Continuity of care

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Introduction

I define continuity of care as the uninterrupted responsibility of one doctor for a patient's care. This obviously implies personal care and links continuity with the doctor-patient relationship. Emphasizing responsibility reminds us that continuity is primarily a moral question. It is a moral question because it concerns commitment and responsibility. It is a moral question also because of the relationship of continuity to knowledge. Our ability to act justly for our patients is enhanced by our knowledge of them: the better we know a patient, the more likely it is that our actions will be in their best interests.

I will return to the moral issues later. First, I want to talk about another aspect of continuity: its relationship to healing. Healing is the restoration of a coherent sense of self in the face of serious illness or disability. In English and Dutch, the words 'heal' and 'whole' are from the same root. To heal, therefore, is to make whole. Healing is not the same as curing. Curing implies the arrest or reversal of a pathological process. A serious illness, however, is more than a pathological process: it is also an assault on the sense of self. Arthur Frank, a sociologist who had a massive heart attack followed by testicular cancer, wrote: 'When the body breaks down, so does the life. Healing the body doesn't always put the life back together again. Your relationships, your work, your sense of who you are and who you might become, your sense of what life is and ought to be – these all change, and the change is terrifying'.[1] Even when the body returns to its previous state, the person is often transformed by the experience of serious illness. When the illness is chronic, the sense of self inevitably undergoes a change.

We all know that the body can be healed without a relationship between doctor and patient: an antibiotic can be prescribed, or diseased tissue removed, as well by one doctor as by another. We know also, that people can become whole without any relationship with a healer; but all we know about medicine before modern therapeutics, and about healing traditions outside medicine, tells us that healing does occur within the context of a relationship. Discoveries about the placebo effect have simply reinforced our conviction about this. Healing in its deepest sense, therefore, requires a relationship. To suggest that one doctor is as good as another, for all purposes, is to adopt a mechanistic and industrial view of medicine in which the doctor becomes a replaceable part. Relationships do not fit with a mechanical model of medicine. Relationships grow and develop organically, in their own time and in their own way. Continuity over time is an important factor in the growth of a relationship. Of course, there are exceptions to this. Sometimes a single meeting with a person of rare quality can change our lives. Usually, however, the mutual understanding and trust on which a good relationship depends take time to grow. But duration of the relationship is not the only factor. Trust is built by the experience of trustworthiness, and this may be established very quickly in times of crisis.

The healing relationship between doctor and patient can take its place beside those other human relationships in which there are strong moral obligations and mutual commitments: the relationships between wife and husband, parent and child, teacher and student. Continuity is important in all of them, but continuity also is not simply a matter of chronological time. There are inevitable breaks of continuity in any relationship. No doctor can be available to patients at all times. A good relationship, however, requires continuity of responsibility and presence at times of great need. When parents are away at work, it is their responsibility to provide care for their child which will be as close as possible to the love which they give the child themselves. At times of great need, responsible parents will feel an intense desire to be with their child, whatever obligations they may have to others. Similarly with a good doctor-patient relationship. A responsible physician will want to provide a deputy who can give care as close as possible to the care he or she can provide, and will want also to be present

at times of great need. One of the things we seem almost to have forgotten in medicine is the importance of presence – what the French call the 'acte de présence', even when, as in the hour of death, there may be 'nothing more to be done'.[2] Continuity of care requires that, as far as possible, we are present at times of great need. Of course, this faces us with many moral choices between obligations to different patients, obligations to our families, and obligations to ourselves.

Another important element in continuity is the connection between continuity and knowledge. There is a direct association between duration of a doctor-patient relationship and the doctor's knowledge of the patient. As Simone Weil put it 'faith is the experience that the intelligence is enlightened by love'.[3] I have thought for long about Weil's meaning here. Weil speaks of 'attention' to a person: the direction of a just and loving gaze on an individual. We know a person differently in loving them. I speak of love here not in the affective sense, but in the sense of what Dostoevsky calls active love. Active love, as he says, is not so much a matter of feeling, as of 'hard work and tenacity and for some people perhaps.... a whole science'.[4] Sticking with someone through thick and thin is hard work. A doctor who knows a patient in this way has more knowledge than he or she can ever write down. Much of it is tacit knowledge which would be difficult to express in words. The same goes for the patient's knowledge of the doctor. This is why continuity of care through the patient's record, though better than no continuity at all, is no substitute for continuity of personal care. Again, love can enter into a short term relationship: chronological time is not the only factor. Even here, though, we can think in terms of continuity. For a person who is critically ill, continuity of personal care by doctor and nurse, over days or weeks, may be supremely important.

To place great value on continuity is not the same thing as saying that it should never be broken. The relationship between doctor and patient is subject to the same stresses, and has the same strengths and weaknesses, as other human relationships. So we see trust and mistrust, love and hate, betrayal and forgiveness. A relationship which has broken irrevocably should not be continued. Unfortunately, doctor and patient may be unable to face the truth about their relationship. Both understand tacitly that trust has gone, but neither is prepared to deal openly with the issue. The relationship continues, but at a distance and without its healing potential.

As long as the relationship is a good one it should not be broken. In our mobile societies, however, there are unavoidable breaks. There are also avoidable breaks, some of them of our own making – a result of viewing medicine as a mechanical process, with the physician as a replaceable part.

