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Learning from diverse contexts: Equity and inclusion in the responses to AIDS

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Abstract

This paper situates the findings of the diverse studies reported in this journal supplement in a global context that both fuels the epidemic through inequality and poverty and also provides new opportunities for global commitments, solidarity and resources. The studies in this issue signal that, while information and awareness about HIV and AIDS is now high, there is still poor access to services for people to know their own risk and a deeper need to address the asymmetries of power and access to resources that influence the control people have over their sexual relationships and lives.

The studies in this supplement describe, in very different contexts, responses to the impact of AIDS that are grounded within the actions of individuals, households and extended families, against a background of existing disadvantage in assets, endowments and access to state and private sector resources. Community networks reduce social isolation and provide solidarity to households struggling to respond to AIDS. The extra work involved is often done by women, particularly where the weakening of the state has left communities disadvantaged. The paper argues that connections across communities to support survival need vertical links to national and global resources, services and markets to support, sustain and transform lives. The studies demonstrate the positive effect of this through primary healthcare systems, non-government organisation support and the social movements of people living with HIV and AIDS.

If the first wave of the global response to AIDS built awareness and an emergency response to prevention, treatment and care, there is now need for a ‘second wave’ that provides strong measures to connect communities to social, national and global resources. Elements of this ‘second wave’ include people’s—especially women and young people’s—access to services to know their individual risk, measures that enhance their autonomy and the need for a massive increase in investment in and access to decent work.

Global contexts for community responses

‘At the core of this unfolding horror is the prospect that an epidemic this intense, layered atop a reality this unjust, imprisons vast numbers of us in a kind of eternal present, unmaking the ability and perhaps even the desire to imagine a different, better world.’ (Marais, 2005: p. 110)

Three decades into the AIDS epidemic, we continue to struggle with its scale, its burdens, the inequity of its impact and the extraordinary social courage it has inspired. Over the two years from December 2003 to December 2005 a million more people were accessing treatment for AIDS, but about five million people in need were not (WHO, 2006). In 2005, nearly five million people were newly infected with HIV globally and the epidemic claimed just over three million lives (UNAIDS-WHO, 2005). The global response had grown markedly, but ‘still did not match the scale or pace of the worsening epidemic’ (UNAIDS-WHO, 2005: p. 5). More needed to be done to demonstrate the resolve or ‘extraordinary’ measures needed to attack the epidemic and its causes.

Today health and treatment access are formally regarded as human rights. Some social movements, governments and global agencies are advancing policies and measures that aim for the social justice and equity outcomes needed to realise those rights. Global obligations are being framed for areas of human security and dignity, recognising their intrinsic value globally. Global and bilateral funds are being organised to meet challenges such as AIDS. At the 2000 UN Millennium Summit, countries in the UN advanced an understanding of the deep links between security and development and expressed global commitments to human security in the Millennium Development Goals (Kaul et al., 2003; United Nations, 2000).

And yet there are massive challenges and counterposing forces. Economic and trade policies have widened inequality and exclusion within and across

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countries. Human security is often subjugated to more military responses to perceived ‘external threat’ or to corporate economic interests (UNDP, 1999). Global policy implementation is dominated by market interests and by the Bretton Woods institutions (IMF, World Bank, WTO) and their doctrines, while UN agencies dealing with social development lack predictable mechanisms for ensuring that their resolutions are translated into action (Martens, 2003). There is a vacuum in critical areas of international cooperation, such as in international tax cooperation, and the resourcing of global social commitments remains unpredictable. Global governance arrangements have weaknesses that confront equitable development, including democracy deficits, as power is concentrated in the hands of a few governments; and compliance deficits as international institutions fail to implement the decisions they make (Helsinki Process report in Foster, 2005).

The World Commission on the Social Dimensions of Globalisation (2004) outlined the consequences of these counterposing forces in a world of:

- Unevenly distributed growth in per capita income across countries, with half the world’s trade in the 22 industrialised countries that have only 14% of the world’s people.
- An increase in unemployment globally, with 185 million people out of work and looking for work in 2003.
- Increasing wealth outflows from countries in the south.
- Net overseas development assistance falling far below the target of 0.7% of GDP, with a resulting loss to development of US$2.5 trillion (WCSDG, 2004).

