Humanity and continuity

Iona Heath

Roland Barthes, the French literary theorist, philosopher and semiotician, died in 1980. His last book, written shortly before he died, is a meditation both on photography and on the loss of his mother who had died three years earlier. He writes:

> 'I must interrogate the evidence of Photography, not from the viewpoint of pleasure, but in relation to … love and death.'[1]

In this paper, I want to argue that our task, as general practitioners, is to follow Barthes and interrogate the issue of continuity of care in relation to love and death and that, if we do so, we must move beyond the reductionist findings of biomedical science.

This position is supported by the English writer, George Steiner, who argues that the phenomenon of music demonstrates that rational, scientific investigation can never describe human experience completely:

> 'Music authorises, invites the conclusion that the theoretical and practical sciences, that rational investigation will never map experience exhaustively. That there are phenomena 'at the centre' ... which will endure, boundlessly alive and indispensable, but 'outside'. … Music is significant to the utmost degree; it is also, strictly considered, meaningless.'[2]

Steiner explains that the more a piece of music matters to us – means for us – the less possible it is to explain why:

> 'The more captive our delight, the more insistent our need of and 'answering to' a piece of music, the more inaccessible are the reasons why. It is a platitude to observe that music shares with love and with death the mystery of the self-evident.'

Continuity matters because there is more to being human than rationality. There are phenomena, like music and love, the importance of which is beyond evidence. Some aspects of human life cannot be proved and do not need to be proved. Continuity is another such aspect. Who ever heard of evidence-based love or evidence-based music? Why do we allow ourselves to be backed into a position where we must produce scientific evidence to confirm the importance of continuity of care before it can be valued?

Relationships are fundamental to human existence and human beings seek to create enduring and trusting relationships in all spheres of life. Medicine cannot be an exception because relationships help to create meaning and meaning mends.[3] One of the key roles of the doctor is to provide patients with an explanation of what is happening to them. A plausible explanation that can be understood by the particular patient within the individual context of their own life-story helps them to feel less afraid and more hopeful. This optimism seems actively to promote recovery. Physiological processes, meanings and relationships are all interconnected and the interactions between patients and those who care for them can either diminish or exacerbate symptoms and suffering.[4] Meaning has biological consequences[5] and can both harm and heal.[6]

Meaning affects the outcome of biomedical interventions. It is invested in the form, colour[7] and reputation[8] of medication, in the attitude of the doctor to the patient, in the degree to which the doctor believes in the treatment he or she is prescribing, and in the quality of the relationship[9] between the doctor and the patient. All of these affect the outcome of medical care.[10]

John Berger suggests that meaning is dependent on the passing of time – on continuity:

> '... when we give meaning to an event, that meaning is a response, not only to the known, but also to the unknown: meaning and mystery are inseparable, and neither can exist without the passing of time. Certainty may be instantaneous, doubt requires duration; meaning is born of the two.'[11]

This seems to make sense of the research finding that the patient reporting that he or she knows the doctor is more important than any strict counting of consecutive consultations.[12]

In recent years, it has been in the interests of the economically and politically powerful to minimise the importance of the subjectivity of the doctor and to reduce the role to one of a competent technician. In this context, any doctor will do and the role and importance of continuity is systematically eroded. The sadness is that this is occurring just when the science of psychoneuroimmunology is beginning to explain mechanism by which continuity of care, and the meaning invested in it, help the patient to mend.

Slowly, we are beginning to understand more of the complex relationships between individual subjective experience and the working of the body's immune system and autonomic nervous system. This understanding begins to explain the ways in which positive and negative emotions can support or weaken the healthy functioning of the human body. Meaningful human relationships promote positive emotions and actively support the body's capacity to mend itself.

Anthony Giddens, the British sociologist and former director of the London School of Economics, has written about trust:

> 'For trust is only demanded where there is ignorance - either of the knowledge claims of technical experts or of the thoughts and intentions of intimates on whom a person relies.'[13]

This is the key. The doctor is not just a purveyor of technical expertise but, privy to the most intimate stories, becomes also an

Auteursgegevens

Iona Heath is huisarts in Londen. Ze is voorzitter van de ethische commissie van de BMJ en lid van de Human Genetics Commission.

intimate on whom a person relies. Doctors must respond to both dimensions of trust: by applying robust biomedical knowledge within the context of a continuing personal relationship.

All of this becomes proportionately more important when we interrogate it in relation to death – in the care of the dying. Even the most mechanistic and reductionist of health service bureaucrats find it difficult to discount the importance of continuity in the care of the dying. However, if continuity is important for the dying, it must also be important for anyone who is fearful or suffering.

