

Claims on health care: a decision-making framework for equity, with application to treatment for HIV/AIDS in South Africa

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Trying to determine how best to allocate resources in health care is especially difficult when resources are severely constrained, as is the case in all developing countries. This is particularly true in South Africa currently where the HIV epidemic adds significantly to a health service already overstretched by the demands made upon it.

This paper proposes a framework for determining how best to allocate scarce health care resources in such circumstances. This is based on communitarian claims. The basis of possible claims considered include: the need for health care, specified both as illness and capacity to benefit; whether or not claimants have personal responsibility in the conditions that have generated their health care need; relative deprivation or disadvantage; and the impact of services on the health of society and on the social fabric. Ways of determining these different claims in practice and the weights to be attached to them are also discussed.

The implications for the treatment of HIV/AIDS in South Africa are spelt out.

Keywords Claims, HIV/AIDS, equity, developing countries

KEY MESSAGES

- Trying to determine how best to allocate resources in health care is especially difficult when resources are severely constrained as is the case in all developing countries.
- A conceptual framework is proposed that assists in thinking through the claims on health care, with an application to treatment for HIV/AIDS in South Africa.

Introduction

While equal access to health care for equal need might be the stated goal of many developing country public health care systems, this equity goal is incompatible with the short- to medium-term realities faced by countries attempting to scale-up access to priority interventions. During the process of scaling-up, many in need will not have access to care (Bennett and Chanfreau 2005). Even in the long-run, resource scarcities and issues of affordability could mean that equal access to care

cannot be achieved, especially if one adds the rider of ‘care of an adequate quality’.

This paper proposes a conceptual framework that could be used to enhance equitable resource allocation in the context of resource scarcities and ongoing unmet need. The framework is based around the notion of a claim (Broome 1991) and communitarian claims (Mooney 1998), where an individual is viewed as having a claim on health care in that she/he is a member of a community or society and by extension, society

has some obligation to provide the care. However, claims are not absolute with respect to their being met. When not all can be met, society needs to allocate resources to those individuals with relatively stronger claims. There is then a need to unpack both the constituents of claims and their relative importance when adjudging equitable resource allocation.

The conceptualizing of equity in health care is difficult. We believe that to set equity in the framework of communitarian claims has certain advantages, as one of us (GM) has set out previously:

‘Given judgments about what constitute barriers and their adjudged heights, the community has the basis for assessing access or relative inaccessibility for different groups. What the community does about reducing the variations in relative inaccessibility for different groups is then based on the community’s willingness to reduce different barriers – their assessment of the strengths of claims for better access of the different groups.’ (Mooney 2009, p. 225)

While this framework has broader relevance, it is applied in this paper to the case of treatment for HIV/AIDS in South Africa. The choice of this as a case study is useful for a number of reasons. Firstly, the South African HIV epidemic poses a significant burden on the public health care system. The epidemic has grown rapidly since the mid-1980s; to date there are approximately 6 million people infected, of whom half a million are in need of treatment annually. Secondly, while effective treatment exists, a relatively low proportion of those in need have been able to access this care. Without care, death normally occurs within 10 years of infection, but with care, life expectancy is increased significantly. Thirdly, there are major concerns regarding the affordability of maintaining even the current levels of access to care (Cleary and McIntyre 2009). There are also concerns about the sustainability of donor funding on which the current programme is somewhat dependent. In sum, while health care resources are always scarce, the case of treatment for HIV/AIDS is starkly illustrative of many of the equity issues posed by unmet health care needs in developing countries more generally.

Conceptual framework

The first step in composing the conceptual framework is to agree on the constituents of claims. A review of the equity literature suggests a wide range of possibilities. These include the need for health care (defined primarily in terms of ill-health); the ‘social context’ of those in need (gender, age, income, having or not having dependents, remote/rural/urban, from minority or dominant culture, etc.); whether or not claimants have personal responsibility in the conditions that have generated their need for health care or their lack of need for care (for example hang-gliders versus joggers, respectively); the impact of the provision of care on the broader health of society (including issues of opportunity cost and allocative efficiency); the impact of illness and care on individuals, households, communities and the overall macroeconomy; and what might best be described as building bricks for a more decent society (including positive discrimination for oppressed

or disadvantaged minorities, social option values that mean that providing equal access for everyone is seen as a social benefit, etc.)