Why raise these issues in a discussion on community responses to AIDS?

The AIDS epidemic is deeply embedded in this global context and sharply reflects it. The greatest share of HIV infection globally concentrates in east and southern Africa, a region of highest poverty globally, with increasing outflows of wealth from the region. In this region of highest burdens and greatest household and gender poverty, 90% of caring takes place in the home and women take on 75% of this care burden (UN Secretary General, 2003; UNAIDS, 2003).

The studies in this journal supplement highlight further examples of the significant demands the epidemic places on the networks of horizontal support within communities and localities, as well as the innovations within those networks. In a context of profound global inequality in wealth, these can, however, become networks for the ‘horizontal sharing of poverty’ unless explicit, systemic and sustained vertical connections are made to institutions, authorities and resources nationally and globally that can transform people’s lives.

There are new opportunities for such ‘vertical connections’. Global public-private partnerships and global funds, such as the Global Fund for AIDS, TB and Malaria, bring significant resources into countries to support responses to AIDS. Their reach often extends beyond the state and, through networks of international agencies, faith based and non-governmental organisations, directly into communities (Fidler, 2004). Networks of civil society now organise globally and offer themselves as a conduit for the voice of communities within global policy forums.

How far do these institutional arrangements, that carry power and resources, provide effective sustainable support for community responses to AIDS?

The studies in this supplement come from diverse parts of the world: Congo, Uganda, Zimbabwe and Kenya in Africa; Brazil and Haiti in Central and South America, India and Thailand in Asia. While these countries have very different levels of wealth and social conditions, the communities in the studies have high levels of economic insecurity and, in some cases, political or social instability. Their age, gender, economic status or social marginalisation places them in environments of elevated susceptibility to HIV and vulnerability to AIDS. If the changes at global level are to produce another, better, world then it is for these communities that it must first and principally do so.

Breaking cycles of insecurity and risk

The introductory paper in the supplement (Loewenson, 2007) suggests that control over the spread of HIV is weakened by low or poor risk perception, disempowering conditions, behaviours determined by more immediate survival needs and interventions that fail to adequately address risk environments or the more structural determinants of risk. It asks whether social networks at community level have been able to challenge these risk environments and whether in so doing they have been supported by state and non-state organisations.

The papers universally describe situations in which information and awareness about AIDS is now high. This is important: in Uganda, a high level of awareness brought about in part by people’s experiences of high mortality from a long standing epidemic was one of the factors that was attributed to have contributed to significant increases in condom use, itself a significant determinant of a decline

Information is, however, also insufficient for change, as it is uniformly high across groups with different levels of risk behaviours and different exposure to risk environments. For generalised awareness of AIDS to translate into individual risk perception, it needs, for example, to be complemented by uptake of services that provide counselling and testing (VCT). While these services have now spread more widely, the studies indicate that there are still gaps in coverage and access for those most in need: in young women in Belo Horizonte Brazil, VCT services now available through the universal healthcare system were primarily accessed during contacts for pregnancy and maternal care, leaving young girls not yet pregnant inadequately covered (Chacham et al., 2007). In the informal settlements in Kenya, women reported victimisation from their partners after an HIV diagnosis that can discourage uptake of testing services (Amuyunzu et al., 2007).

Neither is risk perception sufficient for people to protect against risk. Asymmetries of power related to gender, wealth and social status influence the control people have over their sexual relationships and lives and their ability to make and enforce decisions. The studies give many examples of these asymmetries: the sexual and physical violence against women in situations of political instability, informal settlements and poverty undermines their autonomy at the most profound level. In contrast, open dialogue between individuals and their parents and partners and shared decision making between partners were found to have a positive effect on autonomy, particularly of young people (Amuyunzu et al., 2007; Chacham et al., 2007, Priya & Sathyamala, 2007). Access to training, job opportunities, employment and decent work are shown to strengthen people’s autonomy and resources to respond to risk environments. The studies point to the significance of this for women, who may respond to income and employment insecurity through practices that increase risk, such as migration or sale of sex or alcohol. The quality of work is not irrelevant in this, as the experiences in Congo and India suggest that some jobs may themselves raise risk, particularly if they carry high risk, disrupt social stability or involve migration away from sources of stability (Amuyunzu et al., 2007; Bongou Bazika, 2007; Chacham et al., 2007; Priya & Sathyamala, 2007).

