforcement of implicit and explicit knowledge. We actually see that PV does not stand next to scientific evidence and clinical expertise of the professional, as outlined in EBP, but PV *embraces* scientific evidence and clinical expertise. The patients desire a professional who draws on the latest scientific evidence, and uses his clinical experiences in the clinical encounter. And in that specific encounter he must be responsive and attentive to the patient as an fellow human being. So PV isn't just good listening and shared decision making, it's even a bigger picture. It presupposes a co-production of patient and professional with room for input of the professionals' knowledge, skills and experiences, but also for the patients' narrative; their story, their experiences, their values, their preferences and needs.



PV do not turn out to be static quantities, they appear to be dependent by context. When healthcare problems are uncomplicated, or the remedy is straightforward, one may suffice with prescribing medication, an intervention or clear information (of course tailored to the patient). However, many problems in today's healthcare are not simple and straightforward, but often chronic and complex. All kind of factors in behavior, lifestyle and social environment play an important role in the origin of these health problems, which actually require an active role of the patient, but where low health literacy often play a major role. These are the exact cases where professionals are asked, together with the patient, to extensively explore the unique, individual situation and think along with the patient how to intervene.

A valuable development in this light is the concept of 'positive health', which bridges the gap between healthcare and the social and personal domain. Positive health proposes a broad perception of health in which health is no longer seen as the absence or presence of disease, but as the ability of people to deal with the physical, emotional and social challenges of life and to take control as much as possible. However, just telling patients that they should exercise more or go on a diet is too short-sighted. The patients must be surrounded by a broad spectrum of care providers, whom focus, from their expertise, on the cause of the problem with an eye and understanding for the patient's story.

Perspectives on a Future with PV

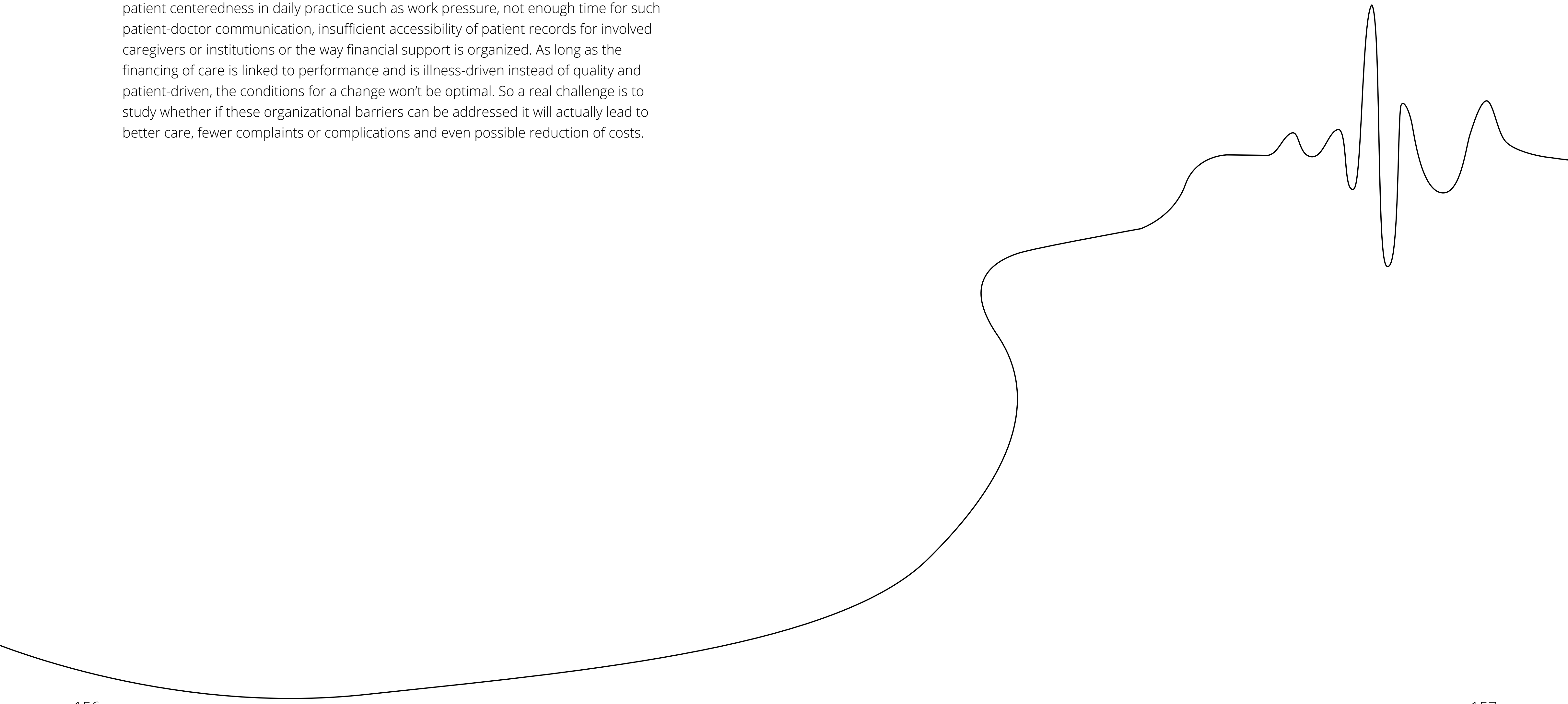
More empirical study is needed to further validate and develop our work. This includes empirical research into the actual behavior and interaction between the patient and the professional in the consultation room, but also the development of the taxonomy by examining multiple settings for its applicability.

Further, it is important to inform all involved sectors in the concept of PV and its consequences for clinical practice and education. A first direction is how the knowledge and awareness of PV can be learned during education. Becoming a responsive professional with a sensitivity for human differences as a prerequisite for partnership may require specific educational strategies and training.

The enhanced scientific insight into PV presupposes a mode of operation in healthcare and education that must consist of advanced knowledge and insight into the paradigm shift towards patient centered care or a better balance in EBP. Additional research is needed on how to find a more equal balance between explicit knowledge such as scientific evidence, and implicit tacit knowledge. This could include adjusting guidelines and protocols and as a result from that, the method of documentation. As example, a change in structure of electronic patient files could lead to awareness of this better balance.

To enable the potential of PV for quality improvement by measurement of patient experiences, the developed PREMs should not be seen as static, but as a dynamic entity and part of a continuous effort to evaluate and improve patient experiences. The set of questions are constantly liable to changes in healthcare and patient expectations. Annual or even continuous analysis of survey results with respect to (new) needs of users should lead to improvement of the questionnaire by going over the same cycle (Chapter 5, Figure 1). Future studies are needed to examine the usability of these new questionnaires for diverse literacy levels. To use the outcomes of PREMs for QI, research should address barriers and promoters in order to enhance methodological quality and study outcomes.

At last, the concept of PCC and the ideas' of involving patients in their care is hardly original, it dates back to the end of the 20th century. Still, the implementation of the concept is less then optimal. Organizational and logistical elements seems to hinder patient centeredness in daily practice such as work pressure, not enough time for such patient-doctor communication, insufficient accessibility of patient records for involved caregivers or institutions or the way financial support is organized. As long as the financing of care is linked to performance and is illness-driven instead of quality and patient-driven, the conditions for a change won't be optimal. So a real challenge is to study whether if these organizational barriers can be addressed it will actually lead to better care, fewer complaints or complications and even possible reduction of costs.



About the author

Carla Bastemeijer was born on 8th of October 1972, in Poortugaal, the Netherlands. After graduating from Albert Einstein Lyceum in Hoogvliet, she enrolled at the University of Applied Science in Rotterdam in 1991. In 1995 she graduated and started at the SOMT University of Physiotherapy, Amersfoort. After obtaining a master's degree in 2001, she attended several comprehensive courses in accordance with the latest developments in physiotherapy practice.

After attaining her bachelor of physiotherapy, Carla worked as a physio-/ manual therapist in a physiotherapy practice in Rhoon, becoming the businessowner in 2000. Aside from this, she has tutored, developed and/or managed at the University of Applied Science and Breederode University of Applied Science, Departments of Physical Therapy, Rotterdam.

In 2013 Carla became interested in the concept of patient values and its place in daily practice. She incorporated the first ideas into a research proposal and thereby passed the entrance exam at the Graduate School of University of Humanistic Studies, Utrecht. In 2019 she continued her PhD research at Erasmus University Medical Center, Rotterdam.

In 2007, Carla became a mother to her daughter Nina. Since 2016 they live together with Carla's new love Patrick and his 2 children Carlijn (2004) and Noah (2007).

PhD portfolio

Name PhD student	Cornelia Maria (Carla) Bastemeijer
ErasmusMC Department	Public Health
PhD period	2015-2021
Promotor	Prof. Dr. J.A. Hazelzet
Co Promotors	Prof. Dr. J.P. van Ewijk Dr. L.P. Voogt

PhD training

Courses		**ECTS**
2015	Extended scope therapist Breederode University of applied sciences	5
2017	Introduction to Research Methods in Humanistic Studies, including Library Skills (UvH)	3.5
2017	Academic Writing in English(Babel) UvH	1.5
2017	Proposal writing workshops, including 'Introduction to Scientificintegrity and Data Management of qualitative research' UvH	2.0
2017	Writing a Review Article UvH	1.5
2017	Basic principles of Endnote EMC	0.1
2017	Systematic literature research with Pubmed EMC	0.1
2017	Systematic literature research with other databases EMC	0.1

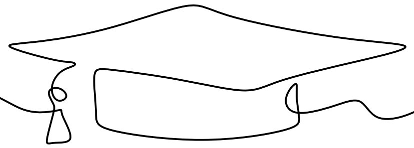
Presentations		**ECTS**
2017	Poster Presentation and participation in Conference UvH	0.5
2017-2019	Individual (and/or small group) supervision meetings UvH	1
2019	Presentations at ErasmusMC (PREM development and implementation strategies for QI	1

Teaching activities

		ECTS
2017-2021	Development and Lecturing qualitative research Master's program Breederode University of applied sciences	8
2019-2021	Supervising and assessing mastertheses	6
2019-2021	Assessor master theses program Breederode University of applied sciences	6

Other activities

		ECTS
2017-2021	Professional field committee Breederode University of applied sciences	4



List of publications

This thesis

Bastemeijer, C. M., Voogt, L., van Ewijk, J. P., & Hazelzet, J. A. (2017). What do patient values and preferences mean? A taxonomy based on a systematic review of qualitative papers. *Patient Education and Counseling*, 100(5), 871-881.

Bastemeijer, C. M., Boosman, H., van Ewijk, H., Verweij, L. M., Voogt, L., & Hazelzet, J. A. (2019). Patient experiences: a systematic review of quality improvement interventions in a hospital setting. *Patient related outcome measures*, 10, 157.

Bastemeijer, C. M., Boosman, H., Zandbelt, L., Timman, R., de Boer, D., & Hazelzet, J. A. (2020). Patient Experience Monitor (PEM): The Development of New Short-Form Picker Experience Questionnaires for Hospital Patients with a Wide Range of Literacy Levels. *Patient Related Outcome Measures*, 11, 221.

Bastemeijer, C. M., van Ewijk, J. P., Hazelzet, J. A., & Voogt, L. P. (2021). Patient values in physiotherapy practice, a qualitative study. *Physiotherapy Research International*, 26(1), e1877.

Other publications

Cornelis, C., den Hartog, S. J., Bastemeijer, C. M., Roozenbeek, B., Nederkoorn, P. J., & Van den Berg-Vos, R. M. (2021). Patient-Reported Experience Measures in Stroke Care: A Systematic Review. *Stroke*, STROKEAHA-120.

Bastemeijer, C.M., van Ewijk, H., Hazelzet, J.A., Voogt L. (2021). Patiëntwaarden in de fysiotherapiepraktijk. *FysioPraxis*, 30(2), 14-17.

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Healthcare professionals strive every day to deliver the best possible care for their patients. To achieve this ambition successfully, they have to balance between two worlds; 1) the rapidly evolving world of medical knowledge and technological possibilities, and 2) the individual values, preferences and needs of patients.
The blending of these two worlds in daily practice appears to be difficult and not straightforward. Increasing criticism has arisen on the weight of explicit, theoretical knowledge due to the fact that it results in a variety of guidelines and protocols where the relevance of the individual patient is lagging behind. An explanation for this conceptual problem could be an ill-defined understanding of what patient values imply and which specific roles they play in healthcare practice.

This thesis presents the journey of exploring diverse perspectives on the concept of patient values and creates a deeper understanding of them. This thesis also gives insight into the additional benefit of patient values to improve care by using patient experiences as a objectifiable derivative. The findings of this research can inform all involved sectors in the concept of patient values and its consequences for clinical practice and education.

Carla Bastemeijer is a physiotherapist in primary care, university lecturer of applied sciences and researcher at Erasmus University Medical Center, Rotterdam,
The Netherlands.