The British writer George Orwell underlined the cruelty of dying among strangers:

> 'However great the kindness and the efficiency, in every hospital death there will be some cruel, squalid detail, something perhaps too small to be told but leaving terribly painful memories behind, arising out of the haste, the crowding, the impersonality of a place where every day people are dying among strangers.'[14]

General practice provides an enduring setting within which it is possible to form relationships with patients while they are relatively well and this provides a robust foundation on which to build a meaningful response to the illness and disease that comes later.[15] When serious, life threatening disease is diagnosed, it is inevitable and appropriate that the struggle against that disease becomes the primary focus of the doctor, but when it becomes clear there is no longer any hope of improvement and death begins to approach, it is essential that the focus shifts, once again, back to the unique suffering individual and that the relationship between doctor and patient shifts from the functional 'I-It' to the full intersubjectivity of Martin Buber's 'I-Thou'.[16] 'I-It' relationships treat people as objects to be studied and manipulated for individual or collective ends and are the foundation of medical science, while 'I-Thou' relationships acknowledge the limitless subjectivity of the other and in so doing invoke and engage the subjectivity of the I. This shift involves real work on the part of the doctor.

When the disease is winning and death coming closer, it is crucial to see the person again, to rehear and rediscover their individual story, their achievements, hopes and fears – to follow the example of the British painter Frank Auerbach who, when painting a portrait, scrapes off the paint back to the canvas after each sitting, so that each time he starts afresh. Doctors too need to attempt a new portrait of the patient, one that leaves the disease behind. In doing this, the time of the individual human spirit can be detached from the time of the disease. The time of the disease is deterministic and inexorable but the time of the person remains their own and dependent on depth and intensity as much as duration.[17] Doctors can only use different dimensions of time if they work longitudinally across time by providing continuity of care.

The Danish researcher, Heidi Bøgelund Frederiksen, highlights the fact that successive consultations do not necessarily create continuity.[18] If there is no genuine understanding in the first consultation and the patient is not taken seriously, then there is no added value in the second and only a mechanical relationship is achieved. However, if the first consultation works, so that the patient feels recognised and heard, there is definite added value in a second consultation and the possibility of establishing a trustful relationship of mutual recognition.

Anthony Giddens also emphasises the intrinsic mutuality of the benefits conferred by personal continuity of care:

> 'Trust in abstract systems provides for the security of day-to-day reliability, but by its very nature cannot supply either the mutuality or intimacy which personal trust relations offer.'[19]

A continuing relationship has the potential to benefit both patients and doctors and to make their interaction immeasurably more rewarding than a succession of brief contacts between strangers.

Undervalued and underused, continuity of care is being slowly lost and this loss evokes the poetry of TS Eliot:

> 'There is only the fight to recover what has been lost
> And found and lost again and again: and now, under conditions
> That seem unpropitious. But perhaps neither gain nor loss.
> For us, there is only the trying.
> The rest is not our business.'[20]

'There is only the trying'. Continuity demands effort, both to use it and to protect it. As soon as medicine moves beyond simple technical procedures, the benefits of practising within ongoing trusting relationships are obvious to practitioners and valued by patients. However, it is difficult for the relatively young and healthy to appreciate how important a trusting relationship becomes for those facing the profoundest fears, and young doctors with limited experience of how much easier it is to provide appropriate care to a known patient have similar difficulties. When most of the electorate and most policy-makers and politicians are also relatively young and healthy, the promotion and support of trusting relationships within health care are unlikely to be awarded the priority they warrant and the current policy situation within the UK bears this out. Nonetheless, our responsibility is to keep trying.

Literatuur

1 Barthes R. Camera Lucida. London: Vintage, 2000.
2 Steiner G. Errata: an examined life. London: Phoenix, 1998.
3 Moerman D. Physiology and symbols: The anthropological implications of the placebo effect. In Romanucci-Ross L, Moerman DE, Tancredi LR (eds.) The Anthropology of Medicine: From Culture to Method. Westport: Bergin and Garvey, 1997.
4 Kleinman A. The illness narratives: suffering, healing and the human condition. New York: Basic Books, 1988.
5 Phillips DP, Ruth TE, Wagner LM. Psychology and survival. Lancet 1993;342:1142-5.
6 Hahn RA, Kleinman A. Belief as pathogen, belief as medicine: "Voodoo Death" and the "Placebo Phenomenon" in anthropological perspective. Medical Anthropology Quarterly 1983;14:3+16-9.
7 De Craen AJ, Roos PJ, De Vries AL, Kleijnen J. Effect of colour of drugs: systematic review of perceived effect of drugs and of their effectiveness. BMJ 1996;313:1624-6.
8 Branthwaite A, Cooper P. Analgesic effects of branding in treatment of headaches. BMJ 1981;282:1576-8.