Short-term projects and simplistic solutions, especially those aimed purely at awareness, are not adequate to reduce the rate of HIV infection (Holden, 2004). The experience in Ewo, Congo suggests (and calls for further investigation) that interventions that seek to deal with more structural determinants, like employment and incomes, within conditions of economic or social instability need to be carefully planned to provide both immediate and longer-term incentives, to build on local institutions while addressing constraints and to build in measures to respond to problems and sustain and diversify inputs. They signal that, rather than large short-term bursts of support, more sustained, even if smaller, support is needed over longer periods, channelled through local institutions (Bangou Bazika, 2007). The paper by Foster (2007) on orphan support, argues the case for integrating external resources within these existing networks of community support, particularly the family and community safety nets that provide the bulk of current support to orphans. External agencies, he argues, do this poorly and often parallel the initiatives that emerge from ‘bottom up’ (Foster, 2007). On the other hand, the experience of rural women farmers and traders in Uganda described by Kanyamurwa and Ampek (2007) signals that some of these existing networks of support have their own internal bias and differential benefits and that non-governmental organisations, if their presence is sustained, can fill gaps in support to the most vulnerable households.

The studies indicate the more structural determinants of risk that need to be addressed to secure and sustain prevention of HIV infection. Poverty creates the conditions for the spread of HIV and the ill health and mortality from AIDS increases household poverty. As the HIV epidemic increasingly coexists with, or becomes, an AIDS epidemic and mortality increases, this two way relationship can predictably worsen unless the vicious cycle is broken. In the specific studies in this supplement some options are given to break that cycle: in the Brazilian, Kenyan and Indian studies measures are proposed to increase peoples—especially women and young people’s—access to services to know their individual risk, within schools to support open dialogue, within society to promote freedom from threat and violence and to promote shared decision making between partners. In all cases across different settings there is a common proposal for measures that massively increase investment in decent work.

Networks of support in responses to vulnerability

The introductory paper argues that households and extended families are playing the largest role in the response to the impacts of AIDS, complemented by community networks that are themselves often weakened by poverty and increasing demands (Loewenson, 2007). Questions are raised about the extent of support from formal state and non-state organisations for these family and community re-
sponses and the resulting extent of equity in the distribution of the burden of impact of the epidemic.

Across different countries and contexts, the studies repeatedly describe responses to the impact of AIDS that are grounded within the actions of individuals, households and extended families at their core, in some cases supported by wider social networks. Whether caring for orphans in sub-Saharan Africa, managing the consequences of infection in informal settlements in Kenya, dealing with adult illness in India or Uganda, the response to AIDS is largely centred within the actions of households and their extended family connections.

Coping responses such as the sale of household assets, including land and cattle, eating into savings and borrowing from various sources, reported in background literature across a range of communities, were also found in the studies described in this supplement (Desmond et al., 2002; Kanyamurwa & Ampek, 2007; Priya & Sathyamala, 2007). These responses often took place against a background of existing disadvantage in assets, endowments and access to state and private sector resources, such as for women farmers in Uganda, threatening survival or deepening poverty, despite efforts to use remaining resources to the maximum.

There is a consistent finding across the studies that care and support during long-term illness of the adult population in poor households primarily comes from families, buttressed to some extent by communities and wider social networks. The support to households comes from informal transfers, particularly from family members and neighbours, most often linked to clear shocks such as death or drought. At community level, Foster (2007) describes a range of short and long term forms of support, such as burial societies and savings clubs that are based on proactive savings, but that may themselves be challenged by household and community poverty. Community based organisations and religious and faith based groups and associations provided treatment and care, credit and welfare support, including for school fees, food security and other longer term needs (Amuyunzu et al., 2007; Foster, 2007; Kanyamurwa & Ampek, 2007; Priya & Sathyamala, 2007).

In Uganda, two innovations suggest options for breaking this poverty trap: some women left farming to carry out trading, giving them improved incomes that they invested into land and livestock, overcoming negative differentials and falling returns on small scale farming through their own economic innovation. Extended families were also noted as an important source of capital for such activities. For those who remained in subsistence farming, women appear to have been more able to tap non-governmental organisation economic and welfare support than their male counterparts (Kanyamurwa & Ampek, 2007). In both cases the women were reported to direct these resources, to a higher level than men, towards immediate family and children’s welfare needs, such as school fees. This signals that the higher levels of community level social networking found amongst women can be tapped as an asset in the response to AIDS, to reduce negative economic and social differentials, if supported by economic or institutional innovation and resources. The organisation of women in informal settlements in Nairobi through the Kenya Network of women with AIDS (KENWA) provides another example of this, bringing treatment resources into groups who would otherwise be amongst the least likely to access them.

These community responses not only provided material support but also forms of social solidarity. The studies provide rich evidence of these social networks. They were the counterface to stigma and to the anger and isolation caused by stigma. Where common, they shifted the spotlight from the stigmatised to the sources of stigma. Hence, as Lyttleton et al. (2007) describe in Thailand, organisations of people living with HIV and AIDS (PLHA) have been able to claim public space, push entitlements, change mindsets and collectively counter the disempowering effects of stigma and exclusion. Instead of their retreating to the dark corners of society, these groups have given visibility to PLHA, their claims and entitlements, more forcefully in many cases than for other groups within society. In Kenya, women in KENWA contrasted the solidarity support from of their support groups with the moral messages of some churches on shame associated with AIDS raising stigma (Amuyunzu et al., 2007). In India, messages on AIDS communicated from medical and counselling services that did not ‘match’ with community self perceptions were reported to raise stigma, while community members also noted the opportunistic use of medical conditions to pursue other vested interests, usually economic (Priya & Sathyamala, 2007).

These horizontal institutions and processes within communities are important for households—they reduce social isolation and provide the solidarity needed for households struggling to respond to AIDS to tap social resources. The contribution comes at a cost. The trade offs made within households and the extra work borne by women and volunteers are one such cost. The voluntary work that people, often women, do in community organisations takes them away from their own homes and draws heavily on personal resources. While the Haiti study shows that community health workers improve the outreach and effectiveness of health services, not
all services finance this contribution as the Haiti services do (Mukherjee & Eustache, 2007).

The studies also signal that the withdrawal or weakening of the state has left communities disadvantaged and, conversely, that strong public and community institutions are critical for an equitable response. In Congo, when government stopped recruiting graduating students under structural adjustment programmes, structural unemployment rose and economic and social insecurity increased (Bangou Bazika, 2007). The Kenya study exemplifies how the overall underfunding of state services, combined with the weak outreach of state services to informal settlements, leaves people living in such areas at extremely low levels of contact with such sources of public sector support (Amuyunzu et al., 2007).

The weakness of state services highlights constraints that these horizontal connections supporting survival face in making vertical links to the national and global resources, services and markets needed to support, sustain and transform lives. There are some contrasting positive examples as well: the international resource support to the provision of integrated primary healthcare in Haiti in ways that seek to reinforce the public sector infrastructure, linking communities to services through community health workers, provides one example of such vertical connections (Mukherjee & Eustache, 2007). The support by KENWA to provide treatment to women in the Nairobi informal settlements is another. In fact, more generally, the introduction of treatment and its widening access in poor communities has had a transformational effect.

These vertical connections have introduced new resources or shifted burdens more equitably and need to be further explored. In Kenya, they were noted to be very significant in women’s lives, but neither predictable nor long term, to exclude many associated aspects of community needs and to leave both KENWA and its members dependent and insecure (Amuyunzu et al., 2007). Further, as the paper by Lyttleton et al. (2007) shows, they do not simply transform peoples’ lives, they also transform their social networks. In Thailand, networks of PLHA were deeply articulated with communities around mutual support or social mobilization, both very different functions, but both demanding deep community links for their success. Treatment programmes have made connections to these groups to enhance outreach and the study argues that they have been increasingly drawn into the imperatives of service delivery and treatment outreach. Questions are raised about the effect of this on the relations between these groups and communities and households and on their ability to continue to mobilise and challenge the imbalances in power and resources that affect wider aspects of HIV risk and vulnerability to AIDS (Lyttleton et al., 2007).

Lessons from diverse contexts: Supporting community responses to AIDS

These studies were carried out with an explicit focus on HIV and AIDS. In situations of high overall illness and mortality, however, an exclusive focus on AIDS does not reflect community perceptions of the range of threats to their health. Early adult illness and mortality produces high costs to households, no matter what the cause, and is experienced due to a range of communicable diseases, violence, unsafe working and living conditions and maternal causes. When health programmes exclusively focus on AIDS, while they may give urgency to the issue, they may also ignore this wider community experience and potentially increase stigma, especially in early stages of the epidemic (Amuyunzu-Nyamongo et al., 2007; Desmond et al., 2002; Priya & Sathyamala, 2007).

We used definitions drawn from the literature categorising households and seeking, in some cases, to explore whether there were differences between those ‘affected’ or ‘non-affected’ by AIDS or to focus on those affected by AIDS. However, it was evident that households are not discrete units, many different relations shape them and their livelihoods and situate them and their entitlements within communities and society at large (Marais, 2005). They live in environments that are changing, with liberalisation, service reform and other policies that reorganise economic conditions and traditional sources of support and that change the nature and claims of citizenship, as pointedly described in the India study. ‘Households’ too are changing, migrating, reforming internally and building new features with these changes that need to be described and cannot be assumed. While people are treated in social analysis as citizens with entitlements, there are new challenges in shaping these entitlements. Environments of poverty, economic instability, conflict and violence deprive people of their rights, as do more explicit public policies. As we seek to understand the differentials in health and well-being that affect responses to HIV and AIDS, we cannot underplay the effects of these changing circumstances on people’s self perception, citizenship and lives.

Nor can the consequences of AIDS, nor the responses to it, be easily quantified. The fear of a woman infected with HIV over her child’s future; the despair of a young girl threatened with physical violence if she asks to use a condom; the sense of solidarity when a woman is able to access treatment from her support group; or of empowerment when a
young person sells goods he has made at a market are not measurable but are immeasurably important.

The papers in this supplement thus help to provide the ‘real time’ information we need to inform and help us to reflect on our work on AIDS at all levels. The paper by Lyttleton et al., (2007) traces how treatment outreach is affecting organisations of PLHA and their functioning and the questions this raises for these organisations and for service providers. The experiences reported in India, Kenya and Brazil suggest that, if insecurity and commodification of sexuality in liberalised economic conditions replaces domination by male authority under more traditional arrangements, women may be trading one form of oppression for another. They challenge us to reflect, from local to global level, more deeply on how both economic and social conditions can build autonomy in women (Amuyunzu et al., 2007; Chacham et al., 2007; Priya & Sathyamala, 2007).

The negative economic impacts of AIDS are well documented and evident in the studies. Has AIDS, however, helped sharpen social responses that challenge wider determinants of impoverishment? What new social arrangements have been given birth because of AIDS?

The studies highlight the institutions and resources that increase community power in responding to AIDS. They suggest that associational networks such as savings clubs, community based organisations, religious and faith based groups play a valuable role in providing solidarity within communities and are critical for household coping. They do this, however, in economic environments that seem to have been determined by national and global forces beyond, and largely unaffected by, the epidemic. The studies do, however, point to institutions and networks that go beyond roles of coping with these conditions and that appear to transform lives or make the vertical connections that redistribute resources and burdens. The politically organised dalit movement in rural Uttar Pradesh, the social movement of people living with HIV and AIDS in Thailand, the Kenya network of women living with AIDS in the informal settlements of Nairobi all have these features (Amuyunzu et al., 2007; Lyttleton et al., 2007; Priya & Sathyamala, 2007).

While some of these movements connect nationally, the organisation of PLHA groups has pervaded almost all corners of society and has assumed a global presence. Groups such as KENWA in Kenya bring innovation in social organisation not only for people living with HIV and AIDS, but generally in settings such as urban informal settlements, where participation in social networks has been low (Amuyunzu-Nyamongo et al., 2007). Their ability to organise and claim entitlements, as well as to change social dialogue and shift mindsets has reached and resonated at global level. Backed by some governments and by the clear inequity of avoidable mortality, they have been a significant factor in motivating the galvanising call for universal access to treatment and in the organisation of global funds to support action on AIDS.

While their effect to date has been remarkable on issues of stigma and treatment access, the studies indicate that, if community responses are to move beyond the horizontal sharing of poverty to deal with current and intergenerational effects of AIDS, and if prevention is to be successful and sustained in those who need it most, we need to look differently at prevention and mitigation paradigms.

There is an opportunity for this. Significant resources are now flowing around AIDS, global commitments exist to universal access to prevention, treatment and care, social movements provide opportunities for vertical connections, as do some state and non-state institutions. There is a need for this. The evidence from these studies shows that many households are struggling to meet survival needs and do so in ways that draw on their own and their family resources, largely unsupported by formal institutions.

The second wave of the response to AIDS

The first wave of the global response to AIDS built awareness and an emergency response to prevention, treatment and care. The evidence indicates that its success lies in the increased awareness, organised social movements around AIDS, significant development of technical responses and mobilisation of immediate resources for the epidemic. The current context, described in this paper and the studies in the supplement, suggests the need for a ‘second wave’ that bridges immediate responses to long-term structural transformation in ways that provide sustainable support to communities. This needs to transform lives—to move from and link short-term coping to longer-term responses that support political organization, collective social networking and economic stability and security.

The first wave of ‘ABC’ (Abstinence, Behavioural change and Condom distribution) now needs to be supported by strong measures that increase peoples’—especially women and young people’s—access to the services to know their individual risk: measures that address the factors limiting their autonomy and through measures that massively increase investment in, and access to, decent work. Of these, the issue of employment and decent work would seem to be a critical imperative to address in order to give people opportunities for autonomy. Perhaps this is the ‘D’ that should now be added to the global campaign alphabet.
The role of social movements in articulating community responses is critical and the force of the second wave will depend on their ability to connect local voices vertically with national and global decision-making. However, the studies suggest that, in the second wave, bringing communities more effectively into the continuum of care and support needed to manage the epidemic and its impacts cannot be so heavily reliant on household, family and community institutions as has been the case in the first decades. While communities have been innovative and resourceful in meeting this challenge, as Marais (2005) pertinently outlines, doing this in under-resourced environments subsidises care provision at the cost of the poorest. It can be understood as a form of ‘privatisation’ of public roles, consigning to the sphere of the home social costs that were born in public and corporate institutions. This follows a neoliberal paradigm that increasingly individualises responsibility for calamity and ill health. It conflicts with the growing understanding of global obligations, responses and benefits highlighted in the beginning of this paper and the intention of commitments to human security made at the UN Millennium Summit.

Each of the papers in this supplement presents options for improved support to community responses: investment in infrastructures for education, especially secondary education; programmes in public schools to discuss gender inequality, domestic violence and sexual and reproductive health; job placement and training programmes that break gender stereotypes and improve outreach of microfinance; extension services and transport infrastructures to support economic activities, especially for women farmers; investment in public sector health service coverage and outreach, especially in primary healthcare and in the public sector reproductive services that reach young women before they get pregnant; and upgrading and formalising of informal settlements, ensuring public sector service access in these areas. The papers indicate that community responses need to be located within a framework of investment in, and entitlement to, essential services, including public sector health services. They further suggest that community solidarity responses be bridged to formal resource flows into communities, through access to secure employment (vocational training, employment opportunities, job quality) and links between community and formal safety nets (e.g. through price subsidies, public works, food, microcredit, cash transfers, supplementary feeding and food for work).

These specific proposals evidently call for deeper vertical connections to facilitate the redistributional policies (related to income, employment and services) that are key to supporting community action. There is common experience of such policies in industrialised countries through the investment in public institutions, subsidies, incentives and regulatory systems used to promote agriculture and industrial development and provide services during their own development (Mackintosh & Koivusalo, 2004). Global institutions and policies need to be questioned and global resource flows redirected, where the flexibilities and options for using these same measures have been blocked for low- and middle-income countries seeking to achieve similar gains.

Research offers an opportunity to learn and to reflect on lessons from practice, challenge paradigms and avoid ‘blindspots’ (Mkandawire in UNRISD/TARSC, 2005). AIDS has helped overcome our blindspot on the global maldistribution of risk that is confronting health and development, tragically, through its massive burden of death and loss. These diverse experiences of community responses to AIDS point to where we need to act to reduce risks and redistribute burdens for the most vulnerable communities, and in so doing give substance to global commitments to human security.

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