These claims can be categorized in different ways. For example, claims based on individuals’ betterment and those based on society’s betterment. Some, at the risk of double counting, may fall in both camps. For example, while the option value of equal access for equal need could be viewed as a social benefit, it also has benefit for the individual in need. Claims may also be arranged along a continuum from ‘no free choice’ to ‘free choice’.

The way in which claims are structured can take the analyst in different directions. However, we have chosen here to build on earlier work, but not specifically on claims, by Olsen *et al.* (2003) and Evans and Stoddart (1990) to present a framework based on ‘no free choice’ and ‘free choice’. (We are all too aware of the likely criticisms of this stance as many will argue that there are no or very few instances where there is genuine free choice for the individual.)

Adopting that framework however and accepting it as somewhat simplistic, many of the claims on the good noted above can be summarized as in Figure 1, which has been adapted from Olsen *et al.* (2003) and Evans and Stoddart (1990). Each claim will be discussed in detail.

Claims based on the need for health care

Claims 1 and 2 are based on need. A certain amount of moral force is often associated with the word need—to have a need for health care is different from wanting health care. The former will also usually involve some third party (often a health care professional) making an assessment while want is in the patient’s mind.

While it might be argued that need is at least one constituent of any claim on health care, there is debate about how need should be defined (Culyer and Wagstaff 1993). Two common definitions as shown in Figure 1 are need as ill-health and need as capacity to benefit from health care. Equating need to ill-health suggests that people who are ill have a claim on health care and people who are more ill have a greater claim on health care. Defining need as illness can lead to resource allocations that focus on the size of the problem as opposed to the amount of benefit that can be obtained from these allocations (Mooney 2003). On the other hand, need defined as capacity to benefit recognizes that health care can only be needed if it contributes to health (Culyer and Wagstaff 1993). However, if a disease exists that can be treated, this does not mean that it should be treated, or that it should be treated with the most effective treatment available. Given scarcity of resources, the opportunity cost of treating one need over another must be considered (Mooney 2003).

The tension between need as illness and need as capacity to benefit is relevant in the debate about the appropriate CD4 count threshold at which to initiate antiretroviral therapy (ART) in developing countries. In South Africa, a patient is medically eligible for ART if she or he has an AIDS diagnosis at any CD4 level or a CD4 count of less than 200 cells/μl at any of the World Health Organization (WHO) stages of HIV

