Journal of Medical Ethics 1998;**24**:268–273

Tensions in setting health care priorities for South Africa's children

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Abstract

The new South African constitution commits the government to guarantee "basic health services" for every child under 18. Primary health care for pregnant women and children under six and elements of essential primary health care have received priority. At present, there is little analysis of the moral considerations involved in making choices about more advanced or costly health care which may, arguably, also be "basic". This paper illustrates some of the tensions in setting priorities for a just macro-allocation of children's health care, given the realities of need and scarce resources, and the commitment to equality of basic opportunities.

(*Journal of Medical Ethics* 1998;**24**:268–273)

Keywords: Children; health care priority setting; justice in health care; macro-allocation; South Africa

Introduction

An intractable problem facing the transformation process in South Africa is macro-allocation of health care resources. Just priority-setting (ranking) decisions in health care provision have to be made which will inevitably require rationing health care, given extreme health care need and scarcity of resources, and social and political constraints.

How can macro-allocation, especially of health care services which go beyond a bare minimum, be done in a rational way rather than by *status quo* default? This paper illustrates some tensions for public policy if it is to achieve or approximate this goal.

Certain realities form the background to any rational discussion of these tensions. First, South Africa has a mixed public/private health care system in which the public sector plays an indispensable coordinating and material role. Less than one quarter of the population has regular access to private-sector health services.[1] Second, the national budget's health care resource allocation has to be balanced against other public commitments to improve health, such as the provision of housing, sanitation, electrification, clean water, and education. And, third, given additional, alternative sources of finance (such as social health insurance, combined with increased user fees for insured patients at public-sector hospitals), South Africa ought to be able to afford public health care services beyond primary health care and prevention.[2]

We focus on children, for several reasons. Children are particularly vulnerable, but they also have opportunities for wellbeing of a uniquely foundational kind, which are unlikely to recur in the same way in later life. Directing resources to the development of children's potential is therefore an investment with a high social return. A society that fails to show an adequate commitment to children's health might have an even weaker commitment to the health of other age cohorts. Consequently, if basic health care services are denied children, it might be even more difficult to make a case for those services being provided to other groups.

Children's rights and public policy

The South African government has confirmed its priority commitment to children. A justiciable Bill of Rights in the new constitution includes a clause which entitles every child under 18 to basic nutrition, shelter, basic health services, and social services.[3] In June 1995, the government ratified the 1989 United Nations Convention on the Rights of the Child with far-reaching implications for children's health.[4 5] To help ensure that children's rights do not remain manifesto rights, South Africa published a national plan of action using the convention, the goals of the 1990 World Summit for Children,[6] and a reconstruction and development programme as a framework. Child health and nutrition are priorities of the action plan, and targets have been set that will produce a drastic reduction in infant mortality and malnutrition among children under six.[7]

The constitution does not define "basic health services".[8] Does the term refer only to a fixed set of primary health care services made available for all children, or does it include health care for children with special needs which may be relatively

rare and costly to treat but which are nevertheless *basic* in the sense of being necessary for *survival* and *adequate functioning*? Without entering this debate, we assume public policy seeks to give content to children's constitutional right to "basic health services" by setting and implementing priorities beyond the bare minimum of essential primary health care.

Public policy implementation

The government has already taken several practical steps, beginning with the introduction of free health care for all children under six and pregnant women.[9] Subsequently, children's access to health care improved considerably, particularly among traditionally marginalised groups, such as children living in rural areas, informal settlements, and on white-owned farms.[9] However, insufficient numbers of primary health care facilities, and inadequate transport services, remain significant barriers to health care for many children. The government has embarked on a massive programme to upgrade clinics. The introduction, in April 1996, of the first stage of a national health service, with a strong public health dimension, broadened children's health care access still further. The government aims to provide an essential primary health care package which will be community-based and universally available.[10] Although the exact nature of the package has to be finalised, it is certain to include preventive and promotive care (for example, immunisation and growth monitoring), the management of common childhood illnesses such as diarrhoeal disease, and limited care for children with chronic disease and acute mental-health conditions.[11]

Not all ill health is amenable to prevention and acute management, and many children with chronic disease and disability require long term interventions. Although much of health care management and rehabilitation for all children will be delivered at community level,[11] there are still many who will need specialised, often costly, care.[12] These numbers will very likely increase as primary health care services detect children with previously undiagnosed chronic conditions and refer them for specialist care. Much uncertainty surrounds the future of specialist services, which will carry this increasing burden, since the Department of Health is committed to redistributing resources between all levels of care and away from tertiary care.[13]

Tensions in public policy implementation

Any attempt to define a rational health care policy by setting priorities for the macro-allocation of children's health care resources would have to contend with formidable tensions, given scarcity and egalitarianism defined in terms of equal constitutional rights-claims to "basic health services" which we assume reach beyond the bare minimum of health care to include specialised (but basic) health care for children with special needs. We illustrate five of these overlapping tensions.

