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AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV

Social capital and HIV Competent Communities: The role of community groups in managing HIV/AIDS in rural Zimbabwe

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Social capital and HIV Competent Communities: The role of community groups in managing HIV/AIDS in rural Zimbabwe

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Community involvement is increasingly identified as a “critical enabler” of an effective HIV/AIDS response. We explore pathways between community participation and HIV prevention, treatment and impact mitigation in Zimbabwe, reviewing six qualitative studies in Manicaland. These find that community group membership is often (not always) associated with decreased HIV incidence, reduced stigma and improved access to some services, particularly amongst women. Participation in formal community groups (e.g., church or women’s groups) and informal local networks (e.g., neighbours, families) provides opportunities for critical dialogue about HIV/AIDS, often facilitating renegotiation of harmful social norms, sharing of previously hidden personal experiences of HIV/AIDS, formulation of positive action plans and solidarity to action them. However, implementation of new plans and insights is constrained by poverty, social uncertainty and poor service delivery. Furthermore, dialogue may have negative effects, spreading false information and entrenching negative norms. The extent that formal groups and informal networks facilitate externally imposed HIV/AIDS interventions varies. They potentially provide vital practical and emotional support, facilitating service access, treatment adherence and AIDS care. However, they may sometimes play a negative role in prevention activities, challenging stereotypes about sexuality or gender. There is an urgent need for greater recognition of the role of indigenous community groups and networks, and the inclusion of “strengthening local responses” as a key element of interventions and policy. Such efforts require great sensitivity. Heavy-handed external interference in complex indigenous relationships risks undermining the localism and bottom-up initiative and activism that might be central to their effectiveness. Cautious efforts might seek to enhance the potentially beneficial effects of groups, especially for women, and limit potentially damaging ones, especially for men. Efforts should be made to facilitate contexts that enable groups to have beneficial effects, through nesting them within wider comprehensive responses, and supporting them through strong partnerships with service providers.

Keywords: community mobilisation; social capital; group membership; HIV-competent communities; community conversations; critical enablers; Zimbabwe

Introduction

Community involvement is increasingly identified as a “critical enabler” of effective AIDS responses (Rodriguez-García et al., 2011; Schwartländer et al., 2011). What role do community responses play in managing HIV/AIDS in Sub-Saharan Africa? Formal interventions (by governments, NGOs or donors) carry a small proportion of the burden, the bulk carried by the communities in which the HIV-affected live their daily lives. To date, discussions of the “AIDS response” have been dominated by formal responses, with less attention to the role of indigenous social relations in promoting health-enhancing behaviour change, and supporting externally driven prevention, treatment and impact mitigation efforts. We review six qualitative studies in Manicaland, Zimbabwe, locating these against the background of longitudinal biomedical and behavioural surveys, all conducted by this paper’s authors. We do so to explore the form taken by this “behind the scenes” support in one particular setting, focussing on local efforts which are often regarded as secondary to the “main action” by health and development professionals.

Zimbabwe experienced a significant decline in HIV prevalence from the late 1990s, accelerated by a decline in risk behaviours, particularly partner

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reduction (Gregson et al., 2010; Halperin et al., 2011). Behaviour change was heavily influenced by peoples’ first-hand experience of AIDS deaths, backed up by prevention programmes, with interpersonal communication playing a key role in mediating their impacts on behaviour (Halperin et al., 2011; Muchini et al., 2011). To date, little work has been done on the social networks through which such communication might have taken place.

Work in eastern Zimbabwe provides a valuable impetus for scholarship in this area (Gregson et al., 2011, 2013). Elsewhere, we have reported on longitudinal surveys involving 10,000 residents of Manicaland, highlighting the role of membership of indigenous community group memberships (Table 1) in this decline. Group membership had a particularly protective effect against HIV infection for women (though not for men) during the period of most rapid risk reduction (1999–2004) as well as being associated with lower levels of stigma and faster uptake of some HIV/AIDS-related services (Gregson et al., 2011). Membership of groups providing opportunities to discuss AIDS was more protective for women than those which did not. Multiple-group memberships provided women with more protection than membership of a single group. Interestingly, women who belonged to local groups that received external sponsorship from NGOs, churches or political groups were more likely to be HIV positive, than members of unsponsored groups (Gregson et al., 2013), suggesting that the indigenous nature of the groups might be a core to their effectiveness. The timing of such groups over the course of the epidemic was also a factor, with the greatest effect in the early stages of the epidemic and a waning effect as time passed by.

Such findings raise many questions, two of which are tackled in this paper:

- What are the processes through which communication in indigenous social groups might impact on peoples’ HIV/AIDS-related behaviours?
- What role can community networks play in supporting external programmes of HIV/AIDS prevention, care, treatment and impact mitigation?

We address these questions through a review of six pieces of research making up the social capital component of the Manicaland Project’s qualitative dataset. This project (http://www.manicalandhivproject.org) is a longstanding research and intervention programme seeking to facilitate more effective responses to HIV/AIDS in Manicaland province, eastern Zimbabwe. Manicaland is an impoverished rural area, where most survive through subsistence farming and small remittances from migrant workers, and a minority work on commercial farming estates and small mines. Peoples’ daily lives have been shadowed by the uncertainty and disruption associated with the country’s economic and political instability. Whilst levels of HIV/AIDS are declining, and the slow roll-out of

<table>
<thead>
<tr>
<th>Group</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Church group</td>
<td>Members from the same congregation meet outside of regular church worship times. Engage in Bible study, discussing marital issues, and community outreach, particularly helping families in need (such as those with sick members or orphans)</td>
</tr>
<tr>
<td>HIV/AIDS group</td>
<td>Loose term to apply to variety of groups including post-HIV-test clubs (mostly PLWHA), HIV/ART support groups often organised by clinics, youth groups, peer education groups, home-based care groups (members go house to house to help families with sick relatives – doing chores, bathing the sick, sometimes collecting pills from clinic, etc.)</td>
</tr>
<tr>
<td>Burial society</td>
<td>Members contribute small sums of money to central fund to cover basic funeral expenses for themselves and other members. Members commit to organising proper burials for one another and often sing at funerals. Generally meet monthly</td>
</tr>
<tr>
<td>Rotating credit society</td>
<td>Members contribute to central fund and when they reach a certain amount the money is shared for income-generating projects such as buying seeds. Members borrow at same interest rate, and loans can be made to non-members at a higher rate.</td>
</tr>
<tr>
<td>Women’s group</td>
<td>Generally linked to government women’s empowerment initiatives. Supported by government income-generating grants</td>
</tr>
<tr>
<td>Sports club</td>
<td>Generally all-male. Organise tournaments against other regions. Primarily soccer</td>
</tr>
<tr>
<td>Youth group</td>
<td>Often organised by political parties or teachers, these seek to develop leadership skills and provide recreation for youth (often into 20s – “end of youth” often determined by marriage)</td>
</tr>
<tr>
<td>Co-operative</td>
<td>Becoming less common in the region. Generally linked to income generation</td>
</tr>
<tr>
<td>Farmer’s group</td>
<td>Farmers, both male and female, meet monthly to plan crops, discuss weather patterns and new technologies, share labour and access NGO assistance (e.g., a bee-keeping group)</td>
</tr>
</tbody>
</table>
anti-retroviral therapy (ART) has turned HIV/AIDS into a chronic disease rather than a death sentence for many, HIV/AIDS continues to be highly stigmatised, and formal service provision remains patchy.

The first and second of our six studies explore AIDS-related dialogue in community groups. The other four explore the role of formal and informal networks in facilitating or hindering (1) ART access and adherence; (2) the outcome of a peer education programme; and the progress of two impact mitigation initiatives, (3) one delivering home-based care, (4) another involving cash transfer to support AIDS-affected households. The overall dataset included a total of 553 participants in 168 in-depth interviews and 60 focus groups and ethnographic observation of healthcare settings. Participants included people on ART, HIV support group members, care-givers of children with HIV, male and female community members, healthcare workers, employees of local companies, sex workers and clients, children, churchgoers and members of the clubs/groups in Table 1. Data were subjected to interpretative content analysis, guided by the six dimensions of an “HIV competent community” outlined below.

**Conceptual framework**

Our discussion is framed by Nhamo, Campbell, and Gregson’s (2010) conceptualisation of the “HIV-competent community” – a context where local people are most likely to collaborate in responding effectively to HIV/AIDS. This concept draws on Campbell and Cornish's (2012) social psychological theory of “transformative communication”. This emphasises the role of dialogue in safe social spaces (Vaughan, 2010), modelled on Fraser’s (1990) notion of “counter-public spheres”, in facilitating the development of health-enabling social norms by individuals and groups. Such dialogue promotes critical thinking and ongoing reflection-action cycles (Freire, 1973) where marginalised groups work together to create more “health-enabling social environments” (Tawil, Verster, & O’Reilly, 1995). The success of such endeavours may be greatly enhanced by partnerships between communities and supportive external agencies in the NGO and public sectors (Campbell, Nair, Maimane, & Sibiya, 2008).

An HIV-competent community is characterised by opportunities for dialogue about HIV/AIDS, which ideally lead to (1) sharing of HIV-related knowledge; (2) critical thinking about obstacles to health-enhancing behaviour change, and discussions of locally realistic strategies for tackling these; (3) a sense of local ownership and responsibility for contributing to the struggle against HIV/AIDS rather than passively relying on government and NGOs; (4) identification of individual and group strengths for this challenge; (5) bonding social capital: a sense of solidarity and common purpose in relation to tackling HIV/AIDS; and (6) bridging social capital: links with supportive external groupings in the public, private and NGO sectors (Nhamo et al., 2010).

We conceptualise social capital as the individual and community-level advantages arising from memberships of local community groups (including formal group memberships such as church and women’s groups, and informal networks of friends, family and neighbours), drawing on elements of both Putnam’s (2000) and Bourdieu’s (1986) understandings of social capital. Bourdieu sees social capital as the benefits arising from an individual’s engagement in “networks of social acquaintances and recognition”, which potentially assist an individual in “getting ahead”, in relation to coping with life’s challenges and advancing their interests. Unequal distribution of social capital is a key factor in advancing social inequalities and their associated negative impacts on health. Putnam argues that high levels of group membership potentially yield benefits not only for individuals, but also have “spillover” effects for all community members, with benefits diffusing outwards to include non-group members. Group memberships can also be a source of negative social norms, social exclusion and discrimination against out-group members (“anti-social capital”) (Portes & Landolt, 1996).

We examine how local community group memberships facilitate or hinder the development of HIV-competent communities, and some of the processes through which this might happen.

**Findings**

**How does group-based dialogue about HIV/AIDS enable more effective community responses?**

An action research study (Scott, Campbell, Gregson, Nhamo, & Nyamukapa, 2011) which sought to facilitate and document the process of AIDS-related dialogue amongst 123 members of 15 community groups illustrated multiple ways in which group memberships facilitated effective responses to HIV/AIDS. In Manicaland, where stigma reduced opportunities for public discussion of HIV/AIDS, conversations amongst group members enabled them to share and process HIV-related information, confide emotional personal experiences of their own or family members’ suffering, discuss positive role models of
effective responses, co-construct feasible action plans and brainstorm ways of accessing help. Group dialogue also provided members with opportunities to challenge one another’s misconceptions about HIV/AIDS, in the process taking ownership of previously alien medical information.

A single quote from this study exemplifies how dialogue amongst female members of a savings club provided opportunities for women to challenge and re-evaluate inaccurate stereotypes or unhelpful clichés (e.g., “good women and bad men”), resulting in more honest and realistic discussions of HIV-related issues.

**JM:** These men are troublesome. They are infecting us. They indulge in unprotected sex and still want to do that when they come home. When he comes home if you ask him to use condoms he will vehemently disagree. Men are a problem. **GR:** [This is not true.] If men come with condoms we women … blame them for bringing the condom home because we think condoms are made for prostitutes. **AN:** The other problem is that we don’t want to have protected sex because the experience is not as pleasant as that without a condom. (Middle-aged women, Savings Club)

However, dialogue could also result in negative group responses, entrenching myths and promoting negative stereotypes (as of “bad women and good men” in the example below).

**AB:** The problem we have that a lot of ladies are the ones that are spreading HIV because they lure us men and they are all after our money. **JO:** It’s a difficult situation. We cannot overcome the problem of sexuality … Ladies of long back were decent and respectful unlike nowadays. (Men in soccer club)

Sometimes lively group debate led to impractical or punitive suggestions (more likely to increase than reduce stigma), such as jailing people for extramarital sex, or beating youth to enforce sexual abstinence. There was also occasional evidence of groups sharing incorrect information, e.g., that condoms “did not work”.

Dialogue sometimes reinforced a sense of helplessness and dependency, with group members talking in circles about the insolubility of the HIV problem. It also sometimes spread a sense of passivity, rather than confidence in the role local people could play in reducing stigma and challenging harmful norms. Group dialogue sometimes simply recycled unhelpful beliefs, e.g., that local behaviour would not change without firm “instruction” from outsiders, or significant external funding for AIDS activities.

**JA:** You people from HIV/AIDS organisations should come into this community and talk to our children about that. **JS:** You people from HIV organisations you are supposed to donate money to us so that we could start our own projects this in turn will result in the reduction of HIV/AIDS. (Women in savings club)

Our parallel study of dialogue in church groups (Nhamo et al., 2011b) highlighted external constraints on group dialogue as an instrument of change. Over an 18-month period, Nhamo conducted 18 community conversations (with 6 groups at 3 points in time) including a total of 77 participants, seeking to promote positive responses to HIV/AIDS amongst church members. Conducted by trained local facilitators, community conversations promote debate about social problems, and identify local strengths for tackling them (UNDP, 2004). In this study, conversations facilitated the development of promising action plans and a sense of common purpose in helping the AIDS-affected to access food and clinics. The potential of these plans was facilitated by increasing ART availability in Manicaland, which revitalised peoples’ sense of hope and engagement with local health services. However, their implementation was hindered by poverty, poor harvests and political unrest. Nhamo’s study also highlighted differences amongst denominational groups, with Apostolic and Catholic (but not Anglican) group conversations reinforcing opposition to condoms and moralistic stigmatising links between “bad” sexual behaviour and HIV (Nhamo et al., 2011a).

**How can community groups and networks support external programme efforts?**

**Treatment: ART access and adherence**

Levels of ART adherence in Africa are extraordinarily high, given constraints (Ware et al., 2009). Multiple obstacles faced people with HIV/AIDS and their carers in Manicaland (Skovdal, Campbell, Nhongo, Nyamukapa, & Gregson, 2011): material obstacles (poverty, food shortages, distance to clinics, unaffordable transport and hospital costs), symbolic obstacles (stigma, gender including health-limiting masculinities, competition between biomedical and traditional healers), relational issues (availability of social support, effective treatment partners and quality of relationships with nurses) and institutional issues (availability and quality of health services). A qualitative analysis of 8 focus group discussions (including 60 people) and 67 interviews (healthcare workers, adults on ART and carers of children on ART) highlighted the role of 3 local network types in facilitating service access and adherence (Campbell,
Scott, Madanhire, Nyamukapa, & Gregson, 2011; Scott et al., 2011). Externally facilitated groups included ART support groups, NGO-led education programmes (promoting stigma reduction and service information) and NGO-led food and financial assistance programmes. The latter helped ART users access food and regain lost social status as breadwinners. Such benefits motivated many to access voluntary counselling and testing where HIV-positive people qualified for food and financial help. Indigenous community-initiated groups included home-based care groups, often linked to church or women’s groups. Thirdly, informal networks and relationships included family, neighbours or friendly healthcare providers.

Dialogue in support groups helped ART users tackle the stigma that sometimes blighted their lives (Campbell, Scott, Mupumbireyi, et al., 2011; Campbell, Skovdal, et al., 2011). They also provided opportunities for men to re-negotiate macho identities (dominant, dominating and invulnerable) that contradicted the “good patient” persona associated with effective ART service use (compliant, willing to wait in queues, take instructions from female nurses, limit alcohol) (Skovdal, Campbell, Madanhire, Mupumbireyi, et al., 2011). This was a contradiction that undermined optimal service access and treatment adherence by men. Group discussions enabled men to reflect on the potential benefits of ART for their productivity and social value, helping some to construct more “ART-friendly” gender identities around more “responsible” dimensions of masculinity, such as their breadwinner roles (2011).

Local community networks (including informal extended family and neighbourhood), as well as more formal groups (including nurses and NGO workers), often played a vital role in facilitating ART adherence by children (Campbell et al., 2012). However, there was some evidence that elderly guardians of children with AIDS were often constrained by restrictions on mobility, memory and finances in ensuring the optimal well-being of children in their care (Skovdal, Campbell, Madanhire, Nyamukapa, & Gregson, 2011). Thus, whilst local networks made vital contributions to tackle HIV-related problems, they were often constrained and in need of further outside support.

Prevention: Peer education

Whilst community networks often played a positive role in facilitating service access and treatment adherence, they were sometimes less positive in prevention efforts. A large donor-funded prevention programme in Manicaland, targeting commercial sex workers (CSWs) and men in beer halls, failed to increase condom use (Gregson et al., 2007). A randomised controlled trial actually showed a trend towards higher HIV incidence in intervention sites than control sites. Similar lack of effect for peer education has been found in other diverse settings (Medley, Kennedy, O’Reilly, & Sweat, 2009; Williamson, Hart, Flowers, Frankis, & Der, 2001).

A qualitative study (Campbell, Scott, Mupumbireyi et al., 2011) drew on 8 focus groups (including 70 people) and 11 interviews, to explore the views of local people (including male and female community members, sex workers and men frequenting beerhalls) and peer education project staff about core challenges facing the programme’s peer education component. Poverty, drought and hyperinflation were said to limit partner NGO participation, hampering efforts to promote alternative income-generation programmes for CSWs. This reinforced CSWs’ economic dependency on the sale of sex, and limited their ability to assert themselves with condom-resistant clients. Yet, in a community where sex work was highly stigmatised, both community members and local project workers continued to interpret the project’s brief as one of “reforming” CSWs to adopt more respectable livelihood strategies.

Some peer educators were not honest [with the programme organisers]. The idea was that they would reform once they assume the peer educator’s role. But most of them did not reform. (Local project organiser)

Local people saw the peer educators’ failure to give up sex work as evidence for the worthlessness of the programme and its behaviour-change messages. The second challenge was that the programme’s CSW focus limited its appeal to more “respectable” community members, particularly women in church and women’s groups. Given that married women are particularly vulnerable to infection by their husbands, this was particularly problematic.

These peer educators did not have the respect of other women. It is difficult for other women to see anything good coming from prostitutes. (Local man)

The model of training CSWs as peer educators was not good. They should have chosen good people who are fit to do that, people who can control their behaviour. (Local woman)

Respectable women sought to limit their husbands’ contacts with a sex-work-associated programme, given their determination to turn a blind eye to their husbands’ engagement in extra-marital sex.
If we were to go get home and try to use condoms with our wives they would suspect that we had been practicing using condoms in beer halls. (Sex worker client)

These wider dynamics limited the diffusion and adoption of messages from those who had attended peer education meetings to the wider community.

The local perception that the aim of the project was to “rehabilitate” CSWs limited honest dialogue about how to make commercial encounters safer for both CSWs and clients. In short, local community norms and networks (in this case the persistent stigmatisation of sex work, and the networks of “respectability” cherished by many women) served to prevent the peer education programme from seriously engaging with local constraints on health-enhancing behaviour change, and to limit the diffusion of its messages from beer halls and CSW meeting places to the wider community.

**Impact mitigation: Home-based care and cash-transfer initiatives**

In Manicaland, home-based care is often the only source of support for people with AIDS who are unable to access ART or regular medical support. In their study of the impact of local community groups in facilitating local-level HIV competence in Manicaland, Nhamo et al. (2010) analysed fieldworker diaries, as well as interviews with 44 individuals and 11 focus groups involving a further 55 people, all members of community organisations or local leaders. The findings highlighted how local community groups, often supported by external NGOs, played a vital role in offering unpaid nursing and welfare assistance. However, their contribution was potentially limited by top–down programme designs which saw them as unpaid workers rather than genuine partners with donors and NGO staff in programme planning and decision-making. They illustrate this with a case study of Anna K, the chair of a local home-based care club, initiated by a donor-funded NGO which had since run out of funding for the project. This was the only local group providing support for people living with HIV and AIDS (PLWHA) in Nhamo’s study site, and whilst Anna and her peers worked with great dedication, they knew little of the wider context of the work.

They no longer bring blankets and food parcels. I am not sure why. . . . I am not sure who initiated this group . . . . We have run out of gloves and need a refresher course . . . . I am not sure of the future plans of this group because I am not part of the management. (Anna K)

There is a growing critique of programmes which interpret “community mobilisation” as the use of local people to deliver unpaid welfare services according to an external agenda, without involving them in wider decisions about project design and management (or at least ensuring that they are well informed about such matters). They may miss vital opportunities to boost local HIV competence through building grassroots capacity in project design, management and decision-making, which might sustain efforts when donor funding ran out.

The balance of risks and benefits arising from community involvement in AIDS impact mitigation strategies was also evident in Skovdal et al.’s (in submission) study of the role played by local community networks in facilitating or hindering the success of a cash-transfer intervention to support AIDS-affected households. Interviews with 42 adults and 4 youth (including local key informants and beneficiaries of various cash-transfer programmes) found that local community groups played a key role in identifying and selecting the neediest households, and supporting and monitoring how money was spent. However, limited funding led to jealousy and conflict from those excluded, and sudden access to cash in a very poor community created opportunities for lying and corruption as everyone scrambled to get a “piece of the pie”.

**Conclusion**

What role do community networks play in facilitating HIV competence in Manicaland? More particularly, what are the processes through which communication in indigenous social groups might impact on peoples’ HIV/AIDS-related behaviours? What role can community networks play in supporting external programmes of HIV/AIDS prevention, care, treatment and impact mitigation? We have reviewed a complex set of findings, which defy easy summary. However, it is clear that community groups play a significant role in framing peoples’ responses to HIV/AIDS. In our studies, they were often a force for good (especially for women), and sometimes for bad (particularly, though not always, for men). Their impacts were more constructive in some studies (of care, support and treatment), less constructive in others (peer education study) and mixed in others (cash-transfer study). Some groups challenged stigma and health-damaging masculinities. Others reinforced these. However, all our evidence suggests that the role of local groups needs to be factored into HIV/AIDS management policies and interventions in particular settings – either to
optimise their potential benefits or to minimise their potential harm.

Resource-poor communities often have recognised “portfolios of assets” (Moser, 1998) including indigenous local groups and networks, which are already carrying the burden of the day-to-day response and playing a key role in mediating and often (not always) enhancing community benefits from prevention, care and treatment programs. There is a need for greater formal recognition of their role by funders, policy-makers and program designers, and the inclusion of “strengthening indigenous responses” as a built-in component of all external interventions. There also needs to be recognition that different groups have different effects, especially relating to gender. Efforts need to focus on enhancing their potential benefits for women and limiting their damaging effects on men. Carefully managed group activities can sometimes be a powerful source of positive change for men, but this cannot be assumed at the outset.

Community-strengthening interventions should pay attention to the parallel need to create contexts that enable and support groups to have optimally beneficial effects – HIV/AIDS-related services need to be accessible and effective, programs implemented fully, and food and transport assistance available where needed. The benefits of groups are optimised when they are part of a wider comprehensive response – with appropriate and genuinely empowering support from external funders, as well as good partnerships with supportive service providers.

The issue of how externally imposed public health and social development interventions might best support and strengthen pre-existing local community resources is a fraught and challenging one however. Some studies have highlighted the positive roles that external sponsorship of local groups can play in facilitating local AIDS competence (Nyambeda & Aagaard-Hansen, 2007; Pronyk et al., 2008; Skovdal, Mwasiaji, Webale, & Tomkins, 2011). However, Gregson’s Manicaland research (this volume) reports a trend towards women in NGO-sponsored groups being more vulnerable to HIV infection than women in unsponsored groups. The extent to which community-level social capital can be manufactured or reinforced by outside interventions remains open to debate (Scott, 2011). External interference in complex and subtle local processes opens the danger of unintentionally derailing the very localism and grassroots initiative and creativity that lie at the core of community group effectiveness. Whilst we have no doubt that group memberships are a key piece in the complex puzzle of facilitating a more effective HIV/AIDS response, many challenges lie ahead for those seeking to turn findings such as ours into action.

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Note

1. We provide illustrative quotes drawn from the empirical studies reviewed in this paper. Readers should consult the original studies for more detailed accounts of data analysis and findings.

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