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Contextualising women's mental distress and coping strategies in the time of AIDS: a rural South African case study

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Abstract

Increasing attention is paid to impacts of HIV/AIDS on women's mental health, often framed by decontextualized psychiatric understandings of emotional distress and treatment. We contribute to the small qualitative literature extending these findings through exploring HIV/AIDS-affected women's own accounts of their distress – focusing on the impacts of social context, and women's efforts to cope outside of medical support services. Nineteen in-depth interviews were conducted with women experiencing depression or anxiety-like symptoms in a wider study of services in KwaZulu-Natal, South Africa. Thematic analysis was framed by Summerfield's emphasis on contexts and resilience. Women highlighted family conflicts (particularly abandonment by men), community-level violence, poverty and HIV/AIDS as drivers of distress. Whilst HIV/AIDS placed significant burdens on women, poverty and relationship difficulties were more central in their accounts. Four coping mechanisms were identified. Women drew on indigenous local resources in their *psychological re-framing* of negative situations, and their *mobilisation of emotional and financial support* from inter-personal networks, churches and HIV support groups. Less commonly, they *sought expert advice* from traditional healers, medical services or social workers, but access to these was limited. Though all tried to supplement government grants with *income generation* efforts, only a minority regarded these as successful. Findings support on-going efforts to bolster strained mental health services with support groups which often offer valuable emotional and practical support. Without parallel poverty alleviation strategies however, support groups may sometimes offer little more than encouraging passive acceptance of the inevitability of suffering -- potentially exacerbating the hopelessness underpinning women's distress

Keywords: *women's mental health; depression; resilience; coping; poverty; HIV/AIDS; community mental health competency; support groups; South Africa.*

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Introduction

"You can't be free if you don't have money. Money sets you free – am I wrong?"
(Interview with distressed AIDS-affected woman in rural KwaZulu-Natal)

How does HIV/AIDS impact on women's mental well-being in deprived contexts, and how do they cope? It is well known that negative social circumstances undermine women's opportunities for mental health (WHO, 2012; Patel et al., 2006). However the precise ways in which women experience and deal with negative social circumstances are less understood. In South Africa women are disproportionally affected by HIV/AIDS (UNAIDS, 2010). Women carry the bulk of the burden of caring for the sick, often without much health and welfare support, particularly in underserved rural areas with limited supplies of anti-retroviral medication. Such burdens may be almost intolerable, increasing vulnerability to physical and emotional breakdown as well as the loss of livelihoods and the economic collapse of households (Campbell, et al.,2008; Orner, 2006). There are growing calls for qualitative studies that shed light on AIDS-affected women's daily lives, and how their efforts to cope with daily struggles meet with success or failure in ways that manifest in emotional distress (Casale & Wild, 2012; Schatz, Madhavan, & Williams, 2011). In response, we report on a study that explored the social factors impacting on the emotional well-being of AIDS-affected women, how they described their emotional distress, and the strategies they used to cope.

Background

Poverty and social disruption are increasingly identified as drivers of mental health world-wide (Patel & Kleinman, 2003; Lund et al., 2011), with people in rural areas least likely to access supportive health and welfare services (Petersen et al, 2010; Saxena et al 2007). 72% of the nation's poor reside in rural areas (May et al., 2000), most existing on 250 R/month (Van der Berg et al., 2006). We contextualise our work within two wider bodies of literature: the general literature on women's mental health in sub-Saharan Africa, and the more specialist literature on the impact of AIDS on rural women.

In relation to the burden and nature of the mental health problems facing rural women in South Africa, Pillay and Kriel (2006) found that women presenting for psychological services reported relationship problems, depression, and suicidal behaviour. Over half of married women in this group reported spouses who were substance abusers and/or violent, and described their partners as disengaged. The South African stress and Health Survey (Seedat et al.,2008) identified that the strongest predictor of depression in women was intimate partner violence. A case review of women presenting at general hospitals for psychological treatment linked depression in township dwelling women to poverty, overcrowding, unemployment, high levels of crime, lack of services and sexual abuse (Ngcobo and Pillay; 2007), consistent with Posel and Rogan's (2009; 2012) accounts of the increasing feminisation of poverty in post-apartheid South Africa. Hamad et al., (2008) point to household size,

lower educational attainment, income instability and lower subjective social status as key correlates of depression, particularly in South African women. Sorsdhal et al. (2012), highlight the negative impacts of food insecurity on social cohesion and psychological well-being in South African households, consistent with other African contexts such as rural Burkina Faso (Nanama & Frongillo, 2012), Uganda (Tsai et al., 2012), and contexts of forced displacement in South Darfur, Sudan (Kim, Torbay, & Lawry, 2007).

For many poor rural women stressed by the burdens of poverty and gender inequality, HIV/AIDS can be the final straw. While access to Anti-Retroviral Treatment (ARTs) continues to expand in South Africa, only half of those eligible (CD4 <350) currently receive treatment (UNAIDS, 2012). Schatz et al (2012) report that HIV/AIDS compounds women's existing worries about caring for children, with some women fearing infection through physical contact with AIDS-affected children, and AIDS-affected women dreading the prospect of dying and leaving children without support. Wingood et al.,(2008) highlight the impact of AIDS stigma on HIV positive South African women's mental health. Kuo and Operario (2011) highlight that caregivers of AIDS orphaned children are significantly more likely to meet criteria for clinical depression than caregivers of non-orphaned children.

The bulk of research on the relationship between HIV/AIDS and mental health is conducted within the framework of mainstream biomedicine and psychiatry (Brandt, 2009; Breuer, Myer, Struthers, & Joska, 2011). Mental illness is conceptualised in terms of decontextualized diagnostic categories that pay less attention to the wider contexts of peoples' distress, and give little attention to patients' own accounts of their illness. Given the poor resonance between psychiatric services and the experiences and life worlds of many African communities (Read, 2012), there is growing attention to the need for phenomenological studies that explore how patients themselves conceptualise and deal with distress, as a way of facilitating improved interfaces between services and users. This literature is heavily influenced by the development of patient explanatory models of distress (See Kleinman, 1980). Such an emphasis takes account of the social and cultural underpinnings of patients' own experiences and representations of mental health and healing, rather than simply imposing bio-medically oriented psychiatric understandings onto patients as is often the case (Kleinman, 1980).

For example, Patel et al. (1995) explore the ways in which primary health care patients in Zimbabwe account for their emotional distress, highlighting patients' emphasis on spiritual factors, particularly the stresses of being bewitched by others, as the most common explanation for distress. In Zambia, Chipimo et al. (2011) and Aidoo et al. (2001) found that patients explained mental distress as social and cultural experience rather than a medical one, defining it as 'problems of the mind', and pinpointing social relationships, poverty and unemployment as primary causal factors. Interestingly the exception here were patients with AIDS, who, despite giving similar accounts of the social drivers of distress, tended to draw on more

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medical terminology in listing the symptoms of their distress probably due to their greater familiarity with western health service settings.

While Kleinman's approach highlights the lived experience of patients who have accessed health services, most contemporary research in his tradition explores the experiences of those whose mental health has *already* broken down. It tends to neglect the body of emotionally distressed people, who manage their own distress rather than seeking biomedical support (Stoppard, 2000). In this paper we seek to expand existing understandings of the everyday lived experience of distressed HIV-affected people in South Africa – focusing on those who manage their mental distress outside of treatment settings. We hope this focus provides useful insights into those seeking to promote positive states of mental well-being in this particular context.

Whilst social ties often play a positive role in buffering mental stress, they may sometimes serve as *causes* of distress rather than solutions (Kawachi & Berkman, 2001). This is particularly relevant among resource-poor women, including carers, whose social connections may be associated with demanding and stressful obligations to provide social support to others. The literature on AIDS-affected carers in Africa reflects this complexity. Kagotho & Ssewamala's (2012) quantitative exploration of depression in AIDS -affected rural caregivers in Uganda indicates that social support systems (including access to external financial assistance) were highly correlated with better reported depression scores, pointing to the potential value of group focused therapy (Petersen et al., 2011) and family structured support to reduce isolation. However, Thurman, Jarabi, & Rice's (2012) evaluation of support groups for guardians of orphans in Kenya indicated that while support group members reported reduced isolation and marginalisation, the psychological well-being of care-givers was not associated with support group membership. This links to findings from one of the few qualitative case studies in the area by Campbell and colleagues (2008) who argue that while particular social networks and relationships (particularly those with families and neighbours) are protective of carers' well-being, others (including participation in faith-based organisations as well as interactions with traditional healers and local leaders) perpetuated AIDS-related stigma and denial which undermined women's efforts to cope with the epidemic in extremely adverse social conditions.

Casale and Wild (2012) report a positive relationships between social support and the mental health of AIDS caregivers in their review of international research. However, they emphasise the paucity of research in Southern Africa and other parts of the developing world most affected by HIV/AIDS, and the need for more qualitative research in a field dominated by large scale epidemiological quantitative studies, to help explore the complexity of coping and resilience in such contexts.

Summerfield's (2001; 2008) work provides a platform for unravelling this complexity. He calls for greater attention to way in which social context frames emotional distress, and to the ways in which people strive to achieve physical survival and mental well-being in challenging social settings. Most relevant to

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our interests, he argues that common mental disorders (e.g. depression, post-traumatic stress disorder) are more usefully regarded as complex socio-cultural responses to adversity, rooted in the meanings that individuals give to their experience, than as disease. He argues that commonly used psychiatric categories are reductionist through their emphasis on individual pathology at the expense of culture and social context, and the need for research to examine "the whole person immersed in the dynamic complexity of a life and a situation" rather than as bearers of clusters of medical symptoms (Summerfield, 2012).

For Summerfield, mental health is optimised in situations where people experience "a sense of social connectedness within a coherent social world" (Summerfield, 2012). In settings of poverty and social inequalities, many mental illnesses, particularly common mental disorders are reactions to negative social circumstances (Summerfield, 2001). Summerfield argues that there is an urgent need for the development of an 'ecologically valid' evidence base to inform mental health service provision in many low and middle income contexts, in the interests of developing conceptualisations of illness and strategies for healing that resonate with local worldviews and realities, and build on indigenous strengths and support systems.

Building on Summerfield's work, Skovdal (2009; 2010) calls for greater attention to the agency and resilience of those in distress. In a study of AIDS-affected children in almost impossibly challenging circumstances, he criticises the tendency for mental health researchers and service providers to position those in poverty as helpless victims - focusing only on their distress, with inadequate parallel attention to their coping strategies. He argues that AIDS-affected children are often poor rather than mentally ill or at risk of deviance, and exercise resourcefulness in tackling their daily adversity. Against this background he concludes that children's well-being would be better served by policies and interventions to bolster resilience and strengthen potential community support networks than by the increased availability of psychological therapies or drug treatments as advocated by many international AIDS agencies. We argue that Skovdal's argument may also be a useful one in research and service conceptualisations of distressed women. The impacts of health care support and interventions could be dramatically enhanced by strengthening the indigenous coping responses developed by women themselves as well as efforts to enhance the abilities of their communities to offer them culturally and contextually appropriate support.

Orner (2006) identifies coping strategies used by AIDS affected women, such as prayer and talking to neighbours. However Casale (2011) urges caution to those who use terms such as 'resilience' and 'coping strategies' in describing the resourcefulness of women affected by the pandemic. Despite affirming the importance of attention to women's local strengths, she argues that such terms may create a false sense of women's ability to ensure the long term survival of their households, drawing attention away from the urgency of providing them with additional support (Casale, 2011;Campbell & Foulis, 2004). Casale suggests that terms like 'coping' should be considered as one-off strategies women use to manage immediate challenges regardless of their

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outcomes, acknowledging that strategies that enable women to persevere in the immediate short term are not guarantees of long term well-being of themselves or their children.

Current understandings of coping among AIDS affected and infected caregivers is predominantly sourced from epidemiological and quantitative studies (Casale &Wild, 2012), with the exception of the aforementioned studies, and recent work by Schatz and colleagues (2011, 2012), who highlight a continuum of coping amongst female household heads. They foreground the role of financial and social resources in accounting for women's ability to remain healthy and manage their households in the face of the pandemic.

Against this background, our study has three goals. First, to offer a fine grained account of possible links between HIV and mental health within an AIDS-affected group of women; to explore women's own understandings of their mental distress, focusing on a non-clinical sample of distressed community members; finally, to explore women's efforts to cope, in the interests of highlighting their agency as well as their distress. We hope that such a focus might be useful for those seeking to develop prevention and intervention strategies among AIDS affected women who are at high risk for mental health problems.

Methods

Study site

Nineteen in-depth semi-structured interviews were conducted as part of a larger study of rural community mental health services in the contexts of social deprivation and HIV/AIDS. The field site is a sub-district located in Umkhanykude health district in Northern Kwa-Zulu Natal (KZN) province, which has the highest antenatal prevalence of HIV at 37 percent (Shisana et al., 2009). The sub district is also the most under-resourced area for mental health in the province, with three psychiatrists overseeing a catchment area of 2 344 038 individuals (Chief Psychiatrist, Area 3 KZN province, personal correspondence December 2010).The province has been indicated as one of the highest risk regions for mental health problems, with the highest proportion of people living beneath the poverty line and second highest murder rate in the county (Burns, 2010).

Sampling and data collection

Participants were randomly selected from a larger community survey administered to AIDS caregivers and their children in Kwa-Zulu Natal (Casale, 2013). Characteristics of individual participants are listed in Appendix A. Informants reflected a range of severity of symptoms (mild – severe) using three psychometric tests exploring symptoms of depression (CES-D 20) anxiety (Beck Anxiety Inventory) and post-traumatic stress (Harvard trauma questionnaire), which have been used on South African populations (Hamad

et al., 2008; Smit et al., 2006). A mild rating equated to having scores on each measure that fell below diagnostic threshold, but still indicated the experience of some distress in their daily lives; moderate equated to having mid-range scores on each, and severe equated to meeting diagnostic criteria on each measure. Semi-structured interviews focused on their lives, stresses and coping strategies and explored the experiences of emotional distress women might have had in mind when completing the symptom surveys. Interviews were conducted with Zulu speaking local research assistants (RAs) who received five days of training in qualitative interviewing skills and common mental disorders. RAs translated between the lead author and participants during the interview, which allowed the lead author to prompt emerging themes. The use of translators as cultural brokers was informed by Swartz (1999) guidelines on the use of interpreters in cross cultural mental health settings.

All participants' self-disclosed details of their experience with HIV/AIDS during the course of interviews. Interviews were conducted by the lead author (with experience with mental health populations) and translators over a six week period in November and December 2010. Audio recordings were translated and transcribed by an independent translation company, with back translations completed for 20% of the sample by an independent Zulu researcher.

Ethical approval for this study was obtained from three different ethics committees associated with: (i) the London School of Economics, (ii) the University of KwaZulu-Natal and (iii) the KwaZulu-Natal Department of Health.

Analysis

Interviews were analysed using grounded thematic analysis (Glaser, 1991). This involved an iterative process with multiple readings of the data. The first pass identified in-vivo codes (excerpts of text). The second progressively categorised these into themes relating to 'social context' and 'coping response.' This large thematic network was then split into two separate coding frameworks – one highlighting women's explanations of their distress, and the other their coping responses (see Appendix B). We found no differences in the accounts of coping strategies given by women varyingly rated as mild, moderate or severe based on the mental health measures. Thus, qualitative themes represented the range of experience in our sample, rather than a particular explanatory or coping model for a particular "type" of individual. Our analysis maps out the diversity of coping mechanisms across this group of women as a whole.

Findings

Women's accounts of their emotional distress resonated strongly with Summerfield's characterisation of mental health in terms of opportunities to experience 'social connectedness' within 'coherent social worlds'. Women's sense of social connectedness was linked most closely to their family

relationships – disrupted in a social world rendered incoherent by poverty, gender inequality, HIV and violence. In contrast with Shatz's (2011) categorisation of individual women as strong, intermediate or weak copers, our findings suggested that rather than consistently coping or not coping, each of our informants used a range of varyingly effective coping strategies, making it difficult to make generalisations about individual women's overall successes or failures. We conclude our findings with a single case study that illustrates the complex interplay of success and failure in one woman's efforts to cope.

The social contexts of women's emotional distress.

Themes of family, poverty, violence and HIV emerged as the key contextual dimensions in women's accounts of their emotional distress.

Family

Women highlighted four particularly challenging dimensions of their family life. The first was abandonment by a husband or boyfriend. In a resource poor community with virtually no local employment opportunities, men often travelled to distant locations as migrant workers, where it was not uncommon for them to find other partners and eventually to stop sending money to their rural wives and children. Given women's often total economic dependence on men, the man in question was always the primary source of financial support for the woman, her children and household. Accounts of such abandonment often fixated on the resulting loss of income rather than loss of love. Ni spoke of her distress related to her abandonment by her husband, now living in a larger city with another woman.

…I am not happy at home because I am always thinking about the father of my children …People who are happy are those who have their husbands because they give them money and support them, but I cry all night because I don't have a husband to support me - Ni

Women described feeling emotionally distressed by problematic relationships within the family. Intergenerational issues involved disagreements with children over dropping out of school (primarily to find employment), pre-marital relationships, and arguments with step-children who disregarded their role and efforts as a mother.

"A lot of things make me sad, like when children don't pay attention to what I'm saying and they do things that are wrong… I tell them to come home straight from school, but they wander around and come home later – if something happens it will look like I don't take good care of them" - Ti

Fighting with siblings and parents over financial resources was a source of distress. Women identified arguments about payment of *lobola*, and lack of contribution to household needs by blood relatives as sources of sadness and stress. Disagreements with in-laws related to expectations of how women

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should behave within the family unit, which is linked to the gender inequities created by a still very largely patriarchal society. The quote below exemplifies this particular difficulty:

P: The hardest thing in life right now is that I have to stay here at my [late] husband's household where my-father in-law does not support me… I have a good job and he doesn't approve … I want to leave but I am not allowed to go and this really hurts me.

The third dimension related to the death of a family member regarded as integral to everyday or future security. Those who had experienced the loss of a mother described an enduring sense of sadness even long after her passing. The loss of brothers and fathers was also cited as difficult as it signalled the need to assume responsibility as head of household, or, loss of a security network to be called on in times of hardship.

"When I think deeply I feel scared and then become depressed – I think about the issue that I am still young but faced with challenges of heading the household now my father has died, there is no one but me" - S

Poverty

The experience of poverty was a driving feature of every woman's life story, and directly linked to discussions of emotional distress by every participant. Poverty manifested in the lives of women through food insecurity – which often intersected with familial issues, for example, a mother's sadness and distress at not being able to feed their children.

"It is impossible not to think about it. When you are at home sitting and the kids are gone without pocket money, you always have the thought about what are they eating while other kids are eating, and you know you didn't give them [anything to eat] - T

Poverty also resulted in worries about housing, with women linking the condition of their homes to emotional distress. They emphasised features such as leaking roofs that offered no protection from violent seasonal rains, inadequate spacing for the size of the family, and open windows that left them vulnerable to crime.

"Look at this house… this house is difficult to manage – it's not proper because I don't have things like a microwave, and as I am supporting many children, I can't afford to build in area like other people…The roof on the house is damaged and leaks onto the children while they sleep… I am always worried about the house falling down – it needs to be fixed" - B

Financial insecurity was the predominant concern, the overriding factor that shaped food and housing insecurities. Women linked insufficient funds to run their homes, feed and clothe their children as a source of distress.

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I don't feel good because I can't get a temporary job to be able to help with certain things, because you can't ask your husband for everything- we women should be able to do something to help [our children] - T

Violence

Women's accounts of violence highlighted emotional distress arising out of victimisation from crime, or fearing crime because neighbours had been victimised. These stories unsurprisingly highlight complex life situations that are impacted by factors such as financial insecurity and housing situations.

"The house that I am living in is not right, the criminals can enter at anytime – look at this window – I'm not happy sister, with the way I am living .They have broken into the neighbour's house and stabbed a girl"

The following quote by B demonstrates a situation where community norms and failed formal social structures enabled vigilante justice. B's comment describes an experience where elder men in the community were looking for her son in relation to a robbery of a nearby home.

"In another nearby house they beat up the mother after finding some stolen goods in her home and her son wasn't there. I thought they were going to kill me too – my sister called my other sister and she challenged them to think that it was not going to help by killing me since the person they are looking for wasn't there. This was a very sad day for me…I am scared of living in this place …the scene of my community makes me unhappy…I wish to move out but I don't have the means or a place to go" - B

HIV

19 interview participants were affected by HIV in one or more of the following ways: 1) themselves HIV positive 2) caregiving for AIDS affected children/orphans; 3) having lost a family member to HIV. Despite the high proportion of HIV-affected women in our sample, HIV did not emerge as an independent driver of their emotional distress, beyond predictable accounts of sadness at the discovery of one's HIV positive status. However HIV was consistently mentioned in relation to its impact on poverty and family. For example, HIV positive women spoke of how HIV related symptoms – most often weakness and pains in extremities - resulted in a loss of agency, which had knock on effects on their ability to provide appropriately for their families. For example, V, an HIV positive mother of 3 shared the following:

"When I found out I was positive it really upset me because I was sick and was in a lot of pain and my hands and feet were in a lot of pain – so I couldn't do things on my own which made me very sad… I want to start medication to make sure I don't wake up one day very sick and unable to take care of myself and my children…I don't want to wait until I am sick, because then they send you to places where you can't do things on your own. " - V

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Women also spoke of how HIV impacts on the lives and relationships of their family members.

"I have two kids, and take care of my sisters two children, she passed away from that disease that is killing people [HIV]… she denied it, but it was clear later that she died because of it. I really was really hurt because we put our trust in her and believed that she had finished school and then she got sick … now I take care of her son and daughter since 2006… it is not easy but I could not turn them away it would be wrong" - M

In sum, women referred to struggles with poverty, violence, family and HIV as the source of their emotional distress. The following section focuses on their accounts of how they attempt to deal with the resulting mix of emotional and material distress that result from these social factors. Women drew on indigenous personal and local resources in the following ways: (i) psychological re-/framing of negative situations, using strategies ranging from a passive acceptance of life problems as inevitable, to confidence-building through more positive self-affirmations and (ii) the mobilisation of emotional and material support from indigenous inter-personal networks, churches and HIV support groups. Less commonly, women sought advice from traditional healers, medical services or social workers, but their access to these was often very limited. A minority of women were able to supplement government grants with their own income generation efforts in ways that successfully supplied what women felt was enough to meet their needs and improve their sense of control in highly precarious circumstances.

Coping with emotional distress- strategies

Women's accounts of their coping strategies were categorised under four broad themes: psychological framing of life situations/contexts, mobilising social support from the community, accessing expert advice, and generating income.

Psychological framing of life situation

Psychological framing of contexts refers to women's use of emotional coping strategies, such as self-affirmations, and acceptance, which were mediated by advice seeking from peers, or family members. For example, where women perceived complicated family dynamics – such as difficult relationships with other wives, the abandonment of a partner and often associated loss of financial support – as unalterable and inevitable, acceptance was used as a route to framing their emotional distress.

"I am not happy in marriage because the father of the household has left and is living in [another town] and I am left to take care of the house alone. I heard that he paid lobola for another wife and is living with her. I was very angry at first, but now I have accepted it … there is nothing I can do, it is just how men are." - N

When women discussed their distress with peers or family members they often advised them in one of two ways: to maintain their on-going commitment to their family rather than attempting to leave a bad situation, or, acceptance of mistreatment from male partners. Both forms of advice lead to women identifying 'acceptance' of their current situation as their response to distress.

A second framing strategy revolved around faith and hope. This strategy was also often advocated by those women turned to for advice, particularly church leaders or other members of their congregation. In these instances, women who drew on faith and hope to frame similarly desperate and unchanging contextual factors were able to sustain a belief that things could improve. In some cases they reported that these narratives led to improvements in their lives. The following quotes highlight how women used faith to frame a bad situation, in the process sustaining themselves in violent community contexts.

"The scene of my community makes me unhappy…I wish to move out of this place but I don't have the means or a place to go… Sometimes I will talk to [my friend] … she takes me to church and then I will forget about troubles after that – there is nothing more to do I just give it to God and pray to make things better" - E

Interviewer: what do you pray about?
L: When you are not happy in your life you just ask them to pray for you so that you can get through it.
I: does that help?
L: esh, yes, it does. Because you know with God it gets better.

Both styles of framing were evident within women's references to managing the discovery of their status. Women described the use of personal affirmations to maintain hope in the face of a positive diagnosis. This was mediated via strategies of advice seeking and sharing stories with peers, who advocated for hope and reminded of positives within a situation.

"With regards to my status I have just told myself that I'm sick and my deep thinking about it will not help me. I have just accepted it, like I have also accepted that I have arthritis" - V

"When I was tested and found to have this illness [HIV] I was hurt and cried the whole night... I shared this sadness with my aunt .My Aunt told me to be patient, and that I am not the first one [to get HIV] I was wondering why this happened to me, I have no mother or brothers to help me with this problem. My Aunt advised to be patient, to remember all the people who are living and that treatment will make me better"- Ni

Mobilising social support from community

Mobilising social support was the strategy most frequently mentioned by women. They derived it from friends, family members and neighbours in times of sadness resulting from poverty, fears of violence in the community,

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loss of loved ones, and intergenerational conflicts with children. Strategies such as advice seeking and unburdening through sharing the stories of their difficulties were prevalent in facilitating social support.

"If I go to my aunt to share my story [about] how poor I am, my worries of how I bring up my children, she says please stay [at the homestead] and be patient and try what you can… But I find myself being afraid a lot. There are times when I don't feel alright because of my children, when they bring their problems to me [needing clothes/food] and I can't help" - N

"When my husband left me, I was very upset…it makes me unhappy but I don't do anything, I just look [let it happen]. I talked to friend about this for comfort, she thinks I should stay in [town] and work and take care of my children …there is no reason for him doing it, men are just men."- A

These quotes also highlight how active strategies like advice seeking, may not always tackle the problematic environments that establish distress when advice also leads to the acceptance of distressing circumstances. However, positives to this strategy remain. Commitment to family has knock on effects in supporting women's use of poverty alleviation strategies (discussed in the following section). The value of advice seeking, when paired with critical thinking about life situations and cultural norms is highlighted by one woman:

" I Talk to my friend about our life, - we talk about building our own homes despite the fact our husbands left us… she told me to stay and to start collecting building materials and blocks to build my own house.. If we are running short of food we share resources with each other, this is [always] helpful to me"- D

This quote also highlights the strategies of pooling resources between close friends, neighbours and family members. Many women described these as routes for coping with poverty and food insecurity. However, such strategies had their limits, as one woman described:

"I used to get money for groceries and to support the house from the father of the baby. After he abandoned us I used to go to the neighbours and ask for food…They eventually started to say bad things about me. They said they would give me poisoned food so we could die because our family is a nuisance. This made me feel very bad" - S

Women also described seeking group-based support, drawing on a range of community groups, including health-related support groups (with one woman forming her own HIV support group) and church groups. These offered a range of emotional and practical assistance. After the death of her husband, P drew on a variety of sources of support. The first was a women's savings group.

I: How did you manage after your husband died? Was there anyone to help?
P: His brother helped us with the funeral.

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I: Was there anyone else?
P: I am a member of a community support group for families. I became a member in March 2010 after my husband died…we support each other with finances to pay for costs of events… like funerals, weddings, graduations… We also support each other in start-up funds for starting our own business like a shop, and encourage each other to save [individually]. We each contribute R30 a month.

The second was a church group.

P: I go to a group of sisters from the church who advise me on life…how a widow is supposed to behave…. They tell me that I have to live without a man in the house for a year, until my husband's family give me permission … I am not allowed to leave the homestead of my late husband or my children will suffer… I will agree with it for now, but I want to meet a new man in the future
I: Is this helpful for you?
P: (laughs) Yes…support from sisters at church is helpful because it guides me away from doing 'bad' things
I: what kind of bad things?
P: Bad things like meeting another husband, because that could lead me to become infected with HIV… This guidance is because of culture – I have to pay respect to husband and respect to the community – it's given to all women whether they choose to follow or not.

Women drew on indigenous social networks in implementing the coping strategies outlined above, which formed a very significant majority of responses in our data set.

Generating income

All 19 women engaged in efforts to tackle the crippling poverty and hunger that blighted their lives. In a context where income generation opportunities were scarce, women discussed attempts to eke out a living from selling fruit, washing clothes and where possible, other part time jobs. However such survival strategies were extremely precarious.

"When I found out I was sick [HIV-positive] he took me to this place, and he left… He doesn't care about me and he is not giving me food… I am now washing linens for cottages, I use that income to pay for food, supplies for the children at school – when I am in too much pain, I cannot do my washing so there is no money to eat… sometimes I have no idea what to feed my kids." - Ni

Government grants, including disability grants, old age pensions, and child support grants, were women's primary source of financial support. Those receiving larger grants (such as the disability grant R1,030/month at time of data collection) spoke of how they used the grants to cover a wide range of family needs.

"…it's ok, because now God is helping me, and I am working and also receiving a grant so things are OK. I have enough food to eat. It helps a lot to prevent the children from going to bed hungry. I use money from child support grants to buy food and cement to build a house for us which really helps." - C

Attempts to supplement grant income through individual or group agency (such as part time jobs or savings groups) were cited by all women. However, only a minority of cases (two) described these efforts as successfully increasing their sense of control over life circumstances. Others asserted that these efforts failed to generate marked improvements in their daily lives, citing such failings as evidence for the on-going desperation of their lives.

Accessing expert advice

A minority of women described occasions where they sought guidance from 'experts' regarding life problems that were causing emotional distress. Women spoke of consulting traditional healers in relation to deaths of family members or conflicts with family members that they believed had resulted in physical illness or mental distress, seeking the help of nurses or occupational therapists in hospital or clinic settings, or, less frequently, seeking advice from social workers when facing problems with children. However access to experts was very limited. Access to public health or welfare services were very limited in this resource-poor setting, where under-resourced and poorly staffed hospitals, clinics and social workers were often overwhelmed with the demands of coping with the twin scourges of AIDS and poverty, and completely unable to offer support to all the needy cases in their geographical areas (Nair & Campbell, 2008)

Coping in context: A case study

As discussed above, in contrast to Shatz et al.'s (2011) classification of individual women in terms of bounded categories of coping or non-coping, our sample presented a much more complex picture, with no single woman presenting wholly as a 'coper' or 'non coper'. Rather it seemed that all women were sometimes able to cope and sometimes not, drawing on a mix of varyingly effective strategies. The case of Sisi illustrates the complex mix of strategies that she drew on from day to day: some passive, some active; some more and some less effective:

Sisi is a 35 year old HIV positive mother of two girls. She told us she had become infected while caring for her mother with AIDS-related illnesses. The death of her mother was devastating - the only time that she had contemplated suicide. Sisi never knew her father, who deserted her mother soon after her birth. Her only remaining blood relatives are her unemployed brother and two daughters. Sisi is estranged from the fathers of her own children; one in prison for theft, and her relationship with the other is particularly strained: "I couldn't even ask him for a pencil if the child needed it". At one stage she tried to implement legal proceedings to force him to support the child, unsuccessfully.

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Sisi speaks openly about her HIV positive status. She says that whilst she felt some sadness on discovering it, it is no longer an issue. She speaks almost flippantly as she recites the formal HIV prevention discourse on condom use. She speaks positively of her work with other HIV positive community members, particularly proud of her initiative to start a support group to give people with HIV a safe place to talk about life struggles, and their emotional reactions to their diagnosis. The only worry that she shares about her status is what will happen upon her death given her daughters' abandonment by their fathers.

Sisi is not on ARVs (her CD4 cell count was 500, higher than the 200 required to access ARVs from public health facilities at the time of the interviews). She views each headache as a potential sign that "this thing (HIV) may beat me". She shares these fears with other members of her HIV support group, who are able to understand them. She acknowledges that "it is important to talk to others who can understand where [I'm] coming from".

Sisi runs a small shop on her property, where she sells cigarettes and alcohol to local men. This small income supplements her disability grant, and despite dual sources of income, her financial struggles persist, and she reports often not being able to feed her children properly, identified as one of her key on-going worries and concerns.

Sisi was the victim of a robbery, but received no support from the police. Eventually, her brothers managed to relocate the lost items themselves. Her eldest daughter is the greatest source of stress in her life – their constant arguments result in her daughter running away from home for days at a time. She talks about this occasionally with a friend, who supports her by reminding her that things will get better. She also occasionally prays about it – citing that only God can really help with her troubles. Their main source of conflict regards Sisi's grandchild, who is often left alone when her daughter disappears to spend time with her boyfriend. When her daughter attempted suicide (whilst staying with her boyfriend), Sisi was directed to a social worker at the hospital to mediate between them. The daughter returned home after that, and though things have improved Sisi cites this conflict as the major concern in her life, something that "hurts her heart" a great deal

The case study of Sisi illustrates the social embeddedness of her emotional distress, and the full range of strategies employed to tackle it. Sisi's scores on the three psychological measures were 'severe' as defined above, placing her at threshold for depression, anxiety and PTSD as defined by the measures. Despite this, she had made many efforts to 'take charge' of her situation, reflected in her exercise of agency in accessing experts, such as hard-to-reach social workers, establishing a support group, setting up a shop and so on. Her brother, though unemployed, was a source of support in some ways, and she had several strong friendships, as well as a strong religious faith buttressed by prayer and church attendance. However, attempts to exercise this agency in other contexts, for instance, in relation to the fathers of her children, and on-going conflict with her daughter (her biggest concerns) were

less successful. Sisi's case illustrates the complex range of varyingly successful responses mobilised by women. Furthermore her story suggests the limitations of approaches that focus narrowly on biomedical or behavioural responses to mental distress, in the absence of efforts to assist the distressed in managing the family and economic hardships that fuel their mental ill health.

Discussion

Our qualitative study has explored how a group of emotionally distressed women experience and seek to cope with their daily life challenges. Our work has been guided by the work of Summerfield who emphasises that opportunities for mental health are optimised when people have opportunities to experience a sense of cohesion in a coherent and actionable social world. Our study responds to calls for greater qualitative research attention to the lived realities of women who cope with their distress outside of the formal mental health service sector. Such research holds the potential to complement existing epidemiological findings that highlight high levels of mental health problems in resource-poor communities, but tell us little of the ways in which such women experience and manage their emotional distress.

Our findings highlight the central role that women give to poverty, cultural norms around marriage and partnership, dealing with the fallout of the migrant labour system (particularly in the form of absent husbands who do not send remittances), unemployment, and intergenerational conflicts in talking about their experiences of their mental well-being. In their own ways, each of these challenges rendered women's social worlds incoherent, in the sense of throwing up problems that were beyond their power to solve and resulting in great personal pain. Our analysis has highlighted the ways in which these factors interweave to shape the relationships that are central to women's experiences of their emotional experiences, with relationships being at the heart of their stories of worry and sadness. For example, in relating the source of their distress, women didn't refer to their own hunger, but rather to the agony of not being able to feed their children. In this instance their narratives of distress arose out of their own desire, as well as broader cultural expectations of a good mother who provides for her children.

We have pointed to the complex mix of success and failure that women achieve in their efforts at coping, in ways that would make it difficult to label particular women as coping or non-coping along a continuum pointed to by recent work of Schatz and colleagues (2011). Even women who appeared stronger or weaker than others in their cohort (based on mental ill health scores), shared stories of success alongside those of significant struggle or failures. Furthermore our findings often stood in contrast to accounts of AIDS-related coping that emphasise the exercise of agency (understood as the exercise of active resistance to negative circumstances) as a core component of successful coping, with the ability to exercise agency seen as a core component of sound mental health (Skovdal et al., 2009, 2012; Lee, 2012). For many women in our sample, in many situations, acceptance of the inevitability of their dire social circumstances was the only response available

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to them in the face of the often insoluble life challenges they faced, and the severe limitations that their poverty and lack of education or confidence placed on their life possibilities. Their accounts highlighted the ways in which inter-locking gendered, cultural and economic constraints limited their ability to exercise agency in many contexts.

Discussions for integrating mental health care into HIV/AIDS programming have gained prominence in recent years given findings that identify high rates of mental disorder in HIV positive and affected individuals (Freeman et al., 2008; Freeman, Patel, Collins et al., 2005). Our findings suggest such programming must go hand in hand with efforts to tackle the social circumstances that shape both their HIV and mental health experiences. HIV/AIDS was not seen as a particularly outstanding problem in their lives, with women primarily referencing how it limited their ability to cope with poverty. This suggests that efforts to empower women to tackle their poverty would be a critical pillar of HIV and mental health programming. The lack of centrality of HIV/AIDS and its effects in the life stories of women living in a pandemic stricken community, may speak in part to recent advances in responding to HIV/AIDS, including the fact that accelerated roll-out of ARV treatment promises to turn the disease from a death sentence to a regular chronic illness for those who are able to source reliable access to the treatment. We are confident that our informants' lack of attention to this topic was not driven by a sense of stigma or denial that plagued KZN women's experiences of HIV/AIDS earlier in the epidemic (Campbell et al, 2008), and continues to be problematic for many HIV positive women (Petersen et al., 2013). At no stage of any interviews did anyone show reluctance to discuss their personal experiences of the epidemic, and all informants were assured of confidentiality and anonymity of their contributions.

The second critical pillar would be for interventions to take account of how women's distress was fuelled by perceptions of their failure to ensure the well-being of their families. Given women's frequent references to the value of local social support and advice seeking from family and peers in this vein, suggestions for interventions to support mental well-being may continue to draw on strategies such as problem-solving therapy (Van't Hof, Stein, Marks et al., 2011), support groups and inter personal group therapy (Bass et al., 2006; Petersen et al., 2011). However, our findings also highlighted how social ties can be as much of a cause as a solution to distress, particularly within family-centred cultures such as those which dominate many African contexts with extensive systems of kin-based obligation.

Whilst advice-seeking is often characterised as an 'active' coping strategy (Moneyham, Hennessy, Sowell et al.,1998), in our particular study, women's efforts to solicit advice from other women and family members did not always promote change in the contexts framing distress. On the contrary, such advice often urged women to accept difficult situations as unchangeable sometimes supported by culturally driven narratives. In this respect, the use of peer-led support groups may not necessarily always be the most effective way to counter the sense of hopelessness and helplessness that was often the very cause of women's distress. In their study of the dynamics of community

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support groups for emotionally distressed women in a similar community in KwaZulu-Natal province in South Africa, Petersen and colleagues (2012) highlighted the way in which support group members often urged one another to 'accept' negative situations (such as tolerating violent breadwinners, in the absence of alternative source of income) that were unsafe for women and families. These findings highlight the ambiguity of well-intentioned efforts to develop community support programmes that respect and strengthen local responses to difficult circumstances. Our study confirms the need to think more critically about how group-based support therapies can be designed to target broader dimensions of women's distress through creating tangible opportunities to challenge the perceived 'unchangeable' aspects of their lives

Elsewhere (Campbell and Burgess, 2012) we have promoted the importance of (i) opportunities to exercise agency, as well as (ii) the need for the provision of supportive social spaces for peer dialogue and support in the interests of developing such agency, as key dimensions of 'community mental health competence' where local people are most likely to work together to support community mental health. This is particularly important given that current emphasis on treating severe mental health issues have resulted in a revolving door phenomenon between the community and hospital settings, with comparatively low access to holistic community level services (Petersen and Lund, 2011).

We have also emphasised the vital need to create social contexts that provide communities with opportunities to develop such competencies (Campbell, Cornish, Gibbs and Scott, 2010). Crucial here is the development of supportive partnerships between communities and external agencies (particularly in the public health and welfare sectors, as well as the NGO sector where appropriate) to assist communities in creating social settings that enable and support the development of health-enabling agency by the highly marginalised groups most vulnerable to poor ill-health. And it is here that a great deal of research and policy thinking remains to be done.

The Movement for Global Mental Health (http://www.globalmentalhealth.org/) (Patel, Collins et al, 2011) is increasingly emphasising the link between mental ill health and poverty (Lund et al., 2010) in a way that opens up spaces of action and analysis of the kind implied by the findings in this paper. Organisations such as BasicNeeds (http://www.basicneeds.org/) are working internationally to pioneer approaches that link mental health to livelihoods, emphasising that economic empowerment needs to be a core component of promoting mental health in highly marginalised settings. The Movement has emphasised the need to expand the research base to inform responses to mental ill health in conditions of poverty and social disruption (Patel, Boyce, Collins et al., 2011). We hope that research such as ours – small-scale studies of peoples' experiences in deprived settings – contributes to the on-going challenge of injecting understandings of local experiences into more global debates about how best to supplement formal mental health services with approaches that take account of both the social factors that exacerbate mental ill health, as well as the possibilities and limitations of indigenous networks in tackling these.

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Appendices

Appendix A: Participant demographic details

Participant unique ID # and Initial	Age	Symptoms of emotional distress (mild, moderate, severe)	HIV context
121135 (E)	42	mild	Resident of HIV affected community
121136 (T)	52	severe	Lost family member to HIV
121195 (B)	68	mild	Lost family member to HIV
121208 (D)	32	mild	HIV positive
121120 (K)	76	severe	Caregiver (grandchildren)
121123 (P)	36	mild	Caregiver
121078 (Tr)	63	mild	Caregiver
121117 (N)	39	moderate	Lost family member to HIV
121077 (S)	35	mild	Caregiver
121252 (Sisi)	35	severe	HIV positive
121041 (C)	55	moderate	Resident of HIV affected community
121071 (L)	42	severe	Resident of HIV affected community
121022 (A)	42	severe	Lost family member to HIV; HIV positive
121076 (R)	43	mild	Lost family member to HIV
121024 (V)	45	moderate	HIV positive
121704 (Mi)	27	severe	HIV positive
121491 (Ni)	43	moderate	HIV positive
121359 (M)	48	severe	Lost family member to HIV; HIV caregiver (nieces/nephews)
121216 (Ti)	42	moderate	Caregiver (daughter)

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Appendix B: Coding frameworks- Accounts of emotional distress and coping strategies in managing distress

Table 1: Social Contexts shaping women's accounts of emotional distress

Global Theme	Organising theme	Examples of basic codes (in-vivo text)
Family	Polygamous relationships	Husband doesn't support my household after marrying new wife
	Abandonment	Husband deserted family
	Loss of family member	Mother died from pneumonia
	Family disputes	My parents are mad that my boyfriend cannot pay lobola
	Intergenerational issues	Daughter and I argue about living with her boyfriend
Poverty	Food insecurity	I feel sad not knowing what to give my children to eat
	Inadequate housing	The house I'm living in is not right the criminals can enter and kill us
	Financial insecurity	We have a grant but it is not enough to support the children's needs
	Unemployment	I am not working- there is nothing I can do there are no jobs here
Violence	Victim of crime	Daughter was raped by the drunk friend of husband
	Witness of crime	Witnessed a mother in a nearby house get beat up by community members
	Vigilante/community justice	Members of the community came to punish my son for alleged crime
HIV	Infected because of husband	I found out I had this sickness and he told me not to tell anyone
	Infected because of care giving	I was taking care of my mother and then found I was infected
	Care giving for AIDS orphaned children	After sister died her children came to stay with me – it is hard but I couldn't turn them away
	Loss of independence to due to pain symptoms	My legs often hurt and i am tired, and I cannot work

Table 2: Coping strategies in managing emotional distress

Coping strategy	Process	Coping behaviour	Context and content (in-vivo codes)
Psychological framing	Acceptance	Self - affirmations	I tell myself to just put my spirit down [calm down] when I worry about my troubles – there is nothing I can do
		Advice seeking (family)	I talk to my mother about my problems with my father in law – she tells me to focus on my children so I have let it go
		Advice seeking (friend)	After husband left talked to a friend who advised to stay and take care of children, and I have just accepted men are just men.
	Faith/hope	Self-affirmations	Only god can help with my troubles – I just pray and give it to him
		Advice seeking (priest)	I talk to the priest about my husband [drinking problem] and he says if we pray for him and it will get better
Mobilising social support	One to one support	Sharing stories (family)	I will talk with my siblings about our troubles and we make each other laugh
		Advice seeking (friend)	When I worry about these things I will talk to the lady from the Nutuli Clan and she will tell me to do my best and be patient
		Sharing/pooling resources	I pool resources together with the other families on the homestead to buy food
		Sharing stories (friend)	Talked about being abandoned with friend because it made my stress go away
	Group based support *(bonding social capital)*	Membership in support group	When you find out you are positive you need someone to talk to – a friend you can trust so you can feel better so I started a support group
		Membership in church/faith group	When daughter in law's family was accusing me of bewitching daughter who died (HIV) my church group comforted me and supported me
Accessing expert advice	Social capital (bridging)	Seeking medical/professional advice	I saw a social worker to help me get a grant for HIV

Coping strategy	Process	Coping behaviour	Context and content (in-vivo codes)
		Seeking medical treatment	I visited the physiotherapist who gave me exercises to help with the pain in my legs
		Seeking traditional healer advice	After my husband died my children couldn't sleep so I asked the traditional healer to help
		Seeking traditional healing	I was sad that I could not have a baby so we saw the traditional healer who helped and I got pregnant after that
Income generation	Individual agency	Part-time job	For extra money I wash linens for the cottages on the reserve
		Juggling financial resources	Use money from grant to buy material to build house 1 brick a month
	Collective agency	Participate in savings group	After husband died I Joined a community support group that encourages individual saving plans as well as group contributions