

# Education and debate

## Sudan: in through the back door

Hans Veeken

Médecins Sans  
Frontières, PO Box  
10014, 1001 EA  
Amsterdam,  
Netherlands  
Hans Veeken,  
*public health  
consultant*

hans\_veeken@  
amsterdam.msf.org

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"Do not worry, she will survive; she has meningitis and is on treatment. You'll see it tomorrow when it is light." William smiles confidently, sweeps his stethoscope round his neck, bends his back, and crawls out of the hut. I'm not convinced and examine the girl once more; I'm glad I brought my torch. She lies naked in the sand, obviously stiff necked, unconscious, and breathing superficially. The hut is pitch dark, and I can just see the shadows of some five relatives who cook and sleep in the same place. Except for nasogastric feeding, I have not much more to offer. I decide to follow the health worker and to re-examine the girl first thing next morning. William has received primary school education and upgraded himself to health assistant through "hands on" teaching for several years by our doctors. I feel proud but also a bit embarrassed at the ease with which he diagnoses severe illnesses so seldom seen in my home country, the Netherlands.

### The most inaccessible place in Africa

We had been dropped at the village, called Lankien, by a small plane. While landing, I noticed a crashed plane at the end of the air strip. "The pilot forgot to pull up the flaps when taking off," the pilot explained casually. Lankien is situated in south Sudan, a "country" that is home to some five million black Africans, who have been driven to the extremes of life by nature, continuous exploitation, and a seemingly never ending war against the north (since 1959) for their liberty. Areas have been cut off for years, making it the most inaccessible area in Africa. During my trip I saw only one car, broken down beside the road, and no people handled money, the economy is based on barter. Walking is the only means of travel, and it is still normal practice to use runners to carry messages from one place to another.

The tribes in south Sudan, such as the Nuer and the Dinka, are semi-nomadic cattle herders. They eke out an existence in surroundings that most people would call hostile. They can do so only by living in close harmony with their cattle: they need the cattle for survival, drinking their blood for nourishment, burning the dung to keep the mosquitoes at bay, and even using the cows' urine for washing their hair. Before coming here, I had been struck by the beauty of the living conditions in a book of photographs of the area, and during my stay I recognised the feeling so well put forward in its introduction: "It is difficult to describe the scenery and not to pass judgement on them, who are not less worthy; one should take care not to seem superior."<sup>1</sup> I experienced the same difficulties in describing what I

### Summary points

Areas of south Sudan have been cut off for years by the civil war, making it one of the most inaccessible areas in Africa with most of south Sudan accessible only from Kenya

The local tribes are semi-nomadic cattle herders, and even without the effects of the war living conditions are extremely harsh

Tuberculosis and pneumonia are highly prevalent as well as kala-azar and brucellosis

In the marshy area of the Sud malaria is an increasingly serious problem

saw. It is obvious that the people have a different concept of cleanliness, forced on them by living in an area with scarce water and in intimate contact with their cattle. That they have survived under these harsh conditions makes me feel very small.

### Clinic in the bush

Lankien and its surroundings are certainly disease ridden. I attend a clinic under a tree. People are carried in on stretchers, one even in a wheelbarrow, and others are lying naked in the sand, too sick to be bothered with privacy. The scene is chaotic and there is little structure, yet William takes his time, stays calm, and without hesitation picks out possible cases of kala-azar and brucellosis for further testing. Most of the people are skin and bone anyway, the tribes are remarkable for their slenderness and height, averaging almost six foot two inches. That afternoon I see several cases of pneumonia that are more severe than anything I have come across at home.

All the villagers have gathered to see the public performance of the doctors. If it were not for the severity of the illnesses, the scenery would carry a flavour of extraordinary beauty. Patients, mothers cradling children covered in rags (some ill, others not, but who can tell without uncovering the bodies?), bystanders, relatives, people that have already been helped, all crowd round us to watch the action. I'm reminded by the frightening sounds of throat clearing that tuberculosis is highly prevalent. Spitting is culturally accepted, and, at best, the phlegm is quickly covered with sand.

I'm aware that any unexpected movement makes me a helpless target for the flying spittle.

I decide to leave the crowd and set up practice under another tree; it will help for only a little while. I'm aware that, as a visitor, it is better for me to let things happen. I attend a woman who is lying on the ground too weak to cough. "TB," says William, "I will show you the AFB tonight." A boy is screaming and seems to be having a fit. I examine him but cannot find anything abnormal and suspect psychosis. Afraid to miss out any disease, I examine him twice. In between the attacks he behaves normally, and I let him go with diazepam. But he will not go and continues to scream during the whole session, forcing me to examine him a third time. In the twilight a woman is brought in with an abscess of the hand, smelling offensively, caused by a human bite. We end up performing a debridement under ketamine, right under the acacia tree (long live ketamine and thanks to Maurice King for his instructions).