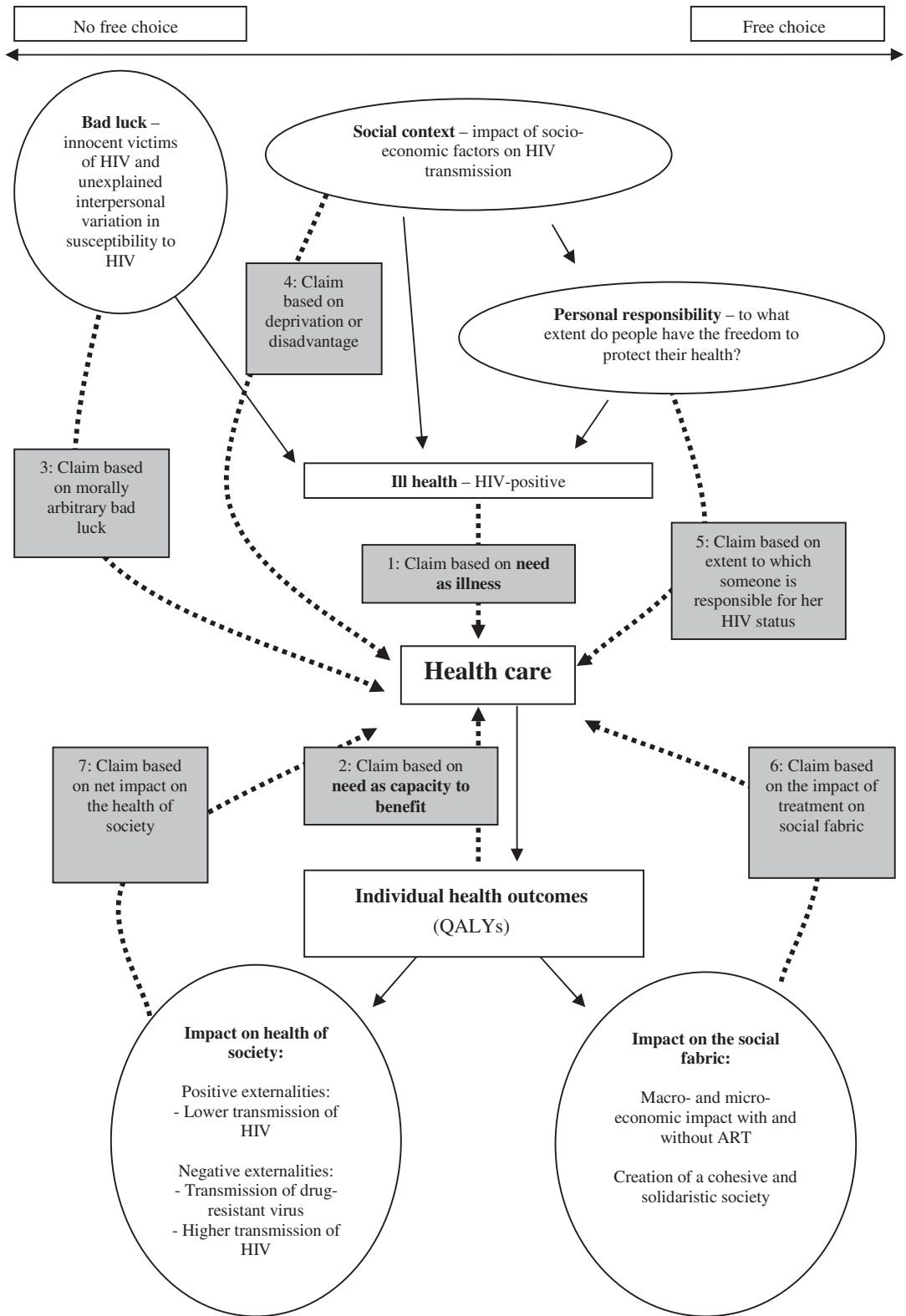


Figure 1 A framework for considering to whom the good should be distributed. Solid arrows show the causes of illness and consequences of health care. Dotted arrows show claims on the good

progression. Two cost-effectiveness studies in African settings have suggested that the incremental cost per QALY or life year gained is lowest for starting ART at $CD4 < 200$ cells/ μ l in comparison to initiating care at higher thresholds (Badri *et al.* 2006; Loubiere *et al.* 2008; Walensky *et al.* 2009); while earlier initiation is found to be more effective, it is also more costly. This means that if the HIV-treatment budget is constrained, the health of HIV-positive people would be maximized by starting treatment at $CD4 < 200$ cells/ μ l.

On the other hand, within the group of patients starting ART with $CD4 < 200$ cells/ μ l, it could be less cost-effective to delay treatment to $CD4 < 50$ cells/ μ l in comparison to starting when the $CD4$ count is between 50 and 200 cells/ μ l (Cleary 2007). If one were to define need as illness, these sicker patients would be prioritized, but if need were defined as capacity to benefit, an opportunity for a better prognosis for those who have enrolled in the programme in a timely manner would be preserved. The conflict between these two principles is likely to be of ongoing concern for health professionals in resource-constrained settings (Coetzee *et al.* 2004), particularly if waiting lists to start treatment are long and if less than full coverage of those in need can be achieved. Prioritizing the sicker patients first despite their limited capacity to benefit could also be viewed as reflective of the values underlying the rule of rescue where, while there is some potential benefit for the rescued, there is also likely to be a social benefit in that society feels better. This is again an example of how claims can reflect the betterment of the individual and society.

Claims related to responsibility and the social context

The concept of personal responsibility suggests that society's recognition of a person's claim on health care could differ if the causes of his/her illness were exogenous as opposed to being partially determined by personal risky behaviour (Edgar *et al.* 1998; Olsen *et al.* 2003). This is illustrated by a free choice continuum at the top of Figure 1. The oval in the top left-hand corner relates to having no free choice in one's health status, while presumably at the other limit one would bear full responsibility. According to Roemer, to operationalize this one would have to ensure that each individual's capacity to choose freely and/or exercise responsibility were similar (Roemer 1996; Roemer 1993). The argument rests on the assumption that there is a core of human nature that is common to everyone. Except for social context and genetic factors, people have the capacity to exercise equal levels of responsibility, but will actually exercise different degrees of responsibility because of circumstances or because of effort. Fairness allows our life paths to diverge through our own effort, but not because of circumstances that are out of our control. What this then means is that the influence of personal responsibility needs to be mediated via the person's social context, as illustrated in Figure 1.