TENSION 1: EQUALITY VERSUS MAXIMISING OVERALL WELLBEING

The first is the fundamental normative tension between two basic moral values which typically underlie distributive choices, namely, equality and wellbeing. Let us assume the constitutional guarantee of equal health care rights for children has as its underlying rationale that children should have equal basic opportunities to flourish fully as human beings by having, as far as possible, their different potentials developed to the full. Let us call this a commitment to "equality of basic opportunities", or "equality" for short. If we also assume it is rational to use scarce resources in such a way that they generate the most overall benefit or the greatest overall wellbeing, in the form of extension of life or improvement of quality of life, then we may have two conflicting commitments. On the one hand, equality requires that children have access to all those formative material conditions, such as health care, necessary for developing their potential. On the other, health care promotes wellbeing, and it is rational to strive towards achieving the most beneficial overall outcome, given scarce resources. But maximising *overall* or *total* beneficial outcome pulls against the demands of justice as equality of *individual* basic opportunities.

Put differently: given scarce resources, setting priorities based solely or predominantly on the ideal of equality would seem to require employing all resources in combating the most severe disability and disease so that every child would have at least some chance to develop his or her potential, and this could mean poor use of resources in terms of overall beneficial outcome, pouring them into the proverbial bottomless pit. However, given scarce resources, setting priorities based solely or predominantly on maximising overall wellbeing might require abandoning some children, for example, denying disabled children a fair chance of getting care since their special needs would result in their receiving less benefit from the same treatment than otherwise similar children without those special needs,[14] thus compromising the best overall outcome.

Finding a balance between equality of basic opportunities and producing the best overall outcome raises the question about the role, if any,

cost-benefit or cost-effective[15] analysis should play in the moral evaluation of health care on a *macro* level. Scales of effective outcomes based on such measurements as the quality adjusted life year (QALY) or quality of wellbeing (QWB),[16] or the more recently developed disability adjusted life year (DALY),[16 17] are typically employed in maximising cost-benefit analyses which would either contradict, or only contingently promote, equality of basic opportunities.[14 15 18 19] Moreover, the shortcomings of the cost-effectiveness approach in health care planning in South Africa are well described.[11]

In sum, equality is a constitutionally mandated ideal and realising that ideal might require not using health care resources in ways that deliver the most overall benefit. But it is rational to use limited health care resources in ways that produce more rather than less good for everyone affected by macro-allocation decisions, which might be inconsistent with creating equal basic opportunities for everyone.

TENSION 2: LOW-COST VERSUS HIGH-COST HEALTH CARE

There probably is universal agreement that basic primary health care for children should be a first priority, and government actions have been consistent with this view. However, given the realities of need and scarce resources, and the commitment to equality of basic opportunities, there is inevitable tension between providing primary health care, and providing health care for children who require more resources, for example, the chronically ill. Hard priority-setting choices have to be made because not all children can receive all advanced health care, given scarce resources, even if this care is "basic" in the sense of being necessary for survival or adequate functioning.

Identifying advanced health care services which should be included in a public health care package for children, primary health care and prevention having been secured, involves a tension between low-cost and high-cost health care, which largely overlaps with the tension between basic primary health care and more advanced health care.[18 19] Cost is a complex concept which embraces, for example, individual and social cost, material and emotional cost, and real and opportunity cost. Moreover, cost has to be weighted or balanced against other morally relevant factual considerations, such as, severity of disease, individual effective outcome, social benefit, or numbers. For example, assuming that we can determine cost, should we give priority to cheaper treatment, potentially providing small benefits to many children, or to more expensive treatment, potentially providing large benefits to a few children, for the same overall expense?[20]

Arguably, weighting cost against other morally relevant variables does not mean that, in general, no health care resources should be channelled towards individual high-cost/high-benefit treatments of smaller numbers. Doing this might, in particular cases, be the best way to promote equality of basic opportunities, even in circumstances of great scarcity in South Africa. Treatment of a relatively small number of children for chronic diseases, such as cystic fibrosis and cancer, is expensive, but it may be justified when cost is weighted against other morally relevant factors.