After the clinic William and I retreat to our camp in the dark and relish our meal of pasta and tuna—what a delight. The team has seen 70 patients in that afternoon, of whom several needed hospital admission, but there is no such facility within reach. The camp is lit by the stars, as the moon is not yet up. A barrel that serves as an incinerator provides some light and warmth. Flames leak round its edges, and we hear unexpected popping sounds. "These are the empty ampoules," says William. We still hear children moaning on the other side of the fence. I tell William that I'm more worried about children who do not cry. James, another health worker, is still busy colouring slides in the light of an oil lamp. James and William have moved out of their tent to let me sleep comfortably; they will bed down on the floor of the hut that serves as the kitchen. I tell them that one of them can, of course, sleep in the other empty bed in the tent. It is a bit odd to offer them one of their own beds. Laughing, they answer, "We both can," and before I'm undressed they are already snoring.

## Further south

The next day we are off to Panyagor, and for the first time I'm lost in the air. "There is the Jonglei canal," the pilot points out with relief. At last he has found a landmark. The digging of the canal, to bypass the world's largest swamp, has been stopped by the war, and the dry canal bed has a surrealistic appearance from the air. I was worried; dark clouds are closing in, and without adequate visibility it would be difficult to land anywhere. "They gave me the wrong coordinates," the pilot says. Flying extremely low, we follow the dirt road next to the canal until we see people waving a sheet. "We will land there," he says, and we skim over the children's heads to get them off the airstrip. Hurriedly, we are dropped off, and the plane is back in the air before the rain starts. Children fight to carry our luggage, the lucky ones place the cases on their heads, and the troop moves on. We hop on bicycles for an hour's ride to the health centre. Within minutes one of us has a flat tyre, the thorns have no mercy.

Ronnie, a Kenyan who teaches laboratory assistants, shows me his laboratory. "I'm proud of my job," he says. "I must exhaust my knowledge and train my brothers. They might in their turn help my children later, it is my duty." He shows me the working files and

the examination questions he has made. To my surprise I see *Hymenolepis nana*, a little tapeworm I have never come across except during my own training. The course seems quite detailed, and I wonder secretly whether I would pass his examination. "The students sometimes look sleepy," Ronnie says. "In fact I found out that they are not sleepy but hungry, so I give them a cup of tea and they can continue. Can we not get food?" he asks with a big smile. The hospital is located in an old veterinary centre. Ronnie shows me his classroom, formerly the stable to breed cattle for research. The hospital is small, yet serves its purpose.

In the evening we cannot miss out the local Dinka dances. We pass soldiers with AK47 rifles slung over their shoulders. But the real warriors gather on an open space and dance to the rhythm of a drum, covered in dust, ashes, and feathers. They jump high in the air to impress the women. We meet some of Ronnie's pupils. There is a small incident because one of them spots the woman who refused to marry him. "She refused," he says, "because I'm not pretty enough." His friends roll with laughter. "She says she is prettier than I am. What do you think?" His friends beat me on the shoulder, and he does not seem to be embarrassed at all.

Later we sit in a "mosquito proof cage" outside. It looks a bit odd, but this lounge is a success and we are not bitten. We discuss the possibilities of extending our activities. The Sud is a vast marshy area of papyrus and water plants as large as England. It is where the Dinka retreat to fish and to find water for their cattle in the dry season. These days, more people are moving to the marshes because of food shortages and security. Living conditions are harsh out there, and I'm told that malaria is increasing. It seems an area in need. "The mosquitoes fly right into your mouth when you talk," Sammy tells me. "They sting you through your jeans. You have to eat like this." Sammy waves his left hand continuously before his opened mouth to chase away the imaginary mosquitoes. I doubt if any of us would be able to live and work under these conditions for longer than a couple of days. It seems difficult to decide where to work in south Sudan. I contemplate simply throwing a dart at the map of Sudan and start working wherever it lands.

1 Nomachi K, Moorhouse G. *The Nile*. Hong Kong: Odyssey Productions, 1989.



In the dry season the Dinka migrate with their cattle to find fresh grazing

TEUN VOETEN

*Health needs assessment***Needs assessment: from theory to practice**

Andrew Stevens, Stephen Gillam

**This is the third in a series of six articles describing approaches to and topics for health needs assessment, and how the results can be used effectively**

Department of Public Health and Epidemiology, University of Birmingham, Birmingham B15 2TT

Andrew Stevens, *professor of public health*

King's Fund, London W1M 0AN  
Stephen Gillam, *director, primary care programme*

Correspondence to: Professor Stevens

Series editor: John Wright

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The purpose of needs assessment in health care is to gather the information required to bring about change beneficial to the health of the population. It is generally, but not universally, accepted that this takes place within the context of finite resources.<sup>1</sup> "Health gain" can therefore be achieved by reallocating resources as a result of identifying four factors:

- Non-recipients of beneficial healthcare interventions (that is, unmet need);
- Recipients of ineffective health care (and releasing the resources for unmet need);
- Recipients of inefficient health care (and releasing resources for unmet need); and
- Recipients of inappropriate health care (for whom the outcomes could be improved).

The subjects of healthcare needs assessment are the populations and patients who are recipients or potential beneficiaries of health care. Populations, of course, include individual patients. The assessment of individuals' needs may form part of the assessment of a population's needs, but it may be costly and it risks ignoring individuals with needs who do not present themselves for health care. Table 1 shows the circumstances favouring individual needs assessment for planning purposes.

