

Who Cares for Whom? Reciprocity of Care at the End of Life

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Abstract

This paper seeks to improve understanding of how patients perceive the physician-patient relationship near the end of life, what it means to them, and what they bring to it. We interviewed people who were dying about their experiences of care from their physicians. Using interpretive phenomenology, patients' narratives were explored. Their narratives reflected how they see themselves as people and as patients illuminating the relationship between their expectations and perceptions of physicians, the care they show for others (including physicians) and evidence of reciprocity. The benefits and challenges of reciprocity of care in the patient-physician relationship are discussed and the need to encourage physicians to recognise, value and accept care from patients as an important and mutually beneficial part of their work with people who are dying is demonstrated.

Keywords: Caring; End of life; Physician-patient; Reciprocity; Phenomenology

Introduction

As Cassell [1] describes them, physician-patient relationships are the channels "through which medical care flows" and are therefore "indispensable for the discovery and relief of suffering". The quality of the physician-patient relationship is pivotal to the quality of life experienced not only by people who are dying and their loved ones but also the professionals responsible for their care [2-7].

Patients can identify physicians and experiences that made them feel cared for [8,9]. Terminally ill patients who report evidence of receiving inadequate emotional support or are dissatisfied with physician-patient communication are more likely to seek more aggressive treatment options or the hastening of death [10]. These decisions are positively associated with poor quality of life and the onset of depression among patients and loved ones [11]. There is also evidence of correlations between satisfaction, well-being and risk of burnout among physicians in end-of-life care and how they interact with their patients [3,12-15].

Although much is known about what a physician brings to and experiences in the physician-patient relationship [3,16-18], Kellehear [18] has pointed out that "one of the major deficits in the field of sociology has been a lack of interest in the ways that dying people and doctors work with each other from the point of view of dying people themselves".

This paper explores the exchange of care from the patient's perspective. The aim is to enrich understanding of the true nature and meaning of physician-patient experiences at arguably the most challenging time for both parties-the end of a patient's life. In Western society, views of the physician-patient relationship tend to fit a paternalistic model. This can be described in terms of Transactional Analysis (TA), the underlying assumption of which is that three states-parent - adult - child exist in all people [19,20]. In keeping with the parent-child model, giving, advising (e. g. how to relieve pain), and the need for and acceptance of support are seen as largely one way. By interpreting the flow of care and support as one-way, we ignore the other social roles that a patient plays in their life which demonstrate their ability, experiences and in some cases need to care for others (e. g., parent, friend, spouse, child). Many interpersonal relationships (e. g., with friends, spouses, colleagues) are reciprocal. Since the times of Plato and Aristotle, and possibly before, many have proposed that a friendship is, indeed, what a patient-physician relationship is and must be regarded as [21]. As Bytheway and Johnson [22] remind us, care implies "active involvement in a number of one-to-one relationships, care relationships are often mutual". Other

conceptualisations of the patient-physician relationship capturing mutuality include that of 'neighbours' [23]. These conceptualisations acknowledge the patient's capacity for empathy - the cornerstone of what it is to be cared.

What evidence is there that such reciprocity is present and, as some aforementioned authors would argue, beneficial in a caregiving relationship? In informal caregiving relationships, a decline in reciprocity is thought to be likely as a care-recipient's dependency on others increases [24]. A lack of reciprocity in such relationships can lead to psychological distress for both relationship members [25]. Reciprocity of care is shown to ease the burden experienced by informal caregivers [25]. There is reason to believe that such benefits to carers would also arise in the context of a professional physician-patient relationship. A physician's role brings numerous stresses, including the emotional burden of demonstrating genuine empathy with patients. Although burnout is well recognised among physicians [26], the education and collegial support required to prevent and manage this is lacking¹ [15,27]. Over time, physicians may develop increasing emotional distance in an effort to protect themselves from the distress that patient care can bring. This approach to coping not only reduces patient wellbeing and satisfaction [24,25,27-30], but also appears to be ineffective in helping the physician deal with the challenges they face [12]. As Janssen et al. [27] asserted, for personal wellbeing, satisfaction, and effectiveness in their work, physicians need not only to care for themselves but also to be cared for by others. Recent studies of care in a social context suggest that qualities of reciprocal dependence underlie much of what is termed "care" [31]. Do patients need to care or benefit

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from caring? Buetow and Elwyn [32] offered the window-mirror model of care, based on the ethical concept of giving equal consideration to equal interests, suggesting it would “illuminate the unmet interests of patients and physicians”.

The findings presented in this paper come from interviews with people who were dying about their experiences of being cared for by their doctors. It was evident that in reflecting on being cared, far wider issues were salient for them, including how they felt about and interpreted their doctors’ behaviour.