TENSION 3: HEALTH CARE FOR THE WORSE OFF VERSUS THE BETTER OFF

Diseases vary in severity, some children being worse off than others. Children with greater impairment of function have greater health care needs. The degrees of importance of different health care needs are measured in terms of the relative seriousness of those needs and "the harmfulness of their medical condition if left untreated".[21] There are different ways in which children can be worse off. Individual diseases have different degrees of severity. Particular diseases may be more severe in different children. Some children suffer from multiple diseases. Others have life-threatening diseases. And there are children with serious diseases which are irreversible if left untreated.

How should the commitment to equality of basic opportunities accommodate the tension introduced by variations in severity of disease or extremity of health care need? Should children who are substantially worse off than others as a result of their disease, and who therefore have a greater need for treatment, enjoy greater priority in comparison with those less seriously ill, even when a cost-benefit analysis establishes that treating the less severely ill child is more cost-effective?[20] There is a widespread social conviction that a worse-off individual has a moral claim to relatively more health-care resources than a better-off individual, but this conviction is, on the face of it, incompatible with cost-effective analysis which is biased towards services that maximise effective overall treatment outcomes while minimising overall costs.[16]

What priority should be given to worse-off children,[20] and exactly how should severity of disease be weighted against other morally relevant considerations, such as beneficial outcome and cost? These questions cannot be answered in the

abstract, but it would seem more plausible to give weighted, rather than absolute, priority to the worse off in resource allocation,[20] otherwise it would be like pouring resources into a bottomless pit.

TENSION 4: HEALTH CARE FOR LARGER VERSUS SMALLER NUMBERS

Some diseases affect larger numbers of children than others, but do numbers count morally? Is the prevalence of a disease a morally relevant consideration in priority setting for children in view of the requirements of equality? Maximising utilitarians would deal with the tension between providing health care resources to the many or to the few by setting common conditions as a high priority while giving rare conditions a low priority, unless doing so would adversely affect *overall* benefit or utility. Primary health care and prevention, which reach large numbers of children, need little argument,[17] and there is a widely held social conviction that society should give a higher priority to diseases with a higher prevalence.

Does it follow from this conviction that higher numbers *by themselves* should count morally, given a moral analysis that accepts equality of basic opportunities as a primary value? Some suggest that "it is not the prevalence of the disorder that makes it a high priority treatment but a host of other considerations, including effectiveness of outcomes and costs".[22] Consider an example with two diseases, the one high-prevalence and the other low-prevalence. Other things, such as cost, being equal, refusal to treat the latter, while treating the common condition, would be an "irrational bias against people and problems that come in small groups".[22] Moreover, giving greater numbers as such priority over smaller numbers would seem to contradict the requirements of equality of basic opportunities. From this it would follow that numbers by themselves would be an inappropriate consideration in setting priorities for children's health care.

Some might none the less argue that numbers should count by themselves in this kind of example. If other things are indeed equal in the sense that other variables are constant, while only numbers differ, what other than numbers could possibly be the basis for a rational or non-random decision? It could be argued, for example, that if resources are so scarce that a choice must be made between funding a cure for AIDS and a cure for some very rare disease which is in every respect (symptoms, prognosis, communicability, etc), other than underlying physiological cause, the same as AIDS, then it would be more rational to be guided by numbers alone rather than by random selection or a lottery. But this choice is largely hypothetical, because in practice other morally relevant factors would most likely enter into the balancing process.

Consider an example which differs from the first in that treatment for the low-prevalence disease costs substantially more per individual than for the high-prevalence disease. Here it does seem intuitively correct to give higher priority to the high-prevalence group of children. In this regard, it has been recommended that "(p)revalence should be a relevant public consideration only when, for example, a decision must be made whether to treat a rare, harmful disorder at such great cost that it stands to squeeze out treatment of a common and less harmful disorder".[23] Why would this be so? Benefit to the many by itself does not outweigh benefit to the few, but priority depends on other morally relevant variables, such as cost, as well. Numbers might appear to be overriding, but in setting priorities other morally relevant facts have to be balanced or weighted in pursuit of equality of basic opportunities.