The priority attached to different needs, whether of populations or of individuals, raises philosophical problems. For example, should the principal criterion be the benefit that could potentially be obtained for each individual, or the severity of their presenting condition?<sup>2</sup> In other words, should greater priority (a greater assessed need) be attributed to the need for surgery of a patient with early stage colorectal cancer or to the need for hospice care of a terminally ill lung cancer patient? In practice the former, the approach that favours the greater benefit, takes precedence in formal needs assessment, but not exclusively. In either case, cost enters the equation. Some marginal benefits cannot be afforded in a publicly funded system because of the other treatments and benefits that need to be sacrificed to fund them.

New practitioners of needs assessment are emerging. *The New NHS* white paper requires primary care groups to contribute to health authorities' health improvement programmes, "helping to ensure that they reflect the perspectives of the local community and the experiences of local patients."<sup>3</sup> More general practitioners will therefore face the dilemmas that needs assessment is intended to tackle.

**Table 1** Factors determining basis for assessing healthcare needs

	Individual basis	Population basis
Case load	Light	Heavy
Cost per patient	High	Low
Hidden patients	Few	Many
Variability in case mix	High	Low

**Summary points**

Healthcare need is the capacity to benefit from health care

The assessment of population benefit includes a measure of epidemiology (how many) and of cost effectiveness (how good)

Other sources, especially comparisons and corporate knowledge, can contribute usefully

An optimal approach requires good information gathering, clinical involvement, and a close relation to the planning process

**From theory to practice**

Different frameworks for healthcare needs assessment have reflected different purposes as well as different times and contexts.<sup>4</sup> The life cycle model, for example, is a framework which encourages needs assessors to think comprehensively about different population groups of different ages.<sup>5</sup> It is an attractive model because of its simplicity, but it does not distinguish need and demand or emphasise the pivotal theme of "capacity to benefit."

A particular purpose of healthcare needs assessment is the spatial allocation of resources. Geographical equity of regions, districts, and even localities (such as housing estates) can be addressed by global and surrogate measures of health, particularly deprivation indices and standardised mortality ratios.<sup>6</sup> Measuring relative deprivation is a step forward from approaches that do not distinguish need from supply and demand, but relative deprivation cannot be used to specify precise needs for service planning; measuring deprivation indicates whether Burnley is less well resourced than Belgrave but does not help in deciding the number of coronary care beds needed in either.

The definition of "need as the capacity to benefit" represents a further advance because it can be directed at specific services.<sup>7-9</sup> It has generated new practical approaches in an area of sometimes paralysing controversy. Four points apply to needs assessment undertaken both at the level of health authority and general practice:

- The population's ability to benefit from health care equals the aggregate of individuals' ability to benefit. For most health problems (but see table 1) this can be deduced more readily from epidemiological data than from clinical records.
- The ability to benefit does not mean that every outcome will be favourable, but rather that need implies potential benefit, which on average is effective.

- The benefit is not just a change in clinical status but can include reassurance, supportive care, and the relief of carers. The list of beneficiaries of care can extend beyond the patient to families and carers.
- Health care includes not just treatment but also prevention, diagnosis, continuing care, rehabilitation, and palliative care.<sup>8</sup>

Such benefits are ideally assessed by an approach that combines epidemiological factors and cost effectiveness, supplemented by “corporate” and “comparative” methods.<sup>8,9</sup> All of these methods include the enumeration of current services. But other contemporary approaches to service related assessment of needs should be noted: not just population healthcare needs assessment but also social services assessments, individual healthcare needs assessment, participatory and Oregon-style planning, population and client group surveys, expert specialty recommendations, and clinical effectiveness research.<sup>10</sup>

The usefulness of these approaches can be assessed with the following criteria:

- Is the needs assessment about populations or individuals?
- Is there a clear context of allocating scarce resources (are the needs assessed in the context of priority setting among competing needs)?
- Is the needs assessment exploratory or definitive (is the object to clarify what should be done or just to highlight problems that are accompanied by no obvious intervention)?
- Is the determination of the most important needs based on expert knowledge or participatory methods?

Table 2 shows how other approaches compare with population healthcare needs assessment on the basis of the capacity to benefit. In population healthcare needs assessment the concern is with the health of populations with a common condition or presentation—for example, all patients with diabetes (known or not known) on a practice’s list. It recognises that resources are finite and avoids focusing on advocacy for individual groups without considering competing priorities. It is definitive rather than exploratory in that client groups are considered together with actual interventions (this is not a feature of, say, some lifestyle or disability surveys), and the needs are determined by expert appraisal of the evidence rather than principally through public participation. However, any approach that contributes information on numbers in a particular group (incidence and prevalence), the effectiveness and cost effectiveness of interventions, and the distribution of



JANE SMITH

current services and their costs will be useful in practice.