A key consideration here is the argument put by Sen (1992) that some people have an inability to manage to desire adequately. If one accepts this proposition (and the authors do) then this means that there is then a need to identify the social context of those people who suffer from this inability and

make adjustments in their positioning on the no free choice/free choice continuum.

Roemer's approach, adjusted to take account of Sen's inability to manage desire, offers a possibility for assessing the strength of claims on a good according to personal responsibility. To do so precisely would require adequately distinguishing between the myriad social contexts of individuals. There is then a risk of penalizing people who have become unwell through no fault of their own (Williams and Cookson 2000). Yet not to attempt this may have yet greater costs as the alternative would seem to be to ignore this factor altogether.

To debate and to try to agree some broad social categorizations where judgments are made about not so much personal responsibilities but more social groupings' responsibilities is more attainable. Smokers, for example, may be too broad a category but Aboriginal smokers in remote areas may be a more acceptable category even if still not precise. Williams and Cookson's concerns here may be real but the best response is not necessarily to abandon the task but rather to approximate in the best way possible.

When applied to HIV-treatment, those who acquired HIV through blood transfusion and other accidental or forced exposure would have recourse to claim 3 on the good. This claim would also include any unexplained variation in susceptibility to HIV owing to personal genetic endowment. On the other hand, because HIV is primarily sexually transmitted, and hence potentially preventable, HIV-positive people have traditionally been subject to high levels of stigma and discrimination; the dominant stereotype of HIV-positive people is therefore one that casts them as immoral (Furber *et al.* 2004). This inevitably leads to discussion of personal responsibility in HIV acquisition. Even if one could argue that an individual has full responsibility for his or her HIV status, one would have to consider the socio-economic and psychological factors that led to this action and whether this was truly a reflection of free choice. Here we have an example of Sen's inability to manage to desire adequately. Even with repeated exposure, there are many unknowns about why some people get HIV and others do not.

The oval entitled social context draws attention to the socio-economic circumstances of the majority of HIV-positive people and to claim 4 on health care which is based on deprivation. Globally, the HIV epidemic is mainly situated within relatively poor countries. Sub-Saharan Africa has only 10% of the world's population, but has over 60% of the world's HIV-infected people (25.8 million) (UNAIDS and WHO 2005). Within South Africa there is evidence to suggest that poorer communities have higher HIV-prevalence (Shisana *et al.* 2002) and these same communities were more likely to experience long-term economic and social discrimination under apartheid. Campbell (2003) argues that two forms of social disadvantage can be key determinants of poor health. These are poverty and symbolic social exclusion caused by a lack of respect and recognition. Poverty can have a direct impact on health and susceptibility to HIV-infection through malnutrition and parasitic infections (Stillwaggon 2002), and can limit a person's access to health-related knowledge and to health services including treatment of STDs, again increasing vulnerability to HIV-infection. Symbolic social exclusion can limit health

enhancing behaviour through reducing a person's feelings of self-adequacy and self-control (Evans and Stoddart 1990).

Both Stillwaggon and Evans and Stoddart however emphasize the individual—the *person's* access to health-related knowledge and the *person's* feelings of self-adequacy and self-control. We would want to place these considerations more at the level of the community. There are many communities in South Africa which lack access to health-related knowledge and which suffer from feelings of lack of adequacy and control. The switch to the community level also makes the tasks of identifying these characteristics and of obtaining relevant data easier.

Claims related to the impact of health care on health and wellbeing

Claim 6 suggests that society should balance personal responsibility against the potential for health care to mitigate the impact of ill-health and/or premature mortality on the social fabric, defined following Haacker (2004) to include social and economic institutions such as households, companies and the government, and less tangible concepts such as social cohesiveness and solidarity. It could be argued that a solidaristic society has a duty to forestall a discourse on responsibility for HIV status. Adopting a distinction between the blameworthy and the blameless erodes a compassionate response to people who are suffering, and encourages stigmatization and discrimination (Kopelman 2002). This may also be related to the rule of rescue; thus 'a decent society cannot stand by and do nothing even if doing something will have no or little impact on health.'

