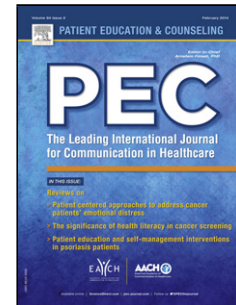


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How do patients experience caring? Scoping review

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Highlights

- This research provides a rich description of caring
- Patients experienced caring when competent professionals communicated effectively
- They did so also, when professionals formed relationships, engaged emotionally, and displayed positive attitudes
- These findings could underpin education for collaborative, interprofessional practice

Abstract

Objective

Summarise empirical research into patients' experiences of caring in order to promote this as a core condition for the work of health professionals.

Methods

A review team: carried out a scoping review with a phenomenological orientation that did not privilege any profession or context of care; comprehensively searched six databases from inception to the present, including all English language articles that report patients' lived experiences of caring; and identified and contrasted uncaring experiences.

Results

43 articles straddled nursing, medicine, and physiotherapy, and a wide range of care settings. Patients experienced caring when competent professionals displayed positive attitudes, communicated effectively, formed relationships, helped them navigate clinical services, and engaged emotionally.

Conclusion

This research provides a rich description of caring, which was derived from patients', rather than professionals', experiences.

Practice Implications

Whilst publications and basic professional curricula are dominated by the perspectives of single professions, this research describes patients' experiences that can prepare all health professionals to be caring in collaborative, interprofessional practice.

'The essence of the practice of medicine is that it is an intensively personal matter.'

Francis Peabody 1927 [1]

1. Introduction

The work of health professionals 'touches our lives at times of basic human need, when care and compassion are what matter most'. [2] Despite caring being central to clinical practice, it is easier to say it is absent [3] than to say what it is. Caring is a core value of the nursing profession. [4] Peabody famously said caring is core to medicine too [1] and this has been reaffirmed. [5] But technical progress since Peabody's time has widened the concept of caring to mean much more than humane behaviour. [6] The number of professions that contribute to interdisciplinary teamwork has increased too, introducing new perspectives on caring. There has been a drive to teach clinical communication, and define and assess professionalism. Whilst this parsing into components has made it easier to teach and assess aspects of caring, it has not made the essence of caring any clearer. And patients have not usually been involved in clarifying what it is. Finding out what caring means to those who benefit from it would help interprofessional practitioners meet patients' human needs and teach students to do the same. This would reinvigorate the core value of patient care.

Contemporary arguments, as well as historical ones, mandate research into caring. Licensing bodies censure doctors who do not 'make the care of your (sic) patient your first concern'. [6] Politicians condemn healthcare systems for providing 'appalling care'. [3] Caring guides curriculum design. [5] Such an everyday word as caring helps lay people enter discussions about professional standards. And its breadth of meaning encompasses values, individual behaviours, and systemic processes. This advantages caring over more specific and technical terms like 'presence', 'compassion', 'empathy', and 'relationship' because it embraces all of them. The word caring sets fuzzy boundaries within which a holistic concept of clinical humanism can take shape. But licensing bodies are not satisfied with fuzzy boundaries. This poses what Schön [7] identified as a central problem of professional education: the 'Meno Paradox'. In a dialogue with Socrates about virtue, his disciple Meno became so frustrated by being unable to define wisdom that he burst out: 'How on earth are you going to set up something you don't know as the object of your search?'

One way of resolving the paradox would be to reach consensus on a definition of caring. Authors have, however, disagreed whether that is worth doing. On one hand, defining caring has been described as 'approximately 350 years out of date' [8]; on the other, researchers have continued to define it. [9] They have usually done so within specific professions or care settings, which limits the applicability of their work. The idea that caring means different things to doctors and nurses is long established. [1] Nurses have laid claim to caring as the essence of their profession [4,10,11] and

nursing journals regularly publish primary and secondary research on the topic (for example [4,12–14]). As well as in medicine and nursing, caring has been researched in physiotherapy [15,16] and interprofessional team working. [9] But when the concept of caring has been made more general by widening the disciplinary mix, it has been made more specific by concentrating on specific clinical settings. These include: palliative care, [9] acute internal medicine, [17] primary care, [18] oncology, [19] and the management of irritable bowel syndrome [20] and substance abuse. [21] Curriculum leaders are in a bind. Regulators require them to graduate caring, pluripotent, interprofessional health workers, yet professionals have only been able to define caring in specific professions or care contexts, if at all.

Socrates would have been unsurprised that professionals have not been able to define caring any better than he could have defined virtue. Perhaps patients could define caring better? As judged by empirical research, however, clinicians, educators, and researchers have been readier to speak on behalf of patients than give them a voice. For example, four of 11 scales that implicitly define caring by measuring patients' experiences of it [22] are rated by professionals (usually nurses) rather than patients. It is unclear how the other seven caring measurement scales reflect patients' self-identified needs. There are, however, early signs that professionals will allow patients to say what caring is. A theory-building review of how 35 articles defined caring [11] found that an important minority were shifting the field from nurse-focused to patient-focused conceptualisations. Four articles identified patients' experiences of caring and eight treated patients as authorities who should define caring. This uncovered a discrepancy between what patients and nurses found important [11,23–25], which shows how important it is to understand caring as experienced by patients themselves and not to conflate that with professionals' experiences. This overview suggests that the quest for a definition of caring may, indeed, [11] be a fruitless one.