### Defining baseline services

Measured needs only take on meaning in relation to the existing services. Needs assessment is about change, and it is essential to know what to change from as well as what to change to. Several steps are involved. Firstly, the service under consideration has to be disaggregated into meaningful units. For example, mental health can be split up into adult, elderly, child, forensic, substance abuse, etc. Adult mental health could then be further subdivided as services for long stay, short stay, day care, community treatment, and so forth. Each of these encompasses a variety of different interventions. There follows a decision on what to measure. Structural factors such as bed capacity, staffing levels, and costs provide a powerful starting point. Measurement of process (for example, throughput) and outcomes (for example, death rate) will have little meaning unless case mix and severity are well defined. A plausible mental health baseline service specification focusing on structure and cost is set out in table 3. The emphasis is on obtaining the information needed to summarise existing levels of service as succinctly as possible.<sup>11</sup>

### Corporate approaches

The “corporate approach” involves the systematic collection of the knowledge and views of informants

**Table 2** Different approaches to healthcare needs assessment<sup>10</sup>

Criterion	Basis	Is resource scarcity clear?	Definitive or exploratory	Expert or participatory
Population healthcare needs	Population	Yes	Definitive	Expert
Individual healthcare needs	Individual	Sometimes	Definitive	Expert
Social services assessments	Individual	Sometimes	Both	Both
Participatory planning	Population	Sometimes	Definitive	Participatory
Oregon-style planning	Population	Yes	Definitive	Both
Population surveys	Population	No	Exploratory	Expert
Client group surveys	Population	No	Exploratory	Both
Specialty recommendations	Population	No	Definitive	Expert
Effectiveness reviews	Population	Yes	Definitive	Expert

**Table 3** Example of table of baseline services<sup>11</sup>

Resource name	Resource function	Capacity	Unit cost	Notes on quality and performance
Acute ward A	Acute assessment	Beds	£1000/bed	Nurse morale problems
Community team B	Community support for mild or stable conditions	Places	£1000/place	Poor coordination with general practice
Long stay facility C	Long stay and dementia	Beds	£1000/bed	Being run down

on healthcare services and needs. Valuable information is often available from health authority staff, provider clinicians, and general practitioners, as well as from users. The box lists possible informants. Although such an approach blurs the distinction between need and demand and between science and vested interest, the intimate, detailed knowledge of interested parties amassed over years might otherwise be overlooked. Furthermore, the corporate approach is essential if policies are to be sensitive to local circumstances. Eliciting local views is not the same as being bound by them. This approach allows sensitivity to local circumstances, particularly those consequent on historical provision. The unmet needs of discharged seriously mentally ill people from closed long stay hospitals or the absence of primary care for homeless groups may be uncovered only by speaking to people. Where cost effectiveness considerations are otherwise equal, local concerns may justifiably attach priorities to particular services. Furthermore, local experience and involvement will make any needs assessment easier to defend.

#### Comparative approaches

The “comparative approach” to needs assessment contrasts the services received by the population in one area with those received in other areas. If nothing else is known about the optimum service to be provided, there is at least reason for investigation if the level of service differs markedly from that provided elsewhere. Comparisons have proved to be powerful tools for investigating health services.<sup>12–15</sup> For example, the need to raise renal dialysis and transplantation levels from 20 per million in the 1960s to 80 per million was indicated by comparison with European countries and subsequently confirmed epidemiologically.<sup>14</sup> New performance indicator packages are being piloted in both primary and secondary care.<sup>15</sup> Although they require sensitive interpretation, comparative process and outcome indicators may help identify deficiencies in provision of services.

#### Epidemiological and cost effectiveness approaches

The essence of needs assessment is an understanding of what is effective and for whom. Critical steps consist of:

##### Corporate informants

- General practitioners
- Hospital doctors
- Nurses and professions allied to medicine
- Public health doctors
- Commissioning managers
- Trust managers
- Voluntary organisations
- Community health councils
- General public
- Patients (service users)

- A clear statement of the population group whose needs are to be assessed (normally a group with a particular disease). In the case of a needs assessment for diabetic services, this might include people who have not yet been diagnosed; in the case of substance misuse it would include past, present, and potential misusers;
- Identifying subcategories of this population (perhaps “health benefit groups”) with particular service needs. People with insulin dependent diabetes would be distinguished from those with non-insulin dependent diabetes; current, dependent substance misusers would be distinguished from intoxicated misusers, those with comorbidities, those in recovery (at risk of relapse), and those at risk of becoming new users;
- Setting out the prevalence and incidence of the subcategories: how many of each are there?
- Setting out the current services available (the baseline)—all services whether in primary care, secondary care, or elsewhere;
- Identifying the effectiveness and cost effectiveness of interventions and the associated services—the essence of evidence based health care; and
- Setting out a model of care that apportions relative priorities.<sup>9–10</sup>

As a general rule, establishing the effectiveness of an intervention must be the most important step. There is little point in counting potential beneficiaries for an intervention which is of no benefit. Most challenging of all is the task of apportioning relative priority to different services and recipients. Cost effectiveness must be taken into consideration. The use of unitary cost-utility measures can be helpful if these are available, and decision matrices render decision making more explicit. However, flexibility around patients’ particular circumstances is often required.

