

## article

# *Caring for the Elderly*

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### **Introduction**

Leon Trotsky once wrote that old age is the most unexpected of all the things that can happen to a man (Trotsky, 1997, p.334). What was true of the turbulent days in which he lived appears not to be true in developed countries at the end of the millennium. Improved standards of health care delivery have ensured that many citizens survive well into their seventies, eighties and beyond. Indeed this fact alone poses considerable problems for governments who find the burgeoning costs of caring for these elderly populations to be amongst the heaviest demands in their health care budgets. Not only they but also both large numbers of the elderly themselves, who have to cope with declining quality of life and multifactorial illness, and their informal carers, who have often with great difficulty to manage these conditions in the context of their family lives, inherit new demands. These various demands presented by the growing numbers of older people pose ethical problems some of which are identified and discussed in this paper.

Yet Trotsky's observation still retains a ring of subjective truth. People's perceptions of old age and their acceptance of it vary greatly. As someone has pointed out old age is always at least fifteen years away (Baruch, 1955). It is certainly not possible to determine at what age one has become old to everyone's satisfaction. These rival perceptions also pose ethical issues in the provision of elderly care, some of which will also be taken up in what follows.

### **Identifying health needs**

There is a temptation throughout medicine to reduce health needs to descriptions of physical or mental malfunction. The temptation finds its roots in the huge advances the application of science to medicine has produced since the Enlightenment. Thus, for example, it is commonplace to cast ill-health in terms of the presence of disease, some form of pathophysiology related to the functions of the various organs in the life of the macro organism of the body. Whilst it is true that our increased knowledge of organic function, such as Harvey's

discovery of the nature of the working of the heart, has increased our ability to treat patients it has also changed subtly our perception of what it is to be ill or unhealthy (Evans, 1998 pp34-39). For the Greeks disease was constituted by a disharmony or disequilibrium in the whole man and not simply in his body. On the Greek account it would not be adequate to identify faulty mechanisms in the various sub-structures of the body to determine the presence of disease or ill-health.

Such a view casts the professional carer in the role of objective expert on the patient's condition and medical consensus replaces the importance of the patient's experience of illness. However a good case can be made for asserting that a given physiological condition, for example, can only be identified as constituting a health need when its current or future role in the life of a person is taken into account. A condition which would cause suffering for one person might not do so for another. Indeed some conditions, such as sterility, are regarded as a blessing by some whereas they are the cause of great suffering to others. Similarly, the degree to which a physical condition interferes in the life of an elderly person can affect our judgement as to whether it constitutes a form of ill-health or not.

There are special difficulties which attach to this determination in the case of the elderly. For example in the development of clinical priority access criteria (CPACs) in the context of the National Waiting Times Project for elective surgery<sup>1</sup> it has been proposed that narrower bands of illness states than those suggested by whole services such as ophthalmology be devised in order to prioritise patients according to urgency of need. This, as we shall see later, is called for in order to avoid injustices caused by making improper comparisons between various illness states. Thus cataract patients might be reasonably ranked in order of need when compared with each other but not so readily with glaucoma or entropion sufferers, which conditions have considerably different profiles and implications (Evans and

Price, 1999 pp45-6). However there are special difficulties which attach to the implementation of this suggestion in the case of many elderly patients who suffer co-morbidities. A given individual might score only moderately in a number of specific disease conditions none of which individually might interfere with that person's life to an unacceptable degree. The result would be that the patient would not be able to access elective procedures in the public health service for any of those problems. Yet taken together they might have a devastating effect upon the life of the person. For example, moderate infirmity caused by an arthritic hip might be tolerable but when taken together with moderate impairment of hearing and sight they might make the continuation of independent life an impossibility. Short of this the combination might severely impoverish the quality of life of the patient by robbing her of her only pastime of reading. Aside from the cost consequences of providing institutionalised care for such patients one has to note the personal consequences for them too. Their well being is grossly impaired whereas an intervention to deal with but one of those conditions could make the difference between a dependent or independent life, or a full or impoverished existence. Insofar as this is true their health needs could be considered to place them highly in any ranking for elective surgery. Thus some means of allowing this element into the clinical judgement of need, together with the general issue of social significance of individual conditions, must be found.