More generally under this claim may fall equality of access. Society may want everyone who is sick to have access to health care. It may be that in some instances the weight that is attached to that claim may be zero but that need not always be the case. Thus given that the 'condition' is HIV/AIDS, the claim related to equality of access may be weighted as zero because society argues that not everyone can have access. For giving birth, society might argue that all should have access; therefore in this case there is a positive weight attached to this claim.

On the other hand, claim 7 assesses the impact of widespread HIV-treatment on the health of society. Under this claim one would need to consider the opportunity cost of allocating health care resources to HIV-treatment as opposed to other needs, as well as the potential positive or negative externalities associated with treatment.

There are a number of positive and negative externalities associated with ART in particular, and the overall impact on the health of society involves the balancing of a number of competing forces. On the one hand, the provision of ART could lead to lower transmission of HIV per sexual encounter, but because people live longer and potentially have a higher number of sexual encounters during this time, net transmission could be higher (Velasco-Hernandez *et al.* 2002). In addition, poorly adherent patients could transmit drug resistant strains of the virus (Blower *et al.* 2005).

Adjudicating over constituents and strengths of claims

The key challenges in operationalizing the claims approach is to develop a mechanism for deciding on, first, the constituents of claims—what we have attempted above—and second, the relative strengths of claims. Insights from procedural justice are helpful in this regard. Rawls (1971) defines a number of different types of procedural justice. Perfect procedural justice can be understood by the example of the division of a cake. If it is agreed that the fairest outcome is for everyone to get a piece of the same size, then one possible procedure would be that whoever cuts the cake gets the last piece. The key constituent of this form of procedural justice is that there is an independent criterion for defining a fair division (i.e. equal shares) and a procedure that is guaranteed to lead to it. This differs from imperfect procedural justice. Here there is an independent criterion for the right outcome, but currently there is no procedure that will lead to this outcome. For example, in the case of criminal trials, it might be agreed that the fair outcome is that those who are guilty are found guilty and vice versa for those who are innocent. The problem is that the criminal justice system is an imperfect procedure that cannot guarantee this outcome. By contrast, the problem posed in this paper is one of pure procedural justice where there is no independent criterion for the right result. In other words, reasonable people will have legitimate reasons to disagree about the constituents and the strengths of claims on health care, but if a fair process is followed in making decisions, the resulting outcomes could be considered to be equitable.

Economists traditionally argue that procedures are only valuable for their instrumental role in promoting better outcomes. According to Wailoo and Anand (2005), this reflects the notion of perfect procedural justice. For example, in the fair division of a cake, the procedure of cutting the cake is valuable if it ensures the outcome of a close to equal division. On the other hand, in pure procedural justice, while procedures continue to have instrumental value, they can also have inherent or intrinsic value. The inherent value of procedures is also suggested by those who advocate for a 'communitarian claims' approach, where it is argued that the community finds value in the process of being involved in decision-making (Mooney 2005; Mooney and Jan 1997; Mooney 1998; Mooney *et al.* 2002).

The situation, however, is more complicated if we bring two added factors into the picture; compassion and varying tastes. Rawls' cake assumes we are individual free-floating atoms each seeking to maximize our goods utility, here enjoyment of the cake. Yet a compassionate mother who cuts the cake for her kids may choose to have the last and smallest piece. The question for any society here is whether they want a compassionate society or one where individualism rules.

The example of Rawls' cake also assumes that everyone likes cake equally and that the society believes that all are equally deserving of cake or that an egalitarian society is what is wanted. These assumptions are open to question and we would argue open to question by the cake-consuming community concerned as a community.

Quite how to get the community involved in setting claims and their relative strengths remains to be determined. There is

a range of possibilities for each. However, setting claims may be best done through citizens' juries (Lenaghan *et al.* 1996; Lenaghan 1999), while the weighting of claims can be achieved using, for example, discrete choice experiment (DCE) techniques (Ryan and Farrar 2000).

Ensuring there is fair process

Daniels (2004) argues that the central requirements of fair process are:

- **Publicity:** the process must be transparent and involve publicly available rationales for the priorities that are set. This has the added benefit of encouraging good governance.
- **Relevance:** stakeholders who are affected by the decisions should agree that they rest on reasons, principles and evidence that they view as relevant to making fair decisions about priorities. This has the added benefit of assuring stakeholders that their voice has been heard.
- **Revisability and appeals:** decisions can be revisited and revised in light of new evidence and arguments. This appeals process provides protection to those who have legitimate reasons for being an exception to adopted policies.
- **Enforcement or regulation:** a mechanism is in place to ensure that the previous three conditions are met.