#### Managing the task

Several challenges are commonly encountered in understanding needs assessment. Firstly, the mosaic of information required for needs assessment reflects its key components: the services already in existence, the prevalence and incidence of client groups (sub-categorised appropriately), and the effectiveness of interventions. The evidence based medicine movement has meant that information on effectiveness can more easily be obtained,<sup>16–17</sup> but this is not true for information on epidemiology or services provided. Good quality local data on the structure and utilisation of health services can be surprisingly difficult to obtain. The absence of common disease definitions, common classification systems, and compatible software—and the partial recording of activity—limits the value of many databases.<sup>18</sup>

The triangulation of information sources is therefore critical. Useful information can be either local or national, either numerical or textual, and collected either routinely or ad hoc. The figure sets out

key items for the needs assessors.<sup>19</sup> The task is greatly aided by skilled librarians with access to a basic range of texts and databases. National sources of epidemiological and effectiveness data offer assessors of health-care needs a firm starting point for their work.

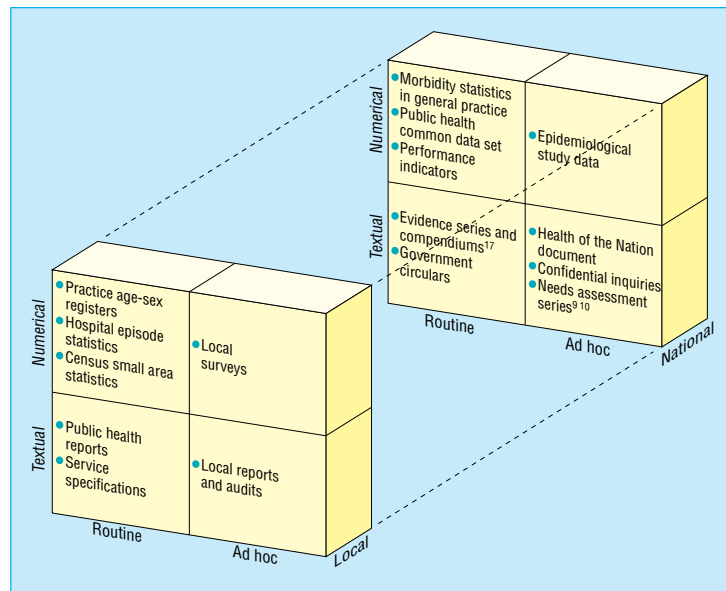
A second challenge is the involvement of health professionals in healthcare needs assessment. The traditionally individualistic approach of doctors in particular may be difficult to reconcile with the utilitarian approach of planners with a population focus. This focus implies a fundamental reappraisal of the doctor's role and the balance of power within the doctor-patient relationship.<sup>20</sup> It is also important not to neglect the contribution of other health professionals. For example, in primary care much information is collected by community nursing staff, and health visitors' skills in particular are easily overlooked.<sup>21</sup> Even where doctors and nurses have a population focus, needs assessment has opportunity costs; not everyone can devote time to it. At the very least, target efficiency—directing services to the people who will potentially benefit the most—requires doctors' involvement.

Thirdly, needs assessment is futile if it does not result in improved services to patients. A key to successful needs assessment is the proper understanding of how it is related to the rest of the planning process. Too much needs assessment is divorced from managers' deadlines and priorities. If the information and recommendations produced are not timely, they will not be useful. The results of needs assessment therefore need to be encapsulated in strategies or business plans. These need clear definitions of objectives: describing what needs to be done, by whom, and by when.<sup>22</sup> The key to effecting change is an understanding of the opportunities that may facilitate and the obstacles that may obstruct what is being attempted—knowing which “levers” to use. An understanding of the sources of finance, their planning cycles, and the criteria used to fund new initiatives is essential. Health authorities and health boards clearly indicate the timing of development bids and the structure of applications they wish to be submitted.

A fourth challenge is to ensure that needs assessment is not just effective but efficient and cost effective. Little is known of the cost effectiveness of needs assessment, but at least one survey found that it led to service change at little cost.<sup>23</sup> Evaluation of different purchasing models should help clarify the population sizes for which needs assessment for different services is most efficiently undertaken.<sup>24</sup>

## Conclusion

In practice, although needs assessment represents an amalgam of epidemiology, economics, and values, it has to be turned into a practical tool. But making needs assessment practical can have two unfortunate effects. Firstly, it is unhelpful to see the outcome of needs assessment as a document—the culmination of a series of easily defined, finite steps. Rather, needs assessment is an iterative, sometimes messy, process that may serve several different political purposes. The most important of these is to develop a consensus among planners, managers, and clinicians regarding priorities for service development. Secondly, needs assessment is



Examples of sources of information

too easily seen as some arcane preserve of public health specialists. The technical skills required can be exaggerated.<sup>25</sup> Basic numeracy and common sense are the most important prerequisites.