It is here that the subjective truth of Trotsky's observation finds its most eloquent expression. It is not just difficult for doctors to access the narratives of their elderly patients. We all struggle with the task of understanding one another and the further others are removed from our own orbit of experience the harder this becomes. Rival narratives emerge in tension with each other and it takes considerable effort to access those which do not sit comfortably with our own. These narratives are informed by sets of values, preferences, biographical details and perceptions which do not find a common home amongst the rivals. For this reason the young often have difficulty empathising with the old and the old with the young. And we might all struggle for meaning in lives which appear to us to be so diminished as to be less than worthwhile. Such is often the case with understanding the elderly when their powers are in decline. But here special care is needed.

### Confusion

It is dangerous to describe old age as being a phase of declining powers for there are many who live to a great age who retain a wide range of faculties, both physical and mental. Nevertheless it is true that for many others their world becomes a very different place from the one which we inhabit, almost a twilight existence, and this is often marked by a decline in powers of memory. Such is the case with degenerative conditions such as Alzheimer's disease and with disabling conditions such those resulting from experience of stroke. We shall consider theirs as the most challenging narratives we have to access in caring for the older patient but much which is true of them will also be true of the less impaired elderly. Here above all other cases we might be tempted to assume that the life of the patient is diminished to the point of being less than worthwhile. Theirs is an existence which might appear intolerable to us and it is certainly not one which we would choose for ourselves.

Given that we have no first hand experience of such a realm as that in which these older people live where might we look for assistance in accessing their stories? We might consult with those who have cared for loved ones in such states, though their accounts might vary considerably one from another. This variety might depend on how well or badly they were able to cope with the demands which such care placed upon them. We might also tap the imaginative resources of writers who have endeavoured to get inside the heads of such sufferers and construct their world for us. Each of these approaches is represented by the work of Philip Larkin, an English poet whose mother suffered Alzheimer's disease. He also had a pathological fear of death and of growing old. In his poem *The Old Fools* he first builds a relationship with the reader by sharing his fears and his alienation from the narrative of the Alzheimer's sufferer (Larkin, 1988, stanza one).

*What do they think has happened, the old fools,  
To make them like this? Do they somehow suppose  
It's more grown up when your mouth hangs open and drools,  
And you keep on pissing yourself, and can't remember  
Who called this morning? Or that, if they only chose,  
They could alter things back to when they danced all night,  
Or went to their wedding, or sloped arms some September?  
Or do they fancy there's really been no change,  
And they've always behaved as if they were crippled or tight,  
Or sat through days of thin continuous dreaming  
Watching light move? If they don't (and they can't), it's strange:  
Why aren't they screaming?*

Larkin describes the patient's state as it strikes him, an apparently dispassionate observer. The vacant and uncontrolled expressions, the incontinence, the confusion and the physical disability and ungainliness all shock him as intolerable states in which to be. And yet what he finds so unutterably intolerable the sufferers seem to accept without complaint or struggle. Why aren't they screaming?

He soon moves on from what might appear to be a lack of sympathy with the sufferers to an effort to make better sense of their lives than the frightening constructions which he at first imposed on their behaviours. And in so doing he offers us a remarkable insight into their narratives (Larkin, 1988, stanza three).

*Perhaps being old is having lighted rooms  
Inside your head, and people in them, acting.  
People you know, yet can't quite name; each looms  
Like a deep loss restored, from known doors turning,  
Setting down a lamp, smiling from a stair, extracting  
A known book from the shelves; or sometimes only  
The rooms themselves, chairs and a fire burning,  
The blown bush at the window, or the sun's  
Faint friendliness on the wall some lonely  
Rain-ceased midsummer evening. That is where they live:  
Not here and now, but where all happened once.*

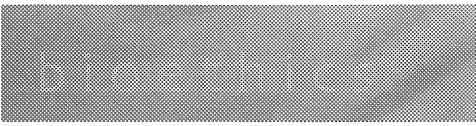
He now sees that their lives are not completely divorced from reality. They are, rather, lives still lived in the past amongst people and surroundings which once were but are no longer, mostly unknown to him but features of their biographies. Loved persons and places, familiar actions and aspects vaguely recalled and together conjuring pictures of some substance to the viewers. The patients' worlds are not entirely unrelated to ours but the connections escape their attention. Are such lives intolerable after all? Are they not worth living? The poet at least gives us pause for thought which might prevent precipitate action unnecessarily to restrict further the lives in question, which restriction might constitute a harm to the sufferers thus accelerating their decline. It might also suggest some interventions which could, in some circumstances enhance those lives, despite the frailty of memory.