9 Ekeland TJ. The healing context and efficacy in psychotherapy: psychotherapy and the placebo phenomenon. International Journal of Psychotherapy 1997;2:77-87.
10 Di Blasi Z, Harkness E, Ernst E, Georgiou A, Kleijnen J. Influence of context effects on health outcomes: a systematic review. Lancet 2001;357:757-62.
11 Berger J, Mohr J. Another Way of Telling. Cambridge: Granta Books, 1989.
12 Schers H, Van den Hoogen H, Bor H, Grol R, Van den Bosch W. Familiarity with a GP and patients' evaluations of care. A cross-sectional study. Fam Pract 2005;22:15-9.
13 Giddens A. The Consequences of Modernity. Cambridge: Polity Press, 1990.
14 Orwell G. How the poor die. In Bamforth I (ed.) The Body in the Library: A Literary Anthology of Modern Medicine. London: Verso, 2003.
15 McWhinney IR. The essence of general practice. In Lakhani M. (ed.) A Celebration of General Practice. Abingdon: Radcliffe Medical Press, 2003.
16 Downie RS, Jodalen H. "I-Thou" and "Doctor-Patient": a relationship examined. In Jodalen H, Vetlesen AJ. (eds.) Closeness: an ethics. Scandinavian University Press, 1997.
17 Roy DJ. Waiting for the (un) expected - experiences of time in palliative care. Journal of Palliative Care 1998;14:3-4.
18 Frederiksen HB. Relationship between patient satisfaction, relational continuity and trust. WONCA Europe Poster BP21, August 2006.
19 Giddens A. The Consequences of Modernity. Cambridge: Polity Press, 1990.
20 Eliot TS. East Coker. 1940.

Discussie

Onvoldoende bewijs voor thiazolidinederivaten bij diabetes mellitus

Jaap van der Laan, Edmond Walma

Het Farmacotherapeutisch kompas en NHG-Standaarden

Het gebeurt maar zelden dat de medicamenteuze adviezen van een NHG-Standaard niet overgenomen worden in het *Farmacotherapeutisch kompas* (FK). Bij de positionering van pioglitazon bij diabetes mellitus in het FK 2007 is dit wel het geval. De Commissie Farmaceutische Hulp (CFH), verantwoordelijk voor de uitgave van het FK, weegt op basis van zelfstandig literatuuronderzoek beschikbare richtlijnen en stelt het advies in het Kompas vast. Het terughoudende farmacotherapeutische beleid van de NHG-Standaarden sluit in de meeste gevallen goed aan bij de opvattingen van de Commissie. Het is dan ook opvallend dat de medicamenteuze adviezen van de nieuwe NHG-Standaard Diabetes mellitus type 2 in het FK maar gedeeltelijk gevolgd worden. De standaard beveelt metformine, sulfonylureumderivaten en pioglitazon als bloedglucoseverlagende orale middelen bij diabetes mellitus aan.[1] Pioglitazon is daarbij alleen geïndiceerd als aanvullende behandeling bij diabetespatiënten met centrale obesitas en cardiovasculaire aandoeningen in de anamnese als de diabetes onvoldoende gereguleerd kan worden met metformine alleen en zij geen verhoogde kans hebben op hartfalen. De CFH volgt dit advies niet. Omdat gegevens over de bijwerkingen en effecten op de langere termijn ontbreken, ziet de commissie alleen een plaats voor een thiazolidinederivaat (ook glitazon genoemd) indien de combinatie van metformine met een sulfonylureumderivaat wegens contra-indicaties of intolerantie niet mogelijk is, terwijl de voorkeur uitgaat naar orale behandeling.

Auteursgegevens

J.R. van der Laan, huisarts te Utrecht; Afdeling Huisartsgeneeskunde Erasmus MC, dr. Molewaterplein 50, 3015 GE Rotterdam: dr. E.P. Walma, huisarts.

Correspondentie: info@praktijkbinnenstad.nl

Mogelijke belangenverstrengeling: JvdL en EW zijn beiden lid van de Commissie Farmaceutische Hulp van het College van Zorgverzekeringen.

Eén trial naar de effectiviteit van glitazonen

Voor de orale behandeling van diabetes mellitus zijn 2 glitazonen op de markt: pioglitazon en rosiglitazon. Inmiddels is één gerandomiseerd dubbelblind onderzoek gepubliceerd. Dit betreft de PROactive-trial bij 5238 patiënten uit de eerste en tweede lijn met diabetes mellitus type 2, centrale obesitas (gemiddelde BMI 30,9) en tevens een cardiovasculaire ziekte in de voorgeschiedenis.[2] Pioglitazon werd toegevoegd aan bestaande behandelingen met orale antidiabetica en insuline. Gekeken werd naar het effect op cardiovasculaire aandoeningen of overlijden. De in het onderzoeksprotocol gedefinieerde primaire uitkomst was niet statisch significant verschillend tussen placebo- en pioglitazongroep. Het ging hierbij om de gecombineerde uitkomst: mortaliteit door alle oorzaken, niet-fataal hartinfarct, CVA, acuut coronair syndroom of perifeer arterieel vaatlijden met noodzaak tot arteriële interventie of amputatie.

Een secundaire uitkomst in het PROactive-onderzoek was wel significant. Ook hier betrof het een gecombineerde uitkomst: mortaliteit, niet-fataal myocardinfarct of CVA. In de pioglitazongroep bereikten 301 patiënten deze secundaire uitkomst tegenover 358 patiënten in de placebogroep (RR 0,84; 95%-BI 0,72-0,98; absolute risicoreductie 0,02; NNT 50). De uitval in beide groepen was vergelijkbaar.
Patiënten in de pioglitazongroep werden gemiddeld maar liefst 4 kg zwaarder dan in de placebogroep. Deels moet dit het gevolg