The current approaches to needs assessment may be limited by time and context. Much needs assessment activity was stimulated by the advent of an internal market and by doubts about the cost effectiveness and appropriateness of care. Health authorities and general practitioners in their role as purchasers require detailed service specification for the first time. However, with increasing evidence of the equivocal efficacy of many healthcare interventions, delayed uptake of effective health care,<sup>26</sup> unexplained geographical variations, and rising costs, the concern with capacity to benefit within finite resources is unlikely to wane. The rhetoric may change, but the demand for increasingly sophisticated approaches to needs assessment will intensify.

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## Coping with loss Loss in late life

Brice Pitt

This is the ninth in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

Department of Psychological Medicine, Imperial College School of Medicine, Hammersmith Hospital, London W2 0HA  
Brice Pitt,  
emeritus professor of psychiatry of old age

Series editors: Colin Murray Parkes and Andrew Markus

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Old age can be seen as a succession of losses, gradual or sudden.<sup>1</sup> Stopping work means a loss of the working role, of the companionship of fellow workers, and of a full, structured day; it means a reduction in income—and, for those who live with someone, less time apart. Some people feel much diminished by retirement, hardly know what to do with themselves, and suffer a loss of status. Most developed societies do little to enhance the image of the “senior citizen,” who is liable to be patronised, marginalised, or simply ignored and is seen as a problem for an overburdened welfare state.

There is a view, though, that successful ageing means compensating for some losses by making the best of change. So, the strains of having to commute, living for the job, and struggling to keep up are also lost; some pensions are at least adequate; there are concessions that make life a little cheaper for the over 60s. Having more time to oneself, for hobbies and interests, and to spend with partner are often regarded as benefits. Though it is usually a sudden event, retirement is (unless there is unheralded redundancy) expected and there is time to prepare for it.

### Many types of loss

Sensory loss afflicts most people as they age. Presbyopia is readily remedied by glasses, presbycusis less readily (or perhaps less acceptably) by hearing aids. These are very gradual processes, usually accepted without distress, though blindness or severe deafness is a different matter. Some memory loss may be normal with ageing; speed seems to be affected more than secondary memory, and verbal IQ is very well preserved.<sup>2</sup> “Benign” memory impairment<sup>3</sup> presents no serious problems, apart from the fear of dementia—which is, unfortunately, realised in a fifth of people over 80.<sup>4</sup>

It is not often acknowledged, except as a rueful and ribald joke, that loss of sexual enjoyment is common and distressing, and not an inevitable part of ageing.<sup>5</sup>

### Summary points

In old age comes a succession of losses: dementia occurs in 20% of those over 80; loss of sexual enjoyment is common but not inevitable; half of octogenarians live alone

Depression in elderly people is often unrecognised; it is often caused by loss and, in turn, causes further losses

Preparation for retirement, health checks for the elderly, continued access to education, and the use of “at risk” registers can mitigate some of the problems of old age

The rationing and limitation of social support for the elderly is not justified

Hormone replacement therapy and prostaglandins may do much to restore sexual function and enjoyment, but some older people are too shy to seek help, fearing that they should be “past it” and may be regarded as ridiculous or as “a dirty old man” (or woman).

The risk of serious health problems—stroke, myocardial infarction, heart failure, falls and fractures, arthritis, obstructive airways disease, cancer—increases with ageing,<sup>6</sup> though many old people are spared serious infirmity until a short final illness. Those who are less fortunate suffer loss of comfort, mobility, and life expectancy. There is a risk of being widowed, especially for women, which represents a major loss after 40 years or more of being together.

Secondary to health problems (which make it difficult to get out and about), to reduced means (for transport and entertainment), and to the dying off of friends and family is isolation, which may be accompanied by loneliness. In Britain, about half of people 80 and over live alone,<sup>7</sup> and the extended family is stretched very

thin by distance and relatively small numbers of children. Another secondary consequence of ill health, and most painful of all for many, is loss of independence.

Since long term care has become ever more arbitrarily and capriciously available from the NHS, old people who own property fear loss of estate. The desire to pass on the fruits of labour, success, sound investment, or good fortune to one's family is fundamental, and the power to do so may increase an older person's self esteem. Thus the costs of continuing care add to the problems of infirmity.

Reduced life expectancy is related to age and sickness. Through life a sense of immortality gives place to the shocking awareness of inevitable death, rapidly replaced (except in time of war, epidemic, or other crisis) by a feeling that it is a long time off or by denial. Birthdays like the 40th or 50th may precipitate fears of finality and an anxious review of achievements and ebbing potential. But still denial is a powerful buffer. Old people make long term plans and refer to peers as "old" but not themselves.

A new concern, as euthanasia becomes less theoretical and more real (as already in Holland and recently in the Northern Territory of Australia<sup>8,9</sup>), may be overlong survival, where life draws on without quality and the burden of infirmity falls on the family. While euthanasia may seem a boon to some, it could be felt to be a duty by others—to stop being a drag on the family's emotional and financial resources.