Such was the case with Mrs. G, a sufferer known to me some years ago whose family story I have permission to share. Unable to live independently any longer she had been cared for in a residential home for some years. Her short-term

memory was extremely poor though she still recognised family. When it was proposed that she be taken some hundreds of kilometres to meet her brother and sister, whom she had not seen for many years, her son said that it would be a waste of time as she would not remember it. His wife insisted and it was done. To the surprise of all she recognised her siblings and for a whole weekend talked incessantly about their childhood, marriages, children and all the rest of the stuff of family life. On the return journey she fell asleep momentarily and on awaking remembered nothing of the visit. 'I told you so', said her son. 'Ah, but didn't she enjoy herself!', replied his wife. Her point was well made. It had been a worthwhile event in Mrs. G's life, remembered or not, for it had facilitated links between the past and present which some had thought long lost and provided an authentic reunion, to everyone's surprise. To have spurned the opportunity would have impoverished Mrs. G's life and, on the basis of a faulty assumption, unnecessarily restricted her range of activity.

### Competence

We have reviewed some features of decline in the lives of older persons which raise the difficult question of the determination of competence to consent to health care interventions. When precisely does that moment come in the cycle of human experience for many of which the Bard wrote so tellingly – the moment when the person moves into the last scene of all, from the sixth to the seventh ages of manhood 'second childhood and mere oblivion...' (Shakespeare, *As You Like It*, Act II Sc vii 160-165)? For many of us such a moment has arisen when parents have been deemed to be no longer capable of making such decisions for themselves. But how are such determinations made? Numbers of criteria have been canvassed to assist in the task, including the ability to comprehend relevant information, the ability to reflect on that information, the ability to envisage a reasonable outcome for the procedure in question, and so on (Roth *et al*, 1982). Whilst these appear to be objective it is impossible to separate their application from the values of the person applying them. For example, there is the celebrated case of the depressed, suicidal psychiatric patient who when offered Electro Convulsive Therapy was informed of the one in many thousands chance of dying as a result of the therapy. Her reply was 'I hope that I am the one' (Roth *et al*, 1982, p.206). The intriguing puzzle is whether she really understood what she was told. In one sense, of course, she did, for her wish to



die would have been served by the possible consequence of the therapy of which she was informed. But the puzzle is created by the fact that what she regarded as a benefit her therapist regarded as a risk. It is therefore often difficult to determine when precisely someone loses the ability, given the opportunity, to make authentic decisions. For this reason we are expected to assume that patients are competent until we have very good reason to suspect otherwise. This constitutes an important protection for many elderly people when surrogates would choose quite differently for them.

But given that on many occasions there is no room for doubt about the incompetence of some elderly patients to make treatment decisions how should we best go about making those decisions? We should aim to approximate as closely as possible to what they would likely have chosen if that had been possible. There are three ways in which we can attempt this, none of which is perfect.

First we can enquire whether an advance directive has been prepared by the person which envisages the kind of situation in which she is now placed. Such documents seem to offer us explicitly the wishes of the patient. In reality few patients will have prepared such documents and even if they have there will be difficulties attaching to their implementation. First, the documents rarely fit the specific situation in which the patient is placed. If such documents are made more precise in order to reduce ambiguity then it is less likely that they will fit the eventualities which befall the author. If, on the other hand, they are too general then the problem of whether they apply in the actual case arises. Additionally it has to be noted that such documents embody hypothetical judgements about what would be an intolerable state. The further in time their creation is removed from their application the less likely they are to reflect the patient's views of the state in question, given the greater possibility of ignorance of likely outcomes for the author at the time of writing and the possibility of change in the intervening time. For example, imagine a man whose joy in life is reading Marcel Proust. He declares that if the time should come that he can no longer read his life would not be worth living. He thus writes that in such an event no effort should be made to save his life were it in danger. Years later he is to be found in a residential home, Proust long forgotten, enjoying the trashy soap operas and game shows on TV. With the onset of his pneumonia should antibiotics be administered? One's view of what is tolerable or worthwhile might be

subject to radical change and such would not be allowed for by rigid adherence to stale advance directives.