These requirements are a potentially useful starting point. Daniels' publicity, however, we would rather see as simply transparency. In most countries, priority-setting decisions are taken behind closed doors. If transparency is to be attained, the full rationales, resultant recommendations and any complaints or disputes related to these decisions would need to be in the public domain in a format that was comprehensible to a lay audience. There are a number of intrinsic and instrumental values to transparency. Firstly, it gives legitimacy to decisions that are taken (Wailoo and Anand 2005) and gives the public greater confidence in the process and the outcomes (Daniels 2004). Secondly, people value knowing why decisions that affect their lives have been taken in the way that they have been taken (Litva *et al.* 2002; Wailoo and Anand 2005). Thirdly, a form of precedence emerges which assists in consistency over time. This has intrinsic value from an equity perspective as it ensures that like cases are treated in a like manner (Wailoo and Anand 2005). Consistency also has instrumental value since the setting of precedence assists in future decision-making, thereby improving the quality of decision-making over time.

Following the relevance condition, society should be able to influence the kinds of rationales that are permitted to serve as a basis for decision-making. These 'reasonable rationales' could be set within a communitarian claims process, where society sets the 'structures, principles or rules on which to base the social welfare function...and hence the basis for priority setting in health care' (Mooney 1998, p. 1173). In other words, society could be consulted about the personal characteristics of people that could serve to justify additional claims or limitations of claims on the good. The latter deals with issues of vertical equity—the unequal but equitable treatment of unequals. It might be decided that HIV-positive people have a disproportionate claim on health care resources given the social context of sufferers and the impact on the social fabric and the health

of society that treatment affords. Communitarian claims is not about replacing the bureaucrat; instead society would play a role in establishing the value base of the health care system and the bureaucrat would have a role in ensuring that the system is managed according to these values (Black and Mooney 2002). Research has shown that society finds intrinsic value in having a voice in decisions; allowing the public to set reasonable rationales provides one avenue for this voice (Litva *et al.* 2002; Wiseman *et al.* 2003; Wailoo and Anand 2005).

The third requirement for fair process is revisability and appeals. This suggests that any decisions will tend to be more acceptable if there are mechanisms which allow decisions to be challenged and reversed if required (Wailoo and Anand 2005). This requirement also allows for the improvement and revisiting of policy over time as resource constraints, technologies or societal preferences change. Revisability is strongly related to the transparency condition because the transparency of the original decision both in terms of rationales and ultimate recommendations facilitates the identification of mistakes. It also provides an avenue for parties affected by decisions to appeal. Further, any changes to decisions would need to be implemented consistently.

The final requirement for fair process is regulation and enforcement. A mechanism needs to be created to ensure that the fair process complies with the adjusted requirements above.

Steps towards the implementation of fair process would include clarifying institutional levels of decision-making, developing structures to address decisions at each level, training to develop competence in fair process, learning from experience, improving the process through training and research, and developing mechanisms for enforcement (Daniels 2004). Although the development of fair process should not stall the scaling up of treatment, as fair process is developed it could have additional benefits through serving as a model for other decision-making in the health care system, improving accountability and empowering communities (London 2003). Rather than framing the poor and marginalized as candidates for redistributive policy by a benevolent state (McIntyre and Gilson 2002), this approach encourages active community participation in resource allocation in health which could improve the ability of civil society to hold governments and donors to account, with both instrumental and intrinsic value.

Conclusion

What does all of this mean for the treatment of HIV/AIDS in South Africa? In principle it means accepting the need to establish a set of principles or a constitution as the value base or philosophy which is to underpin decision-making. No rational decision can be made about how much of the health service budget to spend on such treatment, nor how that is to be spent, without establishing such principles. It also implies or advocates that the South African society as a society needs to be involved in setting both these principles and the claims and weights for claims that are implied in this set of principles. The paper has made the case for such an approach.

At a more practical level the paper has identified different ways of considering claims and has exemplified these using a continuum from 'free choice' to 'no free choice'. It has also

given some examples of what claims might comprise and how the use of these might in turn influence policy on HIV/AIDS.

The case of HIV/AIDS in South Africa is one where resource scarcity is a particularly important issue and the issue of affordability has to be addressed very openly (Cleary and McIntyre 2009). There is every reason to believe, however, that this approach can be applied in all situations where there are scarce health care resources.

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