## Loss and depression

With so many vicissitudes it might be expected that the morbidity for depression in late life would be high. The evidence, however, is inconsistent and contradictory. While suicide rates peak in old age (for women in their late 60s, men around 80<sup>10</sup>) rates of depression are lower in older than in younger people. The epidemiological catchment area study in the United States found a prevalence of 2-3% in people over 65—a fifth of the rate in young adults.<sup>11</sup> Using a different instrument to diagnose depression, a survey of psychiatric disorder in general hospital inpatients aged over 16 in Oxford found that depression was least common in people over 70.<sup>12</sup> Younger people might be more open, older

more guarded. Older people tend to somatise their emotional complaints, and these symptoms might erroneously be attributed to organic disease. Dementia might remove from consideration people who would otherwise have been recognised as depressed, or the researchers might have happened on an unusually contented cohort.

Rates of depressive disorders as high as 17% have been recorded in London,<sup>13</sup> and these accord with rates elsewhere in the United Kingdom found by using instruments specially designed for older respondents—the geriatric mental state examination<sup>14</sup> and its computerised form AGE-CAT,<sup>15</sup> and the SELF-CARE D.<sup>16</sup> Although the syndrome of depressive illness in late life is fairly common, the symptoms are far more so.<sup>17</sup>

Depression in old age is often undiagnosed and untreated

Why might depression be less common in older people? Depression carries a high mortality, so sufferers may not survive into old age. Today's oldest people are hardy survivors of poverty, large families, two world wars, and the pre-antibiotic, pre-welfare state era, and they tend therefore to be resilient. Possibly such benefits as central heating, television, allowances and entitlements, taken for granted by younger people, are appreciated by those who are older and once lacked them, and this offsets some of the losses; not having to work, for example, can be a great relief.

The likelihood, though, is that depression is more common in late life, but is frequently unrecognised. The evidence includes the high suicide rate, already mentioned. Barraclough's classic study of suicide in elderly people on the south coast of England showed that most were likely to have had depressive illness, had attended their general practitioners weeks before the act, and were being treated with tranquillisers, hypnotics, analgesics, and laxatives but not antidepressants.<sup>18</sup> The evidence also includes the increasing rate of first admissions for depressive illness to psychiatric units in England and Wales (though it is more marked in women, from middle life the rate increases in both sexes with every decade, falling off only in those over 85<sup>19</sup>); and the apparent failure of doctors to recognise depression in older people.<sup>20</sup> This lack of recognition may be due to lack of education, motivation ("drugs are likely to be toxic, counselling is hard to come by, and anyway it's hard to teach old dogs new tricks") or the somewhat ageist assumption that to be depressed in old age is both normal and justified.

The use of an "at risk" register and screening for depression may be good uses of finite resources



Old people suffer a succession of losses

Depressive illness in late life often follows a major adverse life event, like bereavement or acute life threatening illness, but the association may not always be that the loss precedes the depression: depression may cause loss. Depressed people do not care to take care of themselves and may become ill, have accidents,



and die from self neglect as well as deliberate self harm.

### What to do about it?

Marriage "till death us do part" was easier to honour when it usually meant 10-15 years rather than, as now, 40-50 years, as the high divorce rates in the more developed (and more aged) societies indicate. Shortage of housing is aggravated by the need of divorcees for two dwellings. A small consolation for high levels of unemployment is that, long before retirement age, many people have been prepared for not working and managing on reduced means. Others may benefit from preparation for retirement classes, and workshops are now provided by most large companies, trades unions, and professional bodies.<sup>21</sup>

"The comfortable state of widowhood is the only hope which keeps up a wife's spirits" (Mrs Peachum in *The Beggar's Opera*)

Health education not to smoke, to eat and drink moderately, to watch weight, and to take exercise may reduce ill health later in life. Health checks, either at set times (like the 75th birthday) or opportunistically ("as you're here, Mr Jones, tell me how you're enjoying your retirement while I check your blood pressure") are a good opportunity for health education. An "at risk" register may be a good use of finite resources for older people who have undergone recent life events—a recent move, illness, or bereavement, or who are known to have chronic infirmity or are living alone.<sup>22</sup> Screening for depression with, say, the geriatric depression scale<sup>23</sup> or BASDEC<sup>24</sup> is a good start to secondary prevention. A positive approach to the treatment of depression in old age is needed: perceiving the mood disorder underlying somatic complaints; using antidepressants with confidence, in sufficient dosage, and for long enough; and recognising the entitlement and likely efficacy of counselling for bereavement and marital problems and in the context of established depression. The consensus statement by the colleges of general practitioners and psychiatrists in 1995 was a good beginning.<sup>25</sup>

Further education is available in many daytime and evening classes and the University of the Third Age. Societies in which the fitter elders help their less able peers and seniors need not be a Utopian dream. Many retired people would and do like to "justify themselves by good works."

"Do not go gentle into that good night/Rage, rage against the dying of the light" (Dylan Thomas)

Finally, despair at the demographic time bomb, when there will be supposedly too many pensioners for the remaining workers to provide for them, may have led governments into premature, panicky withdrawal of services. In the United Kingdom, the Community Care Act aimed to contain the costs of residential care, subsidised by social security, by

transferring responsibility to local government. The consequence has been rigorous means testing, the expectation that people who have the means will contribute in part or wholly to their care, and, as budgets run short, rationing of care to those with greatest need. However, the "doomsday scenario" may be fallacious: though there will be a substantial percentage increase in octogenarians in the next 20 years or so, the increase in actual numbers will be small.<sup>26</sup>

The greatest cause of distress, dementia, may not necessarily prove to be intrinsic to aging. Donepezil can now provide temporary respite for 50-60% of people with early Alzheimer's disease,<sup>27</sup> and it is not too fanciful to expect the pace of research into the dementias to yield more lasting remedies that will offset the morbidity associated with an ageing population.