The second ploy would be to seek a substituted judgement. Such judgements, in line with our previous discussion on accessing patient narratives, would involve those who knew the patient best, usually close relatives, employing the values and preferences of their loved one or friend to construct the judgement they think he or she might have made in the current situation had it been possible. The problem here is the suppression of hidden agendas. Thus, though it would be unwise to depend utterly on either of these approaches to make decisions for the incompetent patient, it would be negligent of the doctor to ignore any directive which existed and to refuse to consult carefully with those who know the patient best in coming to a treatment decision.

What will be called for eventually is a best interests decision made by the clinician. The clinician will have views about what constitutes the best interests of the patient and should not allow his decision to be overruled where non-compliance with clinical judgement would involve only harm for the patient. Nevertheless in coming to a view about what is harmful, consideration of the two foregoing approaches will be useful (for a thorough discussion on these matters see Brock and Buchanan, 1989).

#### Accessing care

Finally in canvassing a range of areas of ethical concerns in the care of older persons we should return to the question of access to health services. The question of what constitutes a worthwhile life has been discussed above and the question of what constitutes a worthwhile health care intervention is related to this. But older people's health needs compete with those of younger people to be met in the context of scarce resources in health care. Where rationing is the order of the day where do older patients stand with respect to purchasing policies? The National Waiting Time Project has already been referred to as an attempt to produce a fairer system of allocation of resources than the old waiting list system by ranking patients in order of urgency of need. As such it is to be applauded. However lurking behind it has been the quest for maximising the benefit produced by the health care dollar. On the surface it seems to be an ethically admirable goal to achieve as much benefit as possible from a scarce resource. In fact such a goal is in conflict with prioritising equity and

elderly people stand to lose more than any other group of patients if policies aimed at achieving this goal are adopted. The matter is well illustrated by considering the application of the Quality Adjusted Life Year (QALY) measure. This tool uses two multipliers to assess the success of health care outcomes – improvement in the quality of life and extension of life. A whole year of healthy life gained as a result of an intervention constitutes one QALY whereas a year of less than healthy life or less than a year of healthy life earn proportionately less than a QALY. Armed with such a tool health planners might go on to invest health care resources in those patient populations which promise to achieve the highest ratio of QALYs to dollars spent. Such theoretical measures are conceptually flawed in a number of respects (Evans and Price, 1999, pp17-22) but for present purposes it is important to note the net effect which their application will produce for elderly people. They will tend to fare badly on both arms of the measure. First the extension of life multiplier will tend to be ageist. Second, given that older people are amongst the group of the population most likely to suffer chronic disease, the degree to which they can expect to improve their quality of life by health care interventions is constrained. The result is that in general the QALY score achieved by the older person will be lower than that attained by younger patients and the temptation presented to purchasers will be to favour those whose outcomes enhance the performance figures of their providers. However in the process the criterion of urgency of need for ranking patients for treatment will have been superseded and injustice will result. Alternative maximisation policies apparently more user friendly to older people will inevitably tend in the same direction for the criteria of urgency of need and capacity to benefit are inevitably in tension with each other.

It is of course the case that there is a logical relation between the capacity to benefit and need, insofar as I cannot be said to need a treatment which cannot benefit me. But it does not follow from this that the degree of benefit should be built into the assessment of need. The Clinically Acceptable Threshold concept in the Waiting Times Project allows only those who stand to benefit at all as candidates for booking. But once the capacity to benefit becomes more than a threshold concept, where for example it is built into the assessment of need, equity is threatened as outlined above. It is interesting to note that there is little evidence of a temptation to run these issues together in acute care.

## Conclusion

The growing proportion of older people in the populations of the developed world present peculiar challenges in the field of health care provision. Many of these are ethical in character and call for a concentrated effort to increase our understanding of what it is to grow old. In the meantime it is incumbent upon us as morally responsible citizens to ensure that standards of care for the older person are not compromised through ignorance. Moreover it is not in the interests of any of us to neglect this duty for, other things being equal, we too shall arrive at such a place and then be judged and treated according to those perceptions and policies which we have been instrumental in forming, thus making the surprise of old age an inevitably unpleasant one.

## Notes

1. The National Waiting Times Project is a Health Funding Authority initiative designed to achieve greater equity in the allocation of elective health care services in New Zealand.

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