Method

Sampling

Staff at hospices in two New Zealand cities was asked to identify people with cancer from their community Hospice programmes who would be willing and able to spend time with an interviewer. These locations were representative of New Zealand’s urban population. Thirteen patients were enlisted (from a daily case load of about 100 patients), including five males and eight females aged between 35 and 72, all diagnosed with terminal cancer. All but one was married. Participants’ demographic characteristics were representative of patients in these hospice communities. It is not known how many refused as the patients were selected by hospice staff - only one was too unwell to undertake the interview. The study was approved by the New Zealand Health and Disability Multi-Region Ethics Committee.

Data collection and analysis

We sought participants’ perceptions of their experiences with physicians using semi-structured interviews which took an interpretive phenomenological approach [33]. Rather than looking at ‘what happened’, phenomenology enables the researcher to get to know the patient and to focus on their subjective experience by hearing the patient’s voice [34]. In-keeping with the humanistic concept of medicine, it seeks the patient’s narrative and emotions regarding what happened and what it was like for them [35]. Within the framework of interpretive or hermeneutic phenomenology, attempts are made to obtain narrative accounts of actual situations rather than opinions, ideology or even “what one does in general” in order to create a text that is detailed and realistic. The interpretive nature of the hermeneutic approach allows the researcher to draw upon the language, context and their own experiences to identify meanings, some of which the participants themselves may not be able to articulate, in order to understand participants’ experiences [33] and “connect with the experience of all of us collectively” [36].

Semi structured interviews were based on prompt questions including: Did they think their doctor cared? (In these questions, we were not specific about whether this was a primary physician or a specialist although most chose to comment on specialists). What of doctors’ behaviour and language demonstrated that? For example, where they felt a doctor did care, what aspects of the doctor-patient interactions help to put the patient at ease (e.g., the time spent by the doctor, the use of eye-contact, touch, an interest in the patient’s worries?) How can doctors ensure they meet the needs of family? How can doctors rekindle a sense of hope as part of their caring relationship? Interviews were carried out by AJ, a non-medical researcher face-to-face with participant in their homes who used the same questions for all participants. Immediately after each interview field notes were made that attempted to reflect the experience of the interview. The recordings were transcribed. These tapes were then listened to whilst reading the transcript. Both authors read each transcript as a whole. The first review

of the transcripts allowed the authors to place the responses in the context of their own understanding, experience and presuppositions. Further interpretive reflection on the texts revealed themes that ran through the interviews. When data analysis was completed, these themes were organized into groups and recorded for review. The purpose of phenomenological data analysis is to derive a description of the essential features of an experience from naive descriptions and specific examples of the experience under consideration. The final aspect of this interpretive analysis involves the identification of paradigms: strong instances of particular patterns of meaning [17,37].

Recruitment and interviewing continued until data reached saturation and no new themes emerged.

Results

The views participants shared of their experiences of care were rich and varied. Their narratives showed that experiences, desires and expectations around offering and receiving care were consistent with their self-identity and a normal part of many of their relationships, including their relationships with physicians. The four themes identified are complementary and all underpin the overarching theme of reciprocity. We offer quotes to illuminate the themes. They are numerically coded in accordance with participants’ study identity. There was no evidence that perspectives on their experiences, varied in relation to participant characteristics such as gender, age or diagnosis. There were remarkably few adverse comments or complaints about doctors.

Theme 1: Self-regard and self-identity

Participants’ identities emerged vividly in their narratives. They described how they saw themselves in relation to their illness, their current role as patient and those around them, including loved ones, health care professionals and other patients. Understanding how patients view themselves provides us with insight into what they feel they bring to the therapeutic relationship.

Some showed a feeling of reduced self-worth when they spoke of themselves as a patient.

‘you feel like an idiot. . . he really made me feel I was a pest... I’m just the woman, just the silly old wife.’ (12)

Several drew on their identities as informal and professional carers.

‘I want to be proactive. I want to be in charge. Perhaps that is thanks to my background - I was a social worker.’ (10)

‘I’d like to be (with my daughter) changing nappies and helping but I haven’t been able to...’ (12)

Some patients clearly felt that they deserved respect and good care. They showed skills in self-advocacy, describing how they actively sought good care if it wasn’t forthcoming.

‘Being absolutely selfish, I was there for me. Number one in that ward was me.’ (1)

‘I started to insist on “I am special, I’m S, the only one on earth ... an individual... I said do not play with numbers please because I am not a number.’ (6)

Whereas others participants saw themselves as ‘lucky’ when care was good or, at least, seldom poor indicating a degree of surprise at times.