Unavoidable breaks in continuity

In contrast to the society which Dr. Huygen describes in his book 'Family Medicine', we, in Western Europe and North America, now live in a society in which it is usual for a person to have several moves of domicile during their lifetime. In Canada and the United States, people move house, on the average, once every five years. At first sight, this sounds highly inimical to continuity of care. But let us look more closely at the statistics. Fifty percent of all these moves are within the same municipality. In other words, they are moves which do not necessarily require a break in the continuity of relationships. Moreover, when we look at the age distribution of moves, we find that the overwhelming majority of them are children and young adults. From the age of 35 onwards, our population is much less mobile. We confirmed this in a study of attrition rates over a five year period in 32 Canadian practices.[5] In the age group 20-29, the average attrition rate over the five year period was 19.8% in males and 23.6% in females. Between 40 and 65, however, it was between 8 and 10% in males and 11.3 and 12.8% in females. Another unavoidable factor is the mobility of doctors. It appears, however, that general practitioners are not a highly mobile group. In our study, for example, only one of the 32 G.P.'s left the area in the five years.

Another unavoidable factor is the fragmentation of services in a very complex health care system – especially in the inner city. Some of these factors are unavoidable, but others are barriers to continuity which, as *Querido* has described, we have created ourselves, either as physicians or as administrators.[6] The way health services are organized, for example, can either encourage or discourage the development of teams, with close and continuing relationships between doctors, nurses, and other health professionals.

A third unavoidable factor, related to fragmentation, is specialization. When we have special needs we all want the highest level of skill available. Referral to a specialized service usually means some break in continuity, especially when admission to hospital is needed. The break can be minimized if the specialized service itself respects the principle of continuity, and if an effort is made to maintain close communication between specialist and generalist. Unfortunately, this is often not the case. Continuity is often not valued in specialized services and patients may see different doctors on different days.

Avoidable breaks in continuity

The most serious avoidable breaks in continuity in general practice are the impersonal deputizing services to which a G.P. can delegate the care of his or her patients out of usual working hours. These services may be provided by the government health care system, or by commercial agencies run by entrepreneurs. In many cases, there is no personal contact between the G.P. and the deputizing doctor, and no access to the patient's records by the deputy. To transfer the care of our patients to an anonymous deputizing service means that we can no longer ethically care for patients who are seriously ill at home unless we exclude them in some way from the on-

call system. We become 'nine to five' doctors. If we treat ourselves as replaceable parts, I think the public will very soon begin to treat us in the same way.

Other avoidable breaks in continuity occur because bureaucratic decisions produce duplication of services or make it difficult for health workers to develop working relationships among themselves. For example, the Ontario government responded to pressure from women's groups by agreeing to set up a network of women's clinics. This, in spite of the fact that Ontario is well supplied with G.P.'s and that a large proportion of these are women. The bureaucratic mind seems to work in this way; if part of the system isn't working very well, create a new part for it – the mechanistic world view again. Ghandi is reputed to have said: 'If your village barber isn't giving you a good haircut, don't go to a barber in the city: teach your village barber to do it better.'

I have already mentioned the avoidable fragmentation that results when the parts of our health care system do not respect continuity. One of the most serious problems in my own experience is poor cooperation between the primary and secondary sectors: general practice and the specialized services. In a survey of patients attending the cancer clinic in London, Ontario, two thirds of the patients were not being followed by their general practitioner.[7]

The public's preferences

What do people want from the health services? Three things, I think: accessibility, competence, and personal continuity. We must not make the mistake of regarding these as unrelated and mutually exclusive. Accessibility and continuity are two sides of the same coin. A doctor who is not accessible is not providing continuity. And continuity of incompetent care is not be recommended.

Knowledge and continuity

Let me now return to the moral issues by continuity of care. I have mentioned that knowledge is related to continuity. Knowing a person in this way means entering into the narrative of their life.

This knowledge provides a framework for making difficult ethical decisions that is not available to those without this knowledge. Let me give as an example a case presented to students as an exercise in medical ethics. A woman reports to the family doctor that her husband, a diabetic, is lying on the sofa at home with severe pain in the foot. The toes are going black and she fears he has gangrene. The patient refuses to let her call the doctor and will not be persuaded. According to the rules of medical ethics, one could argue that respect for the patient's autonomy requires that we do not visit him unless he requests us to do so. The family doctor, however, would probably argue as follows: 'I have known this man for 10 years. From my knowledge of him I feel sure he would act differently if he were fully informed about his condition and the treatment available to him. I also feel that our relationship is such that he would not view a visit from me as an attack on his autonomy. He knows that, if he refuses treatment after we have discussed the options, I will respect his decision. Irrespective of the rules of ethics, I will visit him.' The knowledge that continuity give us is a precious and undervalued asset. Failure to take this into account is a flaw in the rule-governed approach which dominates ethical teaching.

We live in a mechanistic world, dominated by the utilitarian values of production. The mechanistic world view is associated with a utilitarian outlook on things. Relationships tend to be judged by their results rather than by their intrinsic merits. I am sure that those of us who believe in continuity of the doctor-patient relationship will be asked to justify our belief in terms of results. I expect we will be able to do this. I expect for example, that continuity of personal care – for patients with serious illness – will give better results than fragmented and interrupted care. I would expect the results to be better in terms of patient's suffering and response to treatment, and in the cost of care. In the latter case, my experience is that fragmentation and discontinuity lead to overinvestigation, duplication of tests, and excessive intervention.

Above all, however, I do not advocate the continuation of good relationships only because of their good results. I do so because of their intrinsic merits. A good relationship between people is good in itself. One day, when we have replaced our mechanistic world view with a more organic one, we will understand this.

References

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