

The good doctor: the carer's perspective*

Carol Levine

Carol Levine, MA,
Director, Families
and Health Care
Project, United
Hospital Fund,
New York, USA

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ABSTRACT – Carers are family members, friends, and neighbours who perform medical tasks and personal care, manage housekeeping and financial affairs, and provide emotional support to people who are ill, disabled, or elderly. From a carer's perspective, the primary requisite for a good doctor is competence. Assuming equal technical skills and knowledge, the difference between 'good' and 'bad' doctors comes down to attitudes and behaviour-communication. An important aspect of communication is what doctors say to carers, and how they interpret what carers say to them. Body language-stances, gestures and expression-communicates as well. Good doctors are surrounded by courteous, helpful and efficient assistants. Doctors can make two types of errors in dealing with carers. Type 1 errors occur when doctors exclude the carer from decision making and information. Type 2 errors occur when doctors speak only to the carer and ignore the patient. Good doctors, patients and carers confront the existential meaning of illness together.

KEY WORDS: attitudes, behaviours, carer, communication, compassion, competence, culture, dignity, humanities, medical education

Carers (or 'caregivers' in the USA) are family members, friends and neighbours who look after people who are elderly, have disabilities, or suffer from

chronic or terminal illness. They perform medical tasks and personal care, manage housekeeping and financial affairs, and provide emotional support. Typically such caring lasts not just for a few days or a month but for years. As a carer for my husband who suffered a traumatic brain injury in 1990, and for my mother, who died of colon cancer in 2002, I have had many experiences with doctors – good, bad and indifferent.

Arthur Kleinman, a physician and anthropologist, vividly described the carer's place in the patient's journey:

The chronically ill often are like those trapped at a frontier, wandering, confused in a poorly known border area, waiting desperately to return to their native land.... This image should alert us to the... relatives and friends who press their faces against windows to wave a sad goodbye, who carry sometimes the heaviest baggage, who sit in the same waiting rooms, and who even travel through the same land of limbo, experiencing similar worry, hurt, uncertainty, and loss.¹

The good doctor leads patients *and* their carers through this land of limbo in the most sensitive way possible, whether the ultimate destination is recovery, adaptation or death. While medical training, much of bioethics, and certainly most healthcare financing in the USA sees the chronically ill or disabled person as an isolated individual (patient, autonomous agent, or programme beneficiary), most individuals have other people in their lives who care *about* them and care *for* them in times of illness and at the end of life. They are essential in the patient's life and personhood, and must be part of the patient's care.

From a carer's perspective, the primary prerequisite for a good doctor is competence. Compassion should accompany but cannot substitute for knowledge and skills. Competence also includes knowing one's limits. While many people are nostalgic about the 'good old days' when the all-purpose, all-wise doctor knew every patient and family from birth to death, this kind of practitioner is not only out of vogue but often out of touch.

Assuming equal technical skills and knowledge, the difference between 'good' and 'bad' doctors comes down to attitudes and behaviour – communication. Family carers recalling how they heard devastating news can sometimes recount exactly

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Key Points

Assuming equal technical skills and knowledge, the difference between 'good' and 'bad' doctors comes down to attitudes, behaviours and communication

Highly technical language distances physicians from carers who are not medically trained

Type 1 errors are those that exclude the carer from decision-making, from information necessary to provide care at home, and from consideration of the consequences of a care plan

Type 2 errors occur when the doctor speaks only to the carer, essentially ignoring the patient, who may be dying or cognitively impaired

The good doctor follows through and follows up

what they were wearing and where they were standing – but not what the doctor was actually saying. The picture is clear but the sound is on mute.

Some of families' troublesome behaviour – their 'denial', their disagreements, their 'emotionalism' – comes from the very human difficulty of processing complex and often unwelcome information given in an alien environment. Sometimes, however, the carer understands the words but interprets them differently. In Michael Ignatieff's novel, *Scar tissue*, the philosopher narrator says: 'The doctor looks at Mother's PET scans and sees a disease of memory function, with a stable name and a clear prognosis. I see an illness of selfhood, without a name or even a clear cause.'² He tells the doctor, 'You keep telling me what has been lost, and I keep telling you something remains.'

Clearly, an important aspect of communication is language – what doctors say to carers, and how they interpret what carers say to them. Highly technical language distances physicians from carers who are not medically trained. Equally unnerving to carers can be the kinds of offhand professional jargon that physicians use among themselves. In Lorrie Moore's short story, 'People like that are the only people here', a radiologist tells a mother that the diagnosis of her baby's kidney tumour will not be confirmed until the kidney is 'in the bucket'.³ The mother, unable to bear this image of her baby's flesh and blood, likens the colours of the bucket's contents to a bright African flag or an 'exuberant salad bar'.

But words are not all that count. Body language says a great deal – stance, gestures and expression can communicate attitudes like 'I am running late,' or 'Your questions are annoying me,' as well as more positive expressions of concern and reassurance. And it is not only the doctor's attitude and behaviour that affect carers. The receptionist, the nurse, the lab technician – all convey the tone of the office or unit. Good doctors should be surrounded by good – that is, courteous and helpful as well as skilled and efficient – assistants. Carers should not be greeted, as I have been, by a brusque gatekeeper whose first words are: 'Can't you move that wheelchair out of the way?' That wheelchair is my husband!

Doctors can make two types of errors in terms of involving carers. Type 1 errors are those that exclude the carer from decision making, from information necessary to provide care at home, and from consideration of the consequences of a care plan. Typically this occurs when the doctor assumes that the patient's spouse or child, especially a wife or daughter, will provide the necessary care without asking about the carer's willingness or capacity to do so. Concerns about confidentiality are certainly important, but privacy requirements were not intended to keep family members in the dark. Carers who are entrusted with the patient's well-being and medical regimen must be involved in establishing a workable plan of care.

Type 2 errors occur when the doctor speaks *only* to the carer, essentially ignoring the patient, who may be dying or cognitively impaired. Carers want to maintain the dignity and autonomy of their family member. Daniel Callahan, a well known American ethicist, wrote:

Two days before my mother's death, her long-time family physician came to visit her in the hospital. My stepfather and I were there and my mother was fully conscious, perfectly able to talk. Her doctor chatted with us for twenty minutes without once looking at her, even as he was leaving the room. ...It was a stunning act of insensitivity.⁴

All that was needed was a warm greeting, a few words of comfort, a clasping of hands. Surely this basic human expression of caring should not require an advanced seminar or a special reimbursement rate.

The differences between family carers and healthcare professionals can be seen as a cultural divide.⁵ No matter what their language, ethnicity or religion, families are alike in sharing and mostly valuing their long relationships, history, interlocking obligations and love. The dominant medical culture, on the other hand, values technology, certainty, scientific evidence, and hierarchy. The good doctor has to navigate between these value systems, and it can be a hazardous trip. Most of the clashes occur because doctors and families are not, sometimes literally, sometimes metaphorically, speaking the same language. It is in these interactions – where doctors, patients and carers confront the existential meaning of illness – that the cultures of families and physicians can and must be bridged.

Carers' expectations are remarkably modest. They remember the smallest manifestations of kindness, whether in words or action. What they want is courtesy, respect and acknowledgement of their fears and hopes. Translated into behaviour, the good doctor gives information in an understandable way, responds to questions, is available or provides a knowledgeable substitute, and remembers the key pieces of personal history that make up patients' and carers' unique identities. The good doctor follows through and follows up. For some, this comes naturally; for others, this behaviour must be modelled and reinforced within the new realities of healthcare. That is a task for medical education and one that the humanities can inform and enrich.

References

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