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## Statistics notes

# The intracluster correlation coefficient in cluster randomisation

Sally M Kerry, J Martin Bland

We have described the calculation of sample size when subjects are randomised in groups or clusters in terms of two variances—the variance of observations taken from individuals in the same cluster,  $s_w^2$ , and the variance of true cluster means,  $s_c^2$ .<sup>1</sup> We described how such a study could be analysed using the sample cluster means. The variance of such means would be  $s_c^2 + s_w^2/m$ , where  $m$  is the number of subjects in a cluster. We used this to estimate the sample size needed for a cluster randomised trial.

This sum of two components of variance is analogous to what happens with measurement error, where we have the variance within the subject, also denoted by  $s_w^2$ , and between subjects ( $s_b^2$ ).<sup>2</sup> One way of summarising the relation between these two components is the intraclass correlation coefficient, the correlation which we expect between pairs of observations made on the same subject. This is equal to  $s_b^2/(s_b^2 + s_w^2)$ .<sup>2</sup> We can calculate a similar intraclass correlation coefficient between our clusters,  $r_I = s_c^2/(s_c^2 + s_w^2)$ . This is also called the intracluster correlation coefficient.

For cholesterol concentration in the Medical Research Council thrombosis prevention trial the two components of variance were  $s_w^2 = 1.28$  and  $s_c^2 = 0.0046$ .<sup>1,3</sup> This gives the intracluster correlation coefficient  $r_I = 0.0046/(0.0046 + 1.28) = 0.0036$ . Such intracluster correlations are typically small. This trial had an intervention aimed directly at the patient and an outcome measurement for which the variance between practices is low compared with the variability between patients within a practice. Studies where the intervention is aimed at changing the doctor's behaviour may have a greater intracluster correlation. For example, in a trial of guidelines to improve the appropriateness of general practitioners' referrals for  $x$  ray examinations, the intracluster correlation was 0.0190.<sup>4,5</sup> We might expect the intracluster correlation to be higher in a trial where the intervention is directed at the doctor rather than the patient, because it includes the variation in the doctors' responses.

The design effect is the ratio of the total number of subjects required using cluster randomisation to the number required using individual randomisation.<sup>1</sup> It can be presented neatly in terms of the intracluster correlation and the number in a single cluster,  $m$ :  $D = 1 + (m - 1)r_I$ . If there is only one observation per cluster,  $m = 1$  and the design effect is 1.0 and the two designs are the same. Otherwise, the larger the intracluster correlation—that is, the more important the variation between clusters is, the bigger the design effect and the more subjects we will need to get the same power as a simply randomised study. Even a small intracluster correlation will have an impact if the cluster size is large. A trial with the same intracluster correlation as the  $x$  ray guidelines study, 0.019, and  $m = 50$  referrals per practice, would have design effect

$D = 1 + (50 - 1) \times 0.019 = 1.93$ . Thus it would require almost twice as many subjects as a trial where patients were randomised to treatment individually.

The main difficulty in calculating sample size for cluster randomised studies is obtaining an estimate of the between cluster variation or intracluster correlation. Estimates of variation between individuals can often be obtained from the literature but even studies that use the cluster as the unit of analysis may not publish their results in such a way that the between practice variation can be estimated. Recognising this problem, Donner recommended that authors should publish the cluster specific event rates observed in their trial. This would enable other workers to use this information to plan further studies.

In some trials, where the intervention is directed at the individual subjects and the number of subjects per cluster is small, we may judge that the design effect can be ignored. On the other hand, where the number of subjects per cluster is large, an estimate of the variability between clusters will be important.

Division of General Practice and Primary Care, St George's Hospital Medical School, London SW17 0RE  
Sally M Kerry, statistician

Department of Public Health Sciences

J Martin Bland, professor of medical statistics

Correspondence to: Mrs Kerry

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### Corrections

#### *ABC of allergies*

In the article on food allergy by Carsten Bindslev-Jensen (25 April, pp 1299-302) we should have credited the illustration of common products containing preservatives to the artist, Lesley Champkins.

#### *Hypertension treatment and control in sub-Saharan Africa: the epidemiological basis for policy*

In this article by Richard S Cooper et al (21 February, pp 614-7), the graphs accompanying the captions for figures 1 and 2 were reversed.

#### *Cervical screening laboratories should be accredited*

Clinical Pathological Accreditation (UK) points out that Health Services Accreditation is not the only organisation to publish results on the internet (News, 21 February, p 572). It has been publishing a list of fully accredited laboratories on the internet since September 1997 ([www.cpa-uk.co.uk](http://www.cpa-uk.co.uk)).