A Socratic alternative to resolving the Meno Paradox by defining caring would be to acknowledge that caring is indefinable and report, in all their richness, patients' experiences of it. To that end, researchers have examined theory [4,11] and synthesised empirical evidence [13,14,26–28]. They have come at this from several angles: caring [4,11,13,14], patient-centredness, [29] doctor-patient relationships, [26] and systems of care. [27] Empirical reviews have not usually had conceptual frameworks though phenomenology guided one theory-building review. [4] This corpus of work, however, had the same limitation as primary research. It was conducted within specific disciplines - usually medicine [26] or nursing [4,11,13,14] - or in specific clinical contexts.

What is lacking is a synthesis of patients' experiences of caring that draws from more than a single profession and/or clinical context and has a conceptual orientation. Our aim was to summarise

empirical research into patients' experiences in order to promote caring as a core condition for the work of health professionals.

2. Material and methods

2.1 Conceptual Orientation

Our intention to explore the essence of caring by synthesising patients' accounts of their experiences of it led us to take a phenomenological stance. This conceptual orientation is rooted in the work of early twentieth century philosopher Edmund Husserl. [30] Phenomenology is relevant to this research because it combines a theory of being in the world, which acknowledges our interest in the lived experience of being cared for, with a theory of knowledge, which acknowledges our interest in how patients speak about those experiences. Phenomenology is, typically, applied to primary research. Ours was, in contrast, secondary research, reviewing data derived from mostly non-phenomenological research. So our research was phenomenological in so far as this theory provided an ontological and epistemological justification for our approach and a method of analysis. Phenomenologically speaking, the word caring describes 'a state of being', patients' experience of which is of interest.

2.2 Research team

The research was conducted in Canada and Northern Ireland, UK. Two medical students and two physicians, who are also education researchers (a family physician and an internist/ endocrinologist), formed the research team. The medical students had received interprofessional education and both physicians have extensive experience of interprofessional practice.

2.3 Procedural steps

Scoping review is a methodology well-suited to a complex topic like caring because it can map key concepts, types of available evidence, and gaps. We followed the five step approach devised by Arksey and O'Malley [31] as revised by Levac and colleagues. [32]

2.3.1 Identifying the review question

Our starting assumption, justified earlier, was that caring is a fuzzy concept that cannot be defined but exists in patients' experiences. We met personally, conferenced via the Internet, corresponded by email, and discussed the results of a pilot search. Throughout this and the following stages, we followed the phenomenological process of discussing our preconceptions and biases in order to attend to the essence of patients' experiences rather than our own. We defined 'a patient' as any individual receiving any form of healthcare delivered by any healthcare professional (HCP) in any setting. This mandated a broad search, including an unlimited range of types of patients and

healthcare providers. The wording of our review question was: *“What is known from existing publications about the qualities, attributes, and behaviours of healthcare professionals that patients experience as caring?”*

2.3.2 Identifying Relevant Studies

A librarian helped devise a preliminary search. This was piloted in MEDLINE, refined, and tailored to search across six databases. Table 1 shows how searching and selecting evidence complied with ‘STARLITE’ criteria. [33] We devised a search syntax by separating the research question into its component parts. MeSH-terms and text-words for care (empathy, sympathy, altruism, compassion, trust, kindness, social behaviour), experience (perception) and healthcare occupation (doctor, nurse, midwife, counsellor, therapist, pharmacist, occupational therapist, healthcare personnel) were combined to perform the search and adapted for each database. When databases produced over 2000 results, we limited the search to article titles. We decided to exclude non-English language articles because nuanced language might be lost in translation. Although we were searching for evidence that was explicitly about caring, there were articles about relationships that, on careful reading, were about caring relationships and therefore implicitly about caring. Since reflexive interaction between researchers and the materials they are working with is integral to phenomenological analysis, we included these articles.

2.3.3 Selection of relevant studies

Before definitively selecting articles, we conducted a calibration exercise to evaluate and increase the reliability of article selection. This entailed two authors independently screening a random 10% sample of articles. A second exercise entailed two authors (HG and TD) reviewing the abstracts of articles identified in a pilot search and a third author (MK) resolving discrepancies in their application of the inclusion criteria. Fig 1 uses the PRISMA convention to show the selection stages. [34] We developed, applied, and refined the inclusion and exclusion criteria shown in Table 2 as we became more familiar with the nature of the evidence.

Thirty-six articles identified by searching and a further seven identified by screening reference lists directly described patients’ experiences of how healthcare providers affected them. These included primary and secondary studies using qualitative, quantitative, and mixed-methods designs. Although not mandatory for scoping reviews, the Critical Appraisal Skills Program (CASP) toolkit [35] and a simple 5-point scale described elsewhere [36] helped evaluate articles’ trustworthiness. This was not to exclude articles but to give them proportionate weight in the synthesis.

A concern that positive publication bias might have reduced the number of included articles led us to repeat the search using ‘uncaring’ as the key search term. This identified one hundred and ninety

titles, of which seven matched our inclusion criteria. Review of these articles confirmed, but did not add to, the results presented below. We did not include them in the results section since ‘caring’, rather than ‘uncaring’, was the topic of our research.

2.3.4 Charting the Data

We created a data extraction sheet using Microsoft Excel (Microsoft, Redmond, USA), piloted it on a small set of the studies, and refined it. The final form included demographic details, methodological details, and patients’ descriptions of caring (or uncaring) experiences. To maintain the phenomenological emphasis, we extracted all relevant data from each paper in a way that would complete the sentence: *“This research shows that a patient experienced caring as ...”*. In order to achieve consensus about data extraction processes, three members of the research team (HG, SD, TD) independently extracted relevant data from a subset of the included articles and discussed their findings. One author (HG) read and extracted the remaining data items, which totaled 1011 rows in the spreadsheet.