Public-policy decisions about setting priorities (ranking) for macro-allocation need to take rational account of these four tensions. But *who* should make these decisions, and *how*? If ranking decisions follow a democratic process, new tensions are likely to arise between democratic decision making and popular prejudices against vulnerable groups of children, and between different social values which have to be balanced in the process.

TENSION 5: DEMOCRATIC DECISION MAKING, POPULAR PREJUDICES AND CONFLICTING SOCIAL VALUES

In South Africa, because of its history of excluding the majority from decision making and its policies of unjust discrimination and oppression, there is an even greater need than in stable democracies to show that any process of distribution of resources is legitimate by being open and susceptible to critical correction by wide public participation in decision making.[24] To this end, the government supports community involvement in planning health services.[10] Moreover, the government has a duty, as a signatory to the United Nations Convention on the Rights of the Child, to consult with children on all matters affecting their wellbeing[5] and this could, arguably, include setting priorities for their own health care.

As in many societies, however, popular prejudices against certain groups of children, such as the mentally disabled and those with HIV/AIDS, mean that wide public participation is no guarantee that priority-setting decisions would not be

arbitrary and unjust. There are two possible responses. First, one could build mechanisms into the democratic decision-making process to correct the most blatant forms of prejudice. For example, public-policy decision-makers should not simply mirror popular sentiments, but should be sensitive articulators and active protectors of the health care needs of all, including the most vulnerable. Other initiatives might include a minister for children in the cabinet and a statutory children's rights commissioner[25] to monitor compliance with the principles of the convention.

Second, public prejudice can, ultimately, only be combated by community education to remove the causes of bias. Community education programmes, combined with community deliberation, could "both help people see vividly the consequences of their decisions on the lives of real people and instruct them about relevant facts".[26]

Democratic decision-making about resource distribution also has to contend with tensions involving different social values, and therefore tragic choices.[27] This is illustrated by a South African study which underscores deep value differences between physicians and nurses in a neonatal intensive care unit, and mothers of recently discharged survivors.[28] Most mothers did not condone cessation of treatment under any circumstances, and approximately 40% rejected any notion of finite resources. In contrast, the medical team, acutely aware of economic constraints and the potential burden of severe handicap on families and society, exhibited strong utilitarian (cost-effective) attitudes to resource allocation. Here we have a conflict between judgments about the value of a human life and the social utility value of apportioning resources. We are forced to make a tragic choice between individual human life and the overall good, or to put a price on life.

A national forum

Since these tensions make rational priority-setting so intractable, how, in practice, should the government take forward the transformation of children's health care?

In line with the suggestion that South Africa adopts "a deliberate government strategy to foster public involvement in determining health priorities and interventions",[29] we recommend the government appoints a representative body linked, for example, to the proposed National Health Consultative Forum,[30] to generate and review priority-setting policies for the just macro-allocation of health care resources, whilst recognising the special moral claims of children to health care. It should have real powers and wide representation, including lay people, experts in various fields (giving technical advice and ethical guidance), and people who have the necessary social standing to gauge public opinion on national, regional, and local levels. The outcome must be the evolutionary development of priority-setting guidelines and policy choices for the basic but specialised health care of children, complementing the essential primary health care package now being developed.

Conclusion

Enormous social and economic problems in post-apartheid South Africa seriously limit the claims health care can justly make on total societal resources. The government has responded by shifting priorities to primary health care and implementing stringent cost containment measures. Simultaneously, it is morally and constitutionally bound to provide "basic health services", the definition of which will be crucial, for all children under 18. Given scarce resources and a commitment to greater equality in the distribution of health care, a number of formidable, and possibly irresolvable, tensions will arise, mainly between equality of basic opportunities and achieving the most beneficial overall outcome. Other tensions will be created by factors such as treatment cost, and severity and prevalence of disease. Democratic decision-making, as a method of resource allocation, creates its own tensions. Our objective was not to resolve these tensions, but to stimulate public debate on the ethical issues surrounding priority-setting in children's health care in South Africa, the absence of which will perpetuate the *status quo* distribution by default.

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