

**Charting the terrain of childhood, adult sickness and care:
Ethnographic research in a poor, peri-urban community affected by AIDS**

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May 2012

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Acknowledgements

While I am the sole author of this report, I use the second person in the analysis below when referring to the activities, observations and reflections that I shared with Pride Mtetseni, research assistant on this project. I am very grateful for her dedication and insight.

For four days of the second phase of fieldwork, we were joined by Chiedza Mutizwa Mangiza (a trained journalist and visual anthropology student) and Nozuko Ncwalase (local community development worker). We thank them for their assistance with photography, video editing and translation.

I also thank colleagues at the University of Cape Town, namely Helen Meintjes, Lauren Wild and particularly Andy Dawes, for their input in design and support during and after fieldwork.

Purpose of the report

- To share process and findings amongst the Young Carers project team;
- To mount on website (as one of the products of study, as a conceptual foundation for any audio-visuals or policy/practice pieces)
- Ground work for subsequent shorter paper (on substantive findings) & book chapter (on ethical quandaries)

My intention in this report is to tell a story of the research process and its outcomes. I have tried to keep the account moving, while at the same time giving sufficient detail. No doubt there are gaps to be filled, and trimmings to be made...

Upon reading this report, readers will discover:

- what the study found and the implications of findings for the debate;
- the difficulties in knowing about the issues of illness, care, and the messiness and 'holes' in field research;
- the need for continuing reflection on our research enterprise, and what else happens within our drive for evidence-based research, pertaining to children and families living with poverty, illness and other implications of AIDS.

Audio-visual work

Nine of the twelve children participating in this study made short videos about their lives and experiences of adult illness. With support from Chiedza, I drew on three of these to produce a ten minute video commenting particularly on children's relationships with their community. It was designed in response to a call from RIATT for audio-visual resources to show in the satellite session of the ICASA conference in Ethiopia, December 2011.

Importantly, only four children consented to their videos being shown to other members of the community meaning that none of this audio-visual work can be mounted on the web at this point. Seven children consented to their videos being shown to the rest of the Young Carers research team, and all consented to their showing to government or other policy makers, within South Africa or internationally.

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Summary & Policy Brief

Evidence to support broad-based responses to children living with AIDS in the family

Source: Bray, R (under review) 'Young Carers': Ambivalence and contradiction in a South African peri-urban settlement.

Recent in-depth qualitative research amongst children living with sick adults has exposed how they cope and why they become vulnerable, as well as how they respond to neighbourhood resources and specific AIDS-related intervention.

This study is part of the Young Carers project designed to question whether and how living with AIDS triggers different vulnerabilities in children to those arising from other illnesses. Young Carers is a collaboration between South African government, the National Action Committee for Children Affected by AIDS (NACCA), Oxford University and the University of Cape Town. A full report of research methods and findings from this and related research is on www.youngcarers.org.za

The Questions

- What aspects of living with and caring for sick adults do children feel equipped for, and derive benefits from?
- What aspects of caring are beyond children's abilities, add to existing vulnerabilities or cause new stress?
- What prevents families and communities protecting children and enabling them to thrive when caring?
- What kinds of services and supports work?

The Research

- Worked intensively in an informal settlement outside Grabouw, Western Cape province with 14 children aged 9-17 years whose adult relatives have been seriously ill (or died) owing to AIDS or other illness.
- Engaged children in art, drama, video-making and conversational interviews.
- Observed neighbourhood relationships and family life; interviewed adult relatives and social workers.

Finding 1: Children want to care for adults, but face limits to their knowledge and capacities:

- Children are confident in their ability to keep sick adults company, give them food, drink and medicines, and to monitor their well-being.
- Children derive greater personal satisfaction and social value from giving care than from other domestic roles.
- Children live with and care for relatives knowing only some of the causes behind their illness, and little about its prognosis.
- Children often keep silent about sickness at home because they need to be careful about who knows what regarding their own situation and the situation of those close to them, in order to protect the family reputation and to avoid being alienated from their sources of support.
- Cleaning up body fluids is difficult for children and poses health risks when there is no access to clean water or sanitation.
- As adult sickness worsens, children see limits to their abilities to care and rely on trusted neighbours or kin to:
 - Access transport to hospital,
 - Provide adult company prior to, and during, a death.