'I'm very very lucky; I have a wonderful G. P...he's very pro-active on my behalf, he's excellent.' (7)

'It's magnificent... They talk to you like a human being. They respect you...Prof M, he's first class...You talk to him and he listens to you. That might sound silly to you but he listens to you and he helps you.' (11)

'There's just that one nurse that ever upset me...it only ever happened once so I've been very lucky haven't I?' (4)

Theme 2: Caring relationships with others

Participants described their relationships with loved ones and other patients.

Their words reflected the feelings that such relationships evoke in them, including empathy, guilt, admiration, security, hope and purpose.

'Honestly the last 4 months even though I have been through pain... they are the best 4 months of my life...I didn't know that I had so many friends. It is unbelievable; I am loved by so many people' (6)

'(My partner) picked up - and she does cos she's amazing - picked up that I wasn't right...(she is)critical to my wellbeing and an essential part of my life.' (13)

Participants had genuine sympathy for other patients and appreciated opportunities to share and support each other.

"it doesn't matter what you talk about, you can talk about cancer or constipation or goodness knows what, they're all rife in the world of cancer ...we're all afflicted with the same type of animal eating us. They've been very good." (2)

Theme 3: Physicians as human

Some participants recognised physicians as human individuals with personal lives, imperfections, vulnerabilities and needs of their own.

'(the physicians) are not gods, they have done everything they could and it doesn't depend on them only, it depends also on the patient... It must be very hard to be considered as a god or be treated as a god or think about yourself as a god, and you are not god, you are just a human being with very small resources. They don't have anything really... they can't offer you a cure, a miracle.' (6)

'it comes to the stage they can't smile anymore because something happened to them the night before with the wives or kids' (8)

Theme 4: Reciprocity

Patients cared for their physicians. In their interpretations of physicians' behaviour, their relationships with physicians and how they felt about these, reciprocity was evident. Empathy and friendship were the basis of many feelings described.

Participants were motivated to excuse poor care.

'It was the day I was told I had cancer but it was a person I'd never seen before.... I felt very sorry for him - he told me I had cancer and walked out of the room. I don't think he could handle it.... I felt for him as well afterwards; he had the poor job of telling me and we felt there was just no support there for us; it was a pretty hard day.' (7)

Participants' empathy for physicians and students was clear.

'It's pandemonium; they're worked off their feet. It's so hard.' (1a)

'He said he felt embarrassed about the mistake he had made; and I

being very pious said to him 'oh well, you know, it's one of those things. We all make mistakes' (9)

For some participants, trust in their physician was a marker of the care they felt they shared with them.

'You can only be hopeful and know that they are doing the best they can for you' (5)

They identified or introduced an element of friendship in the relationship and wanted to support their physicians.

'I just felt relaxed with them...they're like a friend.' (4)

'I think people can make the difference as well. If you make light of it, if you go in there with a positive attitude. I always joke about dying and they are used to me now - have a bit of a joke and it lightens it. (Physicians) find it easier to talk whereas if you go in there doom and gloom then they don't know what to say.' (7)

Discussion

Our results have shown that explicit demonstrations of caring behaviour by physicians, described by Kleinman [38] as the "nitty-gritty" of caregiving, are not a prerequisite for a patient to sense and reciprocate care. Where patients described a physician who did not demonstrate care they avoided assuming s/he did not care. Using their own caring approach patients sought to fill the gap between what they perceived as the physician's capacity and intention to care and the physician's actions suggesting that believing a physician is caring and trusting them to do their best is sometimes enough.

Interpretive or hermeneutic phenomenology views a phenomenon or experience as a way of interpreting the being of human beings. The goal of study, in this case the nature of care, is to see that phenomenon in its own terms. By utilizing such methodology this study supports existing evidence that patients' experiences of care are not always the trusting and positive encounters we would hope for. Nonetheless, some patients do have the capacity to cope with care that fails to meet their expectations in addition to the challenges they face directly as a result of their illness. In challenging circumstances, some patients seek ways to resolve conflicts between expectations and reality and to empathise with others around them including their physicians. Consistent with this, when asked to describe their experiences of receiving care, patients chose to include reflections on their identities as people who, themselves, participate in an array of caring relationships across their lives. Clearly, patients viewed their role as caregivers as salient and worthy of attention. They showed their ability to offer care, forgiveness and compassion to others, including their physicians, and their sense of a person's right to receive care.

The findings suggest that patients play their part in upholding the egalitarian model of care described by Buetow and Elwyn [32]. This model proposes that patients and physicians alike are not only entitled to receive care, according to their capacity they are morally obliged to provide it. Kleinman [38] suggests that "caregiving begins with the clinical ethical act of acknowledging the situation of the sufferer, affirming their efforts and those of family and friends to respond to pain and impairment and demonstrating emotional and moral solidarity with those efforts." To the extent that patients' rationalising or excusing a lack of care was possibly a way to cope and maintain hope, it shows that patients benefit from caring for their physicians. When they perceive a physician to be struggling, some patients may compromise rather than enhance their own wellbeing however, by minimising their needs or concerns as an act of care and support for their physician [5,34,38]. It is possible that this apparent care

for physicians is a self-protective mechanism (denial perhaps) but it could also be a simple acknowledgement of their acceptance of human frailty and the need to acknowledge that physicians are vulnerable too. Kleinman [39] reminds us that "caregiving is a defining moral practice. It is the practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human". Part of our shared human nature and shared concepts requires us to have the capacity to be able to enter the subjective world of another - to be empathetic [27].

We know that as care providers, physicians' perceptions of care differ from patients' [9,13,40]. Additional data from participants in this study show that as care recipients, feeling cared for relied on displays of empathy, compassion, physicians recognising themselves and their patients as unique human beings and being willing to develop an authentic human relationship with the patient [9]. What defines caring where patients are giving rather than receiving care?

In demonstrating a desire to reciprocate care participants saw there was more to the physician than their professional role. Many appreciated that physicians are first and foremost human beings and similar to themselves in many ways with their own flaws, fears and vulnerabilities and needs for care. In this, participants drew upon the resources intrinsic to their identities as individuals experienced in caring, by offering empathy, respect, understanding, forgiveness and friendship. Whereas for physicians, care-giving may include more technical and physical offerings, we suggest that empathy, concern and regard for the physician may be elements of the patient's capacity to give care. In other words, in this context, a patient's demonstrations of empathy towards their physician amount to care-giving or as Kleinman [39] puts it as caregivers "they offer cognitive, behavioural, and emotional support."

Many patients can see that to a large extent physicians are technicians using the skills and tools available, rather than the bearers of mystery, power and wisdom some would hope and believe. But do all patients welcome the human side of a physician when that presupposes vulnerability and imperfection? Perhaps the extent to which a patient is comfortable with the level of equality a physician fosters in a relationship with them varies among individual patients. Further research is needed to empirically investigate what underlies a physician's need, in spite of many patients' desires for humanness, to present themselves as powerful through the possession of social and charismatic powers and the contexts in which such apparent power can bring comfort to patients.

Do physicians feel and perceive the care offered by a patient? For a physician's empathy to be effective it must be sensed and experienced by patients [4]. Presumably, this is also the case in reverse. This is an area for further research. Three key issues are relevant here. Firstly it would depend on what care means to a physician not only as care provider but also potential care recipient. Secondly, we need to understand physicians' expectations and perceptions of patients. The stereotypical patient role does not allow for the capacity or intent to provide care. Physicians whose perceptions of the patient role are shaped by this stereotype may misinterpret or fail to recognise care from patients. They may even create a wide 'professional boundary' in order to avoid becoming 'overinvolved' [41]. Finally, it would depend on how physicians perceive themselves, their own care needs and their preparedness to be cared for by patients. Some may actively refuse to recognise or accept care from patients given the implications this could have for their power and status. Buetow et al. [42] have demonstrated

that not only do patients who care about their physician, care more about themselves but also that those patients (and those physicians) are associated with the care recipients caring more about themselves. This finding needs to be empirically tested further; The study of Buetow et al.'s involves family physicians who are more likely to have longstanding relationships with patients and no measures of actual behaviour are reported. Nonetheless, there are possibilities for a combination of such a questionnaire with a qualitative enquiry such as is reported here to further illuminate this complex relationship.

Limitations

These participants represent a specific subset of the population of people who are dying in New Zealand. They were all of European origin, aware of the nature of their illness and prognosis. There could be a possible bias as these participants were all clearly willing to respond to the questions. There was no evidence of a relationship between participants' perspectives and their demographic status. This may be detectable in a larger sample and its potential existence is worthy of consideration in future research. We recognise these potential limitations and acknowledge that views may differ among those less willing to participate in such research.

Conclusion

In the context of palliative care, human relationship is invaluable. In its ability to bring 'a profound sense of oneness, strength and peace and an experience of what it means to be fully human' it offers physicians and their patients 'an opportunity to reaffirm purpose in life and to be profoundly transformed' [43]. In this study, participants were amenable to displays of humility, imperfection, and human fallibility by their physicians. Are physicians amenable to these aspects of themselves? The healing and supportive power of a shared humanity during serious illness is undeniable. Given this, future research and education is needed to encourage physicians to play their part in fostering this humanity with patients. Physicians must recognise the people they are caring for as caring individuals themselves, appreciate that those people may also be offering care to them and perhaps most importantly acknowledge themselves as vulnerable human beings.

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