2.3.5 Collating, summarising and reporting results

Given the heterogeneity of studies and outcomes reported, we used a narrative approach to collate, summarize, and map data. Most articles reported positive experiences of care. Negative experiences were too few to support separate analysis and mirrored positive ones. Since our intention was to identify dimensions of caring rather than position patients’ experiences along those dimensions, we reworded negative experiences positively; for example, ‘... a nurse not listening to me’ became ‘... a nurse listening to me’. We reviewed the dataset, discussed our interpretations, and developed a coding framework with six main themes. HG maintained an audit trail of procedures, team meetings, and analytical decisions. As we clustered items into well-defined categories and synthesised an interpretation, we chose labels that stayed as close as possible to the words patients used to describe caring experiences. For brevity and to minimise repetition, we have sometimes abbreviated the phrase ‘was experienced as caring’ to ‘was caring’. Peer-review identified epistemological tensions so we focused the ‘voice’ of the article more clearly and consistently on patients’ lived experiences

3. Results

Table 3 shows that the final set of articles, which represented the views of over 1,000 patients aged 19 - 91 years, spanned a range of clinical contexts and geographical locations. Patients experienced a heterogeneous group of qualities, attributes, and behaviours as caring. An individual HCP did not necessarily demonstrate all these; rather, there was a complex interplay between what individual HCPs demonstrated, and individual patients experienced as caring. Specifically, patients experienced:

1. Competence
2. Positive attitudes
3. Effective communication
4. Relationships
5. Being helped to navigate clinical services
6. Emotional engagement

Table 4 summarises these findings, referring to source publications and presenting illustrative quotations. We now present the findings in more detail.

3.1 Competence

Patients experienced caring when HCPs applied requisite knowledge and skills in a deliberate and determined manner; when they made diagnoses correctly and managed patients' symptoms appropriately; when they did more than prescribe medication; when they thought and acted beyond patients' immediate symptoms, and treated underlying causes of illnesses. Patients experienced caring when HCPs combined technical competence and experiential knowledge. Patients recognised, however, that HCPs were not infallible. Recognising mistakes, apologising, and making efforts to rectify them was experienced as caring. The net effect was for patients' to experience their needs as proficiently met.

3.2 Caring HCPs displayed positive attitudes

Patients experienced caring when professionals displayed positive attitudes: when they were sincere, thoughtful, sensitive, and friendly to patients and colleagues. Patients experienced caring when HCPs were appropriately positive and optimistic, approachable, and understanding, displayed commitment and enthusiasm, expressed supportive emotions (empathy, compassion, and sympathy), and were sensitive to patients' needs and wishes. When HCPs were supportive, understanding, and respectful, patients' experienced caring. Being reliable and trustworthy was experienced as caring, as was acting with sincerity, honesty and respect. Being patient and working in a calm, yet confident, manner; being attentive, efficient, and vigilant; being encouraging, supportive, and helpful; and being cheery, good humoured, and polite were all experienced as caring. Not being judgmental, patronising or condescending was caring. Patients experienced caring when professionals were genuine.

3.3 Effective communication

Caring communication extended beyond dialogues between doctors and patients to communication within teams and with other professional disciplines. Caring communication could be subdivided into four categories.

3.3.1 Talking

Patients experienced caring when HCPs chose their words carefully, made helpful comments that responded to patients' needs, and answered questions; when HCPs were forthright and straightforward but not abrupt. Caring was feeling that your illness had been acknowledged because information was given in clear and sensitive ways, which balanced honesty and tact. Having questions answered empathically and respectfully, receiving thorough explanations with measured amounts of information, not being subjected to medical jargon, and not being patronised were caring.

3.3.2 Listening

Patients experienced caring when HCPs spent time listening to them. This created an open space in which patients could express concerns and ask questions without being interrupted. Caring was interest being shown in what patients said. It was being actively listened to, responded to meaningfully, and actions being taken. It was an HCP listening to and understanding patients' views. It was having their concerns taken seriously and their experiences not belittled.

3.3.3 Non-Verbal Behaviour

Various non-verbal behaviours were experienced as caring: appropriate body language, eye-contact, and smiling. Caring was not feeling threatened because HCPs appeared to be comfortable during consultations and touched patients sensitively. This silent language established a sense of mutual understanding.

3.3.4 Sharing Knowledge

Caring was being offered explanations and information periodically or continuously according to patients' individual wishes. It was sharing in clinicians' experiential knowledge and being told what to expect. It was being advised, not being dictated to. It was involvement in decisions and experiencing a sense of partnership. It was HCPs acknowledging patients' expertise about themselves and their illnesses, and showing interest in their opinions. It was receiving verbal and written information, and being directed towards additional sources of information.

3.4 Relationships

Patients experienced caring within meaningful relationships that made them feel comfortable and at ease. Caring relationships 'connected' patients with HCPs. Such relationships gave patients an experience of HCPs understanding their illnesses and how these affected their lives and activities.

Patients experienced similarities between caring relationships with HCPs and relationships with family members and friends.

3.4.1 Trust and respect

Caring relationships gave an experience of mutual trust and respect, and being valued. This trust created partnership between HCPs and patients, and sometimes with patients' families or lay carers. Patients experienced HCPs accompanying them on their 'journeys' and getting to know them and their illnesses better as caring.

3.4.2 Patients as individuals

Caring was the experience of being at the centre of a relationship with an HCP. It was being treated as an individual rather than a disease entity. It was an HCP acknowledging and respecting that one patient had different wishes from another patient. It was receiving personalised information and support. It was account being taken of patients' personal values and clinical care being integrated into their individual circumstances.

3.5 Being helped to navigate clinical services

Patients experienced caring when HCPs ensured that clinical processes were efficient, prompt, reliable, holistic, and responsive to patients' needs.

3.5.1 Caring was internally motivated

Caring was experiencing HCPs as genuinely wanting to help; being supportive, guiding, and encouraging. It was feeling that an HCP had taken trouble to make referrals to other services or for religious or spiritual support. It was a sense that HCPs were motivated by a genuine desire to help rather than status or pay. It was experiencing an excellent service, which went above and beyond expectations. It was experiencing privacy and dignity.

3.5.2 Caring was continuing

Continuity of care, preferably within one-to-one relationships that persisted over time, was experienced as caring. This temporal relationship provided more than just treatment and monitoring; it fostered trust. Caring was experiencing continuity between different HCPs and different teams. It was experiencing HCPs collaborating and communicating with one another and involving members of clinical disciplines other than their own when needed. Caring was being helped to navigate transitions between primary and secondary care.

3.5.3 Caring included patients

Patients experienced caring when HCPs encouraged them to be active participants in their own care, share in decision-making, and arrive at shared goals. Caring was being given control, independence, and choice, whilst knowing that advocacy was at hand when required.

3.6 Emotional engagement

Caring was experiencing HCPs as emotionally engaged, accessible, and easily contactable. It was not being made to feel rushed and feeling good use was being made of time. It was the experience of an HCP taking the initiative to contact or visit a patient. Caring was being made to feel safe, secure, and able to relax in clinical environments. It was feeling protected from harm by the presence of an HCP. It was feeling empowered, enabled, and encouraged to take control of one's illnesses and treatments.

4. Discussion and Conclusion

4.1 Discussion

4.1.1 Principal findings and relationship to earlier publications

The findings of this study are encapsulated by the aphorism that 'whilst the treatment of a disease may be entirely impersonal, the care of a patient must be completely personal'. [1] Patients experienced caring when HCPs tailored a range of relational and organisational skills, values, and behaviours to their personal needs and preferences. Attributes that contributed to this experience included being appropriately skilled and knowledgeable, maintaining continuity, and being prompt, efficient, reliable, accessible, and seemingly unhurried. Less tangible, yet still powerfully experienced, were values and emotions that underpinned those behaviours. These included being concerned for others, being intrinsically motivated, and being humble. Admitting fallibility and apologising when things went wrong gave rise to such experiences as did a variety of often small actions that engendered the mutual trust, respect, and safety that lay at the heart of therapeutic relationships. Patients experienced caring HCPs as genuine. They knew this when they experienced it, but genuineness defied a simple behavioural definition.

A value and behaviour that runs through the findings and deserves special mention is reciprocity. Patients experienced caring within the dynamics of consultations that gave patients the independence and choice they wanted and needed to navigate systems of care. Caring was listening and conversing *with* rather than communicating *to*. Skill was necessary for this but not sufficient; sharing control called for genuine respect towards others.

A strength of this research was to take the phenomenological assumption that patients' needs and experiences should be the central preoccupation of healthcare as the starting point for a scoping review. This allowed the findings to transcend professional assumptions about what is good for patients, and crossed the boundaries of individual professions, specific contexts, and systems of care. It uncovered the intimate link between competence and caring.

The findings agree with earlier secondary research into patients' experiences [13,14,26,27], which has defined caring as displaying appropriate professional behaviours, being competent, being present, forming relationships, communicating well, and managing services. Most publications included just one or two of our dimensions and none included all six. It is a matter of opinion whether, for example, communication is better served by separating it from the broader construct of caring. Suffice it to say that this research provides a rich description of caring, with a central focus on patients' experiences and reciprocity with professionals.

4.1.2 Limitations

An important limitation is that all clinical members of the team were students or practitioners of medicine. This reflects the current state of health professions education where practice is mostly interprofessional but basic education is mostly uniprofessional. Whilst we synthesized evidence from any profession that has researched caring, our disciplinary perspective best equipped us to inform the uniprofessional or interprofessional education of doctors. Other professions and all contexts of medical care might, nevertheless, find it informative. Another limitation was dominance of the evidence by nursing publications. There was also an apparent generosity bias in that more publications reported caring than uncaring behaviour. The limited number of negative reports, arguably, led us to accentuate that bias by rewording negative experiences in positive words. Our intent, though, was to define dimensions along which patients' experiences may be negative as well as positive. Another limitation is that we did not question patients' authority to define caring and reported only their experiences, not HCPs'. This limitation applies, particularly, to behaviours that require professional training to judge. Clinical competence is an important case in point. This raises the troubling question of when it is better to be brusque and have no mistakes to apologise for, and when caring equates with recognising one's mistakes, apologizing, and trying to rectify them. Likewise, reassuring a patient that all is well is less caring than explaining the distinctly un-reassuring fact that a scan shows extensive liver metastases. Competence and caring are not at odds with one another but patients' ability to judge those aspects of competence that can only be judged objectively is inevitably less than their ability to experience social aspects of caring.

Our findings risk idealising caring without acknowledging that busy and under-resourced care settings may constrain it. No health worker can reasonably be expected to care ideally in every possible regard so our counter-argument is that defining a set of dimensions allows positive behaviour along one – striving to be attentive and pleasant, for example – to offset another – having little time available.

4.2 Conclusion

To rewrite dictionary definitions of caring would be simplistic and impractical. Instead, we have provided a rich description of factors, which influence whether or not patients experience caring. Whilst the evidence is limited compared with the numerous descriptions and definitions of caring provided by professionals, it has intrinsic moral authority and suggests numerous ways HCPs can make patients' experiences of clinical encounters more or less positive. Simple practical behaviours lead to caring experiences. These are often neglected in the erudite climate of universities yet clinicians can easily model them and help learners display them. Caring comprises many attributes, values, and behaviours. Different practitioners have different quantities and qualities of them and none, alone, is sufficient. The essence of caring is to combine them in a way that meets an individual patient's needs at a particular moment.

4.3 Practice Implications

Educational practice was the main target of this research. Caring can only be a core value of health professional practice if it is reinforced in the basic, early postgraduate, and continuing phases of lifelong health professions education. Because experienced practitioners and novices work together, education can be mutually reinforcing if all phases are included, or doomed to failure if they are not. So, education for caring has to be systemic. Moreover, contemporary health care systems are interprofessional so education has to shift from its traditional, uniprofessional focus.

The first practice implication is that we have provided a rich description of caring that is applicable to contemporary, interprofessional curricula for practitioners at all levels of experience. Its validity comes from focusing on the central focus of attention of all professionals – patients – and piecing together commonalities between individual professions. This helps curriculum leaders out of the awkward situation of being expected to graduate caring, pluripotent, interprofessional health workers when care could hitherto only be defined in specific professions or care contexts. Its validity rests on

first exploring what attributes it would be desirable for graduates to show and then deriving educational implications rather than the more usual reverse.

A second implication is that the set of interrelated values and observable behaviours described here can be modeled by practitioners and assessed in formative and summative assessments.

A third one is that our account challenges the dichotomy between competence and caring. Both are important but neither alone is sufficient. We have resolved interprofessional differences of emphasis that strengthen a false dichotomy between the two.

A fourth implication is that our account of caring promotes reciprocity between patients and practitioners. The pressured conditions in which practitioners deliver contemporary healthcare challenge their values and lead to stress and burnout. Reciprocity could keep their values alive and serve as an antidote to stress.

The fifth and arguably most important implication is that small, simple things make big differences to patients' experiences. Rather than adding new layers of complexity to health professions education, our findings suggest that practitioners are caring when they allow their basic humanity to bring their professional attributes into alignment with individual patients' needs. To foster caring, teachers and practitioners should emphasize the individual, genuine, and often momentary nature of care.

The final implication is that caring has many dimensions, at least some of which reside in patients' lived experiences, defy definition, and can only be experienced – not taught. We have not resolved the Meno Paradox. Like virtue, learning to be caring is a career-long journey that leads each individual HCP to a distinctly personal destination. Therein lies the attraction and reward of working in a caring profession.

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Figure Caption

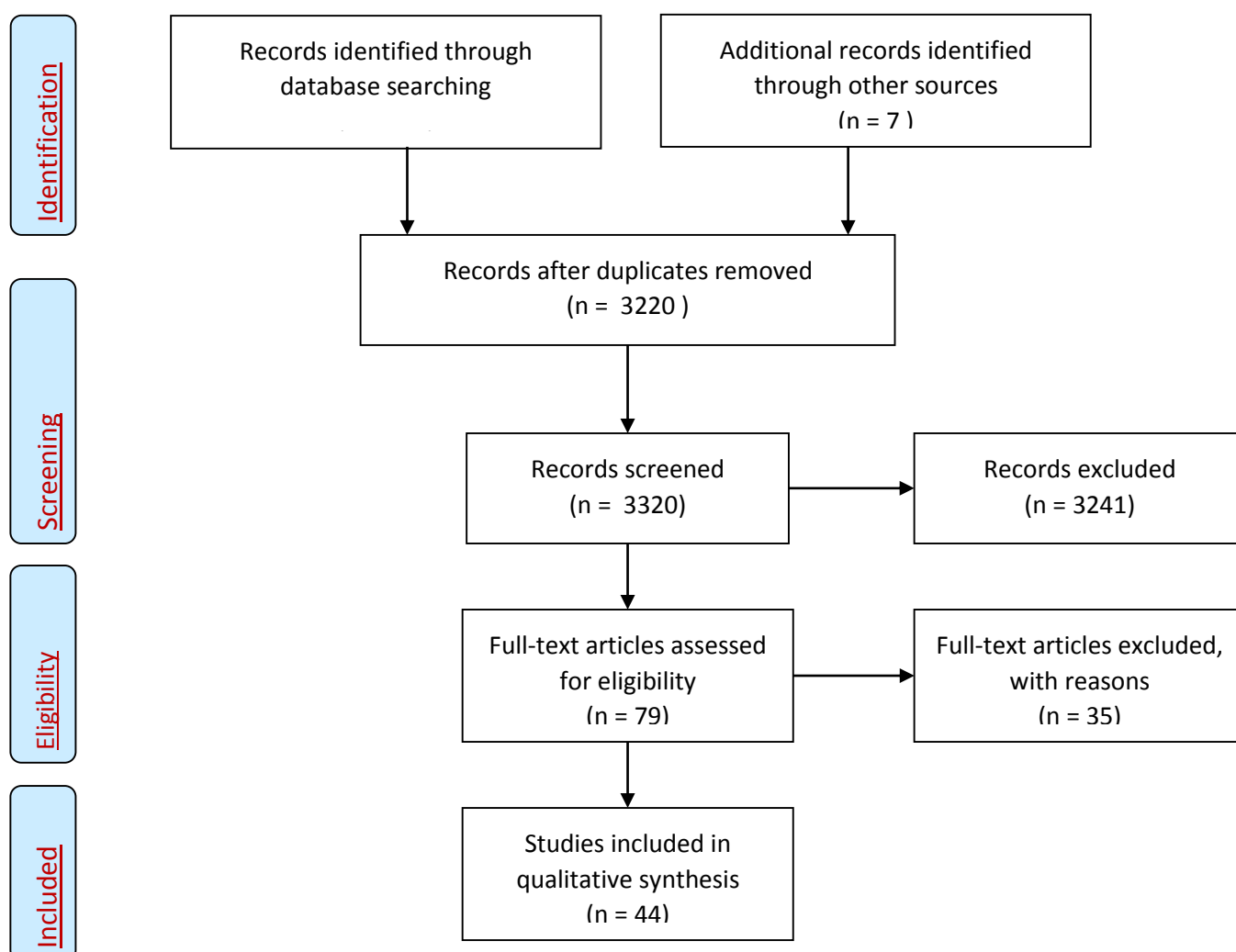
Figr-1 **Figure 1: PRISMA 2009 Flow Diagram**

Table 1: Search Strategy**(a) STARLITE Summary of Search Strategy**

S	Sampling Strategy	Comprehensive – attempting to identify all published material		
T	Type of Study	Any study – qualitative or quantitative, provided quantitative instruments were developed by first exploring patients' experiences.		
A	Approaches	Searching electronic databases and screening the reference lists of included articles		
R	Range of Years	From inception of individual databases to February 2016		
L	Limits	English language articles; adults		
I	Inclusion / Exclusion	See Table 2		
T	Terms Used	See text		
E	Electronic Databases	Ovid MEDLINE Web of Science	SCOPUS CINAHL	PYSCHinfo ERIC

Table 2: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • About caring and caring relationships • Reporting patients' or lay-peoples' experiences • Related to healthcare • Written in English • Concerning adults • <u>Could complete the sentence: "This research shows that a patient would feel cared for if (s)he experienced..."</u> 	<ul style="list-style-type: none"> • Reporting professionals' opinions and experiences rather than patients' • Defining caring by means of quantitative data where patients had not been actively involved in the development of the data collection tool • 'Care' as an outcome of resources, equipment, or treatment options rather than clinicians' behaviour • Describing patients' experiences of a particular illness, not the care received • Case studies, commentaries editorials, dissertations, conference abstracts, and research letters

Table 3 : Summary of included studies

Resource Number	First author	Year	Country	Context	Discipline	Patient Respondents			Method of data collection	Methodology	Aim
						N	Male : Female	Age Range			
1	Ahl [37]	2012	Sweden	Pre-hospital care	All HCPs	20	8:12	34-82	Semi-structured interviews	Ricoeur's interpretation theory	Interpret the meaning of pre-hospital caring from the patient's point of view
2	Attree [17]	2001	UK	Acute medical ward	All HCPs	34	18:16	19-89	Semi-structured interviews	Grounded theory	Explore patients' and relatives' perceptions of care, via descriptions of actual experiences
3	Bendapudi [38]	2006	USA	14 Medical Specialities	Physicians	192	50:50 split	Not reported	Telephone interviews	Thematic Analysis	Develop a profile of ideal physician behaviours
4	Berg [39]	1996	Sweden	Obstetric Care	Midwives	18	0:18	23-38	Interviews	Interpretative phenomenology	To describe women's experience of the encounter with the midwife during childbirth
5	Berg [40]	2007	Sweden	Hospital care	Nurses	7	3:4	51-75	Semi-structured interviews	Interpretative phenomenology	Illuminate patients with long term illnesses' experiences of care
6	Bramley [41]	2014	UK	Hospital care	Nurses	10	5:5	18-91	Semi-structured interviews	Qualitative exploratory description	Understand how patients experience compassion within nursing care
7	Calman [42]	2006	UK	Hospital care	Nurses	27	Not reported	20-78	In depth interviews	Grounded theory	Examine what is meant by competent nursing
8	Canzan [43]	2014	Italy	Hospital, geriatric care	Nurses	20	2:18	66-80	Semi-structured interviews	Qualitative descriptive study	Understand how older patients experience nursing care
9	Cockedge [44]	2013	UK	General Practice	Physicians (General Practitioners [GPs])	11	7:4	50->80	Semi-structured interviews	Constant comparative qualitative analysis	Explore GPs' and patients' experiences of using touch in consultations

10	Conner [45]	2008	UK	Palliative care	Physicians and nurses	10	Not reported	Not reported	Narrative interviews	Thematic content analysis	Explore the views of patients referred to a specialist palliative care team about their healthcare services
11	Copeland [18]	2003	USA	Primary care	Primary care providers	50	0:50	18 - >55	Focus groups	Thematic analysis	Examine African American women's views of the doctor-patient relationship, their satisfaction with that relationship, their knowledge of the health care system, and their beliefs about what makes a good doctor
12	Den Bano Aledo [15]	2014	Spain	Outpatient physiotherapy/rehabilitation services	Physiotherapists	57	33:24	<30 - >45	Focus groups	Thematic analysis	Identify elements of the physiotherapist-patient interaction that are considered by the patient when evaluating the quality of care
13	Fletcher [46]	2007	USA	Hospital care	All HCPs	17	13:4	20-81	Interviews	Grounded theory	Explore what is important to patients about bedside interactions with physician teams
14	Greenfield [16]	2010	USA	Orthopaedics / Acute care / rehabilitation	Physiotherapists	9	3:6	31-77	Semi-structured interviews	Phenomenology	Understand the essential meaning of caring behaviours from patients undergoing physical therapy
15	Griffiths [47]	2012	UK	Carers/ Cancer service users/ older people /mens health/ parents/HIV service users	Nurses	52	23:29	Not reported	Focus groups	Framework analysis	Inform curriculum development via qualities patients sought in nurses
16	Halldórsdóttir [48]	1996	Iceland	Obstetric care	Nurse-midwives	10	0:10	33-42	True dialogues	Phenomenology	Clarify women's experience of caring and uncaring encounters during childbirth

17	Halper t [20]	2011	USA	Patient s with Irritabl e Bowel Syndro me	Physic ians (GPs, gast-roent erolo-gists), nurse s	57	10:47	Mea n = 41.1 (SD= 14.04)	Expres sive writing	Qualitativ e content analysis	Examine patients' perspectives on their relationships with HCPs as communicated in their expressive writing about IBS
18	Haugli [49]	2004	Nor way	Patient s with rheum atic disease	Docto rs	26	4:22	20-80	Focus groups	Qualitativ e analytical processes	Evaluate what patients with rheumatic disease perceive as important in health-care encounters
19	Hershberger [50]	2008	USA	Fertilit y clinic	Nurse s	8	0:8	33-46	Qualita tive descrip tive intervi ews	Phenome nology	Describe pregnant donor oocyte recipients' perceptions of the essence of nurses' caring behaviour
20	Hudon [51]	2013	Can ada	Primar y care	Physic ians (GPs)	30	13:17	35-75	In-depth intervi ews	Qualitativ e descriptio n	Identify physicians' enabling attitudes and behaviours from perspective of patients with chronic diseases
21	Hunt [52]	1999	Aust ralia	Intensi ve care unit	Nurse s	12	Not reported	Not reported	Semi-structu red intervi ews	Thematic analysis	The cardiac surgery patients' expectations and experiences of nursing care in the intensive care unit
22	Jannse n [53]	2010	New Zealand	Comm unity hospice progra mmes	Docto rs	13	Not reported	Not reported	Semi-structu red intervi ews	Interpret ative phenome nology	Hear what patients approaching death had to say about doctor-patient interactions and care
23	Jannse n [54]	2010	New Zealand	Hospice care	Physic ians (non-specia lists in palliat ive care)	13	5:8	Not reported	Semi -structu red intervi ews	Interpret ative phenome nology	Better understand the nature of medical care from the perspective of people approaching the end of life
24	Johnst on [55]	2006	UK	Acute hospita l / hospice	Expert palliat ive care nurse s	22	Not reported	Not reported	In depth intervi ews	Phenome nology	Study the perceptions of patients and nurses on palliative care

25	Johnston Taylor [56]	2003	USA	Oncology	Nurses	21	10:11	Not reported	Semi-structured interviews	Miles and Huberman's approach to analysis	Determine what patients with cancer expect from nurses with regard to having their spiritual needs addressed
26	Kendall [57]	2006	UK	Primary care	Physicians (GPs)	14	7:7	35-70	Discussion groups	Action research	Involve patients with cancer and their carers in designing a framework for providing effective cancer care in primary care
27	Kvale [58]	2010	Norway	Oncology ward, regional hospital	Nurses	20	10:10	25-80	Interviews	Phenomenology	Clarify how and why patients' perceptions of nurses' knowledge about cancer and its treatments relates to quality care
28	Lafferty [19]	2011	UK	Oncology ward	All HCPs	47	0:47	Not reported	Focus groups	Thematic analysis	Explore the concept of continuity of care from the perspective of women diagnosed with breast cancer
29	Laird [59]	2015	UK	Variety of hospital wards	Nurses	26	7:19	Not reported	Narrative interviews	Structural analysis	Illuminate the experiences of patients of care received in hospital wards during an intervention programme to develop patient centred practice
30	Larabee [60]	2001	USA	Medical/surgical ward	Nurses	199	107:92	Mean: 39	Written comments	Qualitative descriptive study	Identify dimensions of nursing care quality from patients' perspective
31	Levine [61]	2012	USA	Ambulatory care	Physicians, nurse practitioners & physician assistants	168	50:118	21-70+	Telephone interviews	Critical incident technique	Determine (i) how patients and clinicians define quality care, (ii) in what ways patients' and physicians' definitions differ and (iii) whether patients' definitions vary by ethnicity
32	Lundgren [62]	2007	Norway	Obstetrics	Midwives	96	0:96	Not reported	Analyses of transcripts	Qualitative secondary analysis	Clarify central concepts of the woman-midwife relationship
33	McLaughlin [63]	2000	Northern Ireland	Illicit drug users	All HCPs	20	13:7	18-56	Focus groups	Thematic analysis	Clarify how illicit drug users experience being cared for

34	McLean [64]	2013	Australia	Obstetrics	All HCPs	6	0:6	31-41	Semi-structured interviews	Thematic analysis	Clarify how women who have miscarried experience being cared for in hospital
35	Mok [65]	2003	China	Palliative care	Nurses	10	6:4	40-78	Open ended, unstructured interviews	Phenomenology	Explore aspects of nurse patient relationships in the context of palliative care
36	Nolan [66]	2005	UK	General practice	Physicians (GPs)	60	23:37	24-67	Semi-structured interviews	Thematic analysis	Aspects of the relationship between doctors and depressed patients that enhance satisfaction with primary care
37	Pejner [67]	2015	Sweden	Geriatric ward	Nurses	18	6:12	80-96	Semi-structured interviews	Grounded Theory	Clarify processes that contribute to emotional support
38	Quirk [68]	2008	USA	Community	Physicians	46	16:30	Not reported	'Think aloud' exercises, video rating & focus group discussions	Cognitive scale development	Define caring behaviours, to create a 'patient centred' caring attitude checklist
39	Radwin [69]	2005	USA	Oncology	Nurses	22	7:15	27-82	Semi-structured interviews	Grounded theory	Clarify how patients perceive the attributes and outcomes of quality nursing care
40	Richardson [70]	2002	UK	Community hospice care	Nurses	12	5:7	35-80	Semi-structured interviews	Phenomenology	Identify and describe palliative patients' perceptions of factors within the interaction with palliative care nurse that enhance feelings of health and wellbeing
41	Rush [71]	2006	UK	Community care	Nurses	96	Not reported	Not reported	Focus groups	Phenomenology	Identify what makes a good nurse
42	Schmidt [72]	2003	USA	Academic medical	Nurses	8	3:5	Mean:	Interviews	Grounded theory	Discover patients' experiences of care in hospital settings

				I centre				55.8 5			
43	Schroder [73]	20 06	Swe den	Psychia tric care (in- and out- patient)	Nurse s and physic ians	2 0	Not repo rted	24- 64	Semi structu red intervi ews	Phenome nographic approach	How patients perceive the concept of quality of care in the psychiatric setting
44	Ziebla nd [74]	20 11	UK	Lymph oma care (in NHS)	Physic ians and nurse s	4 1	19:2 2	27- 84	In depth intervi ews	Thematic analysis – constant comparis on and axial coding. Narrative analysis	Illuminate the disparity between public perceptions of NHS Care and individuals' experiences

Table 4: Summary of main findings.

Theme (Patients experienced ...)	Description	Sub-theme	Description	Illustrative quotations	Resource Number
Competence	Patients experienced caring when HCPs applied knowledge and skills to meet patients' needs proficiently.			I just want them to be really competent and really good at what they do – and that makes me feel good. [50]	1,3,5,7,8,12,15,16,17,20,23,24,27,30,31,34,39,41
Positive attitudes	Patients experienced caring when HCPs displayed positive attitudes; for example, sincerity, kindness, and respect			You could tell from his attitude that he was very strong, very positive, very confident, that he could help me. His confidence made me feel relaxed. [38]	2,3,6,8,13,15,16,19,21,22,29,30,34,37,38,39,40,41,44
Effective communication	Patients experienced caring when HCPs effectively communicated with them.	Talking	Patients experienced caring when HCPs choose their words carefully, made helpful comments and answered questions.	[Doctors should] ...tell everything there is to know, not just what doctors think you should know. [42]	7,10,14,22,25,31,38,41
		Listening	Patients experienced caring when HCPs spent time listening to them.	There is one oncologist who is absolutely splendid ... very willing to listen to what I wanted in the way of therapy, how I felt...I can't speak too highly of him. [53]	10,12,14,15,17,24,25,31,36,38,41,44
		Non-Verbal Behaviour	Behaviours, such as appropriate body language and eye contact were experienced as caring.	A smile does a lot. [56]	9,15,19,20,22,38,41
		Sharing knowledge	Communication which led to the effective sharing of knowledge was experienced as caring.	They always explain what the medication is and what it's for, and that's the main thing. [69]	2,10,13,14,17,18,19,20,26,27,34,36,40,41,42,44
Relationships	Patients experienced caring with meaningful relationships	Trust and respect	Being valued, with mutual trust and respect was experienced as caring.	With a trusting relationship, as patient I could tell her everything I need ... The nurse was not only a	4,6,11,16,20,31,32,35,38

	<u>that made patients feel comfortable and at ease.</u>			healthcare professional, she was also a good friend, part of the family. [65]	
		Patient s as individu als	<u>Being treated as an individual, with account being taken of patients personal values was experienced as caring.</u>	The oncologist said, “so tell me about yourself” . . .I was so stunned because nobody had ever said that. . .[usually] you’re just a melanoma or a bunch of symptoms. [69]	1,2,4,6,8,10,14,15,18,20,21,23,24,30,32,35,39,43
<u>Being helped to navigate clinical services</u>	<u>Caring was experiencing HCPs as genuinely wanting to help, being supportive, guiding and encouraging.</u>	<u>Caring was internally motivated</u>	<u>Caring was experiencing HCPs as genuinely wanting to help; being motivated by a genuine desire rather than status or pay.</u>	That’s the difference, the real difference – we get the feeling that they really care [70]	7,10,11,13,14,16,18,20,22,25,29,35,38,43
		<u>Caring was continuing</u>	<u>Continuity of care was experienced as caring. Temporal relationships fostered trust.</u>	Familiarity, I want him to remember me and what my problem was the last time I was there so we can pick up from that and keep on going [18]	5,9,11,20,25,28,36,44
		<u>Caring included patients</u>	<u>Patients’ experienced caring when HCPs involved patients in their care.</u>	My GP. . .is absolutely fantastic. She says to me “this is what I think, what do you think? We can do this or this, what do you think?” [69]	2,4,9,20,21,22,23,26,29,32,39,42,43
<u>Emotional engagement</u>	<u>Caring was knowing HCPs were emotionally engaged, accessible, and easily contactable.</u>			I didn’t want them to go, to leave me. I knew that it was a safe place that I came to but the ambulance personnel gave me a sense of security that I know I would not get there [at the emergency ward]. In the emergency ward I have to ask for everything, no one asks me, no one sees anything. The only thing they give me is a button to push if I want something. [37]	1,2, 6, 8, 13,14,18,19,20,22,23,24,26,28,30, 32,35,37, 38,40, 42 43