Finding 2: Caring poses less of a threat to children's well-being than social violence and ineffective schooling

- Frequent violence (muggings, rape, assault) in the neighbourhood prompts parents to try to keep children at home to ensure their safety, a strategy that largely fails and further reduces children's abilities to befriend adults in the vicinity who can support them when caring;
- Efforts of children and adults to protect each other are undermined by the inability of schools to deliver the level of education that is expected to provide a route out of chronic poverty.

Finding 3: Targeting 'young carers' or 'AIDS-affected children' cannot address the core issues:

- When children live with severe sickness (in a parent-figure or sibling) their strengths and vulnerabilities are not determined by their caring role, but by the qualities of their relationships with family and specific community members;
- Services explicitly geared towards AIDS (or families in crisis) may fail because they threaten these small protective networks and will be avoided by children and adults who fear attracting stigma.

Conclusion: The well-being of children living with or caring for sick adults (regardless of illness cause) is best protected through:

- Locating care and services in hubs accessible to all children & families,
- Adults who listen carefully to children & act upon what they have heard,
- Free and available transport to health facilities, & adult access to medicines,
- Food security,
- Functioning schools able to provide quality, relevant education & support,
- Safer neighbourhoods.

Introduction

In 2009 a two year panel survey of over 6,000 children was initiated in six urban and rural sites in three South African provinces where HIV prevalence is over 30% in order to improve understanding of the multiple impacts of AIDS on children. The study was titled 'Young Carers' owing to its specific intention to explore what children do, voluntarily or involuntarily, towards providing medical, intimate and emotional care for sick adults in the home, and how these activities or other implications of living with a sick adult influence their well-being. The panel study was designed to offer the first prospective longitudinal research able to follow a vulnerable group of children through parental illness and death, and yield comparative data from rural and urban settings with high HIV prevalence. The objectives of the study are defined as follows:

1. To examine impacts of being a carer on children's social, psychological, health and educational development and life opportunities
2. To understand mechanisms of risk and resilience.
3. To develop evidence-based policy for 'Young Carers' of unwell adults.

One of the policy issues that this suite of studies seeks to address is whether or not this population of children requires targeted interventions, or whether their needs should be catered for within generic community-based interventions for families and children who are made vulnerable by poverty and other challenges including illness.

This report explains the conceptual underpinnings, process and findings of a small qualitative ('bolt-on') study designed to dig deeper into some of issues under investigation, to inform the interpretation of survey data and to offer a lens through which researchers and practitioners can reflect on the conceptual frameworks currently in use. The qualitative study seeks to complement the panel by providing a more in depth understanding of the manner in which children are called upon to assist in providing support when household members fall ill, and how children respond to such demands.

Setting the scene

The starting point for the qualitative research was to situate children's experiences of adult-caregiver¹ illness and care performed by children within a broader context of neighbourhood and familial relationships in a particular setting. The focus was on growing up in Rooidakke (an informal settlement in Grabouw Western Cape in which one of the Young Carer panels has been conducted), as a means of situating children within the social dynamics around illness and care. We aimed to learn what it is like to be young, aged 10 to 14 years specifically, within this particular neighbourhood and in a contemporary context of prevalent serious illness and premature death.

¹ Throughout the document I use the term 'caregivers' to refer to adults who have responsibilities for a child's everyday needs and care, and may or may not be considered by the child to play a parental role.

Figure 1: Looking from the informal settlement towards the new housing in Rooidakke



A core aim in the qualitative study was to work with the everyday realities and concerns of children and significant adults in their lives, in order to build a picture of responses to illness (and death) and their implications in a specific setting. Thus, this study must draw not only from the literature suggesting links between adult illness and child well-being, but from the body of anthropological work on childhood, family and community in areas of contemporary South Africa where poverty and illness cut deep lines in the social fabric (examples include Henderson, 2012 and Ross, 2009)

The majority of research investigating the effects of chronic adult illness, disability or substance abuse on children has been conducted in developed, Anglophone countries, with the exception of a small but growing enquiry into the effects of adult AIDS illness on children in the global South (Bauman and Germann, 2005; Cluver et al., 2012a&b). A comprehensive review of the literature is beyond the scope of this report. For this purpose, I refer readers to recent publications synthesising studies with a specific focus on the care of unwell or dependent adults by children (Bray 2009; