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Gillespie, H., Kelly, M., Duggan, S., & Dornan, T. (2017). How do patients experience caring? Scoping review. *Patient Education and Counseling*, 100(9), 1622-1633. Advance online publication. <https://doi.org/10.1016/j.pec.2017.03.029>

Published in:

Patient Education and Counseling

Document Version:

Peer reviewed version

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

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1 **How do patients experience caring? Scoping review**

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22

23 **Abstract**

24 **Objective**

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

27 **Methods**

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

32 **Results**

33 43 articles straddled nursing, medicine, and physiotherapy, and a wide range of care settings.
34 Patients experienced caring when competent professionals displayed positive attitudes,
35 communicated effectively, formed relationships, helped them navigate clinical services, and engaged
36 emotionally.

37 **Conclusion**

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

40 **Practice Implications**

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

44 *'The essence of the practice of medicine is that it is an intensively personal matter.'*
45 Francis Peabody 1927 [1]

46 1. Introduction

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

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

71 One way of resolving the paradox would be to reach consensus on a definition of caring. Authors
72 have, however, disagreed whether that is worth doing. On one hand, defining caring has been
73 described as 'approximately 350 years out of date' [8]; on the other, researchers have continued to
74 define it. [9] They have usually done so within specific professions or care settings, which limits the
75 applicability of their work. The idea that caring means different things to doctors and nurses is long
76 established. [1] Nurses have laid claim to caring as the essence of their profession [4,10,11] and
77 nursing journals regularly publish primary and secondary research on the topic (for example [4,12–

78 14]). As well as in medicine and nursing, caring has been researched in physiotherapy [15,16] and
79 interprofessional team working. [9] But when the concept of caring has been made more general by
80 widening the disciplinary mix, it has been made more specific by concentrating on specific clinical
81 settings. These include: palliative care, [9] acute internal medicine, [17] primary care, [18] oncology,
82 [19] and the management of irritable bowel syndrome [20] and substance abuse. [21] Curriculum
83 leaders are in a bind. Regulators require them to graduate caring, pluripotent, interprofessional
84 health workers, yet professionals have only been able to define caring in specific professions or care
85 contexts, if at all.

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

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

108 What is lacking is a synthesis of patients' experiences of caring that draws from more than a
109 single profession and/or clinical context and has a conceptual orientation. Our aim was to
110 summarise empirical research into patients' experiences in order to promote caring as a core
111 condition for the work of health professionals.

112 2. Material and methods

113 2.1 Conceptual Orientation

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

125 2.2 Research team

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

130 2.3 Procedural steps

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

134 2.3.1 Identifying the review question

135 Our starting assumption, justified earlier, was that caring is a fuzzy concept that cannot be
136 defined but exists in patients' experiences. We met personally, conferenced via the Internet,
137 corresponded by email, and discussed the results of a pilot search. Throughout this and the
138 following stages, we followed the phenomenological process of discussing our preconceptions and
139 biases in order to attend to the essence of patients' experiences rather than our own. We defined 'a
140 patient' as any individual receiving any form of healthcare delivered by any healthcare professional
141 (HCP) in any setting. This mandated a broad search, including an unlimited range of types of patients
142 and healthcare providers. The wording of our review question was: *"What is known from existing
143 publications about the qualities, attributes, and behaviours of healthcare professionals that patients
144 experience as caring?"*

145 2.3.2 Identifying Relevant Studies

146 A librarian helped devise a preliminary search. This was piloted in MEDLINE, refined, and tailored
147 to search across six databases. Table 1 shows how searching and selecting evidence complied with
148 'STARLITE' criteria. [33] We devised a search syntax by separating the research question into its
149 component parts. MeSH-terms and text-words for care (empathy, sympathy, altruism, compassion,
150 trust, kindness, social behaviour), experience (perception) and healthcare occupation (doctor, nurse,
151 midwife, counsellor, therapist, pharmacist, occupational therapist, healthcare personnel) were
152 combined to perform the search and adapted for each database. When databases produced over
153 2000 results, we limited the search to article titles. We decided to exclude non-English language
154 articles because nuanced language might be lost in translation. Although we were searching for
155 evidence that was explicitly about caring, there were articles about relationships that, on careful
156 reading, were about caring relationships and therefore implicitly about caring. Since reflexive
157 interaction between researchers and the materials they are working with is integral to
158 phenomenological analysis, we included these articles.

159 2.3.3 Selection of relevant studies

160 Before definitively selecting articles, we conducted a calibration exercise to evaluate and increase
161 the reliability of article selection. This entailed two authors independently screening a random 10%
162 sample of articles. A second exercise entailed two authors (HG and TD) reviewing the abstracts of
163 articles identified in a pilot search and a third author (MK) resolving discrepancies in their
164 application of the inclusion criteria. Fig 1 uses the PRISMA convention to show the selection stages.
165 [34] We developed, applied, and refined the inclusion and exclusion criteria shown in Table 2 as we
166 became more familiar with the nature of the evidence.

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

173 A concern that positive publication bias might have reduced the number of included articles led
174 us to repeat the search using 'uncaring' as the key search term. This identified one hundred and
175 ninety titles, of which seven matched our inclusion criteria. Review of these articles confirmed, but
176 did not add to, the results presented below. We did not include them in the results section since
177 'caring', rather than 'uncaring', was the topic of our research.

178 2.3.4 Charting the Data

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

188 2.3.5 Collating, summarising and reporting results

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

202 **3. Results**

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

- 209 1. Competence
- 210 2. Positive attitudes
- 211 3. Effective communication

- 212 4. Relationships
- 213 5. Being helped to navigate clinical services
- 214 6. Emotional engagement

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

217

218 3.1 Competence

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

227

228 3.2 Caring HCPs displayed positive attitudes

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

240

241 3.3 Effective communication

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

245 3.3.1 Talking

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

253 3.3.2 Listening

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

259 3.3.3 Non-Verbal Behaviour

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

264 3.3.4 Sharing Knowledge

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

271 3.4 Relationships

272 Patients experienced caring within meaningful relationships that made them feel comfortable
273 and at ease. Caring relationships 'connected' patients with HCPs. Such relationships gave patients an
274 experience of HCPs understanding their illnesses and how these affected their lives and activities.
275 Patients experienced similarities between caring relationships with HCPs and relationships with
276 family members and friends.

277 3.4.1 Trust and respect

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

282 3.4.2 Patients as individuals

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

288

289 3.5 Being helped to navigate clinical services

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

292 3.5.1 Caring was internally motivated

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

298 3.5.2 Caring was continuing

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

305 3.5.3 Caring included patients

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

309

310 3.6 Emotional engagement

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

317

318 **4. Discussion and Conclusion**

319 4.1 Discussion

320 4.1.1 Principal findings and relationship to earlier publications

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

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

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

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

350 4.1.2 Limitations

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

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

375

376 4.2 Conclusion

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

387

388 4.3 Practice Implications

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

395 The first practice implication is that we have provided a rich description of caring that is
396 applicable to contemporary, interprofessional curricula for practitioners at all levels of experience.
397 Its validity comes from focusing on the central focus of attention of all professionals – patients – and
398 piecing together commonalities between individual professions. This helps curriculum leaders out of
399 the awkward situation of being expected to graduate caring, pluripotent, interprofessional health
400 workers when care could hitherto only be defined in specific professions or care contexts. Its validity
401 rests on first exploring what attributes it would be desirable for graduates to show and then deriving
402 educational implications rather than the more usual reverse.

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

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

408 A fourth implication is that our account of caring promotes reciprocity between patients and
409 practitioners. The pressured conditions in which practitioners deliver contemporary healthcare

410 challenge their values and lead to stress and burnout. Reciprocity could keep their values alive and
411 serve as an antidote to stress.

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

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

423

424

425 Acknowledgments

426 We thank Ms Heather Ganshorn for helping construct and run the searches, the late Professor Karen
427 Mann for reviewing the manuscript, and Professor Gerry Gormley for encouragement throughout
428 the project.

429

430 Funding

431 This research did not receive any specific grant from funding agencies in the public, commercial, or
432 not-for-profit sectors.

433

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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

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

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	Cocksedge [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	2003	USA	Primary care	Primary care	50	0:50	18 - >55	Focus groups	Thematic analysis	Examine African American women's views

	[18]				providers						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	Physio-therapists	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	Physio-therapists	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	Halldórs-dóttir [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	Halpert [20]	2011	USA	Patients with Irritable Bowel Syndrome	Physicians (GPs, gastroenterologists), nurses	57	10:47	Mean = 41.1 (SD=14.04)	Expressive writing	Qualitative content analysis	Examine patients' perspectives on their relationships with HCPs as communicated in their expressive writing about IBS
18	Haugli [49]	2004	Norway	Patients with rheumatic disease	Doctors	26	4:22	20-80	Focus groups	Qualitative analytical processes	Evaluate what patients with rheumatic disease perceive as important in health-care encounters
19	Hershberger [50]	2008	USA	Fertility clinic	Nurses	8	0:8	33-46	Qualitative descriptive interviews	Phenomenology	Describe pregnant donor oocyte recipients' perceptions of the essence of nurses' caring behaviour
20	Hudon [51]	2013	Canada	Primary care	Physicians (GPs)	30	13:17	35-75	In-depth interviews	Qualitative description	Identify physicians' enabling attitudes and behaviours from perspective of patients

											with chronic diseases
21	Hunt [52]	1999	Australia	Intensive care unit	Nurses	12	Not reported	Not reported	Semi-structured interviews	Thematic analysis	The cardiac surgery patients' expectations and experiences of nursing care in the intensive care unit
22	Jannsen [53]	2010	New Zealand	Community hospice programmes	Doctors	13	Not reported	Not reported	Semi-structured interviews	Interpretative phenomenology	Hear what patients approaching death had to say about doctor-patient interactions and care
23	Jannsen [54]	2010	New Zealand	Hospice care	Physicians (non-specialists in palliative care)	13	5:8	Not reported	Semi-structured interviews	Interpretative phenomenology	Better understand the nature of medical care from the perspective of people approaching the end of life
24	Johnston [55]	2006	UK	Acute hospital / hospice	Expert palliative care nurses	22	Not reported	Not reported	In depth interviews	Phenomenology	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	Analysis 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 centre	Nurses	8	3:5	Mean: 55.85	Interviews	Grounded theory	Discover patients' experiences of care in hospital settings
43	Schroder [73]	2006	Sweden	Psychiatric care (in- and out-patient)	Nurses and physicians	20	Not reported	24-64	Semi structured interviews	Phenomenographic approach	How patients perceive the concept of quality of care in the psychiatric setting
44	Ziebland [74]	2011	UK	Lymphoma care (in NHS)	Physicians and nurses	41	19:22	27-84	In depth interviews	Thematic analysis – constant comparison and axial coding. Narrative analysis	Illuminate the disparity between public perceptions of NHS Care and individuals' experiences

Table 4

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 that made	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 healthcare	4,6,11,16,20,31,32,35,38

	<u>patients feel comfortable and at ease.</u>			professional, she was also a good friend, part of the family. [65]	
		Patients as individuals	<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



Figure 1: PRISMA 2009 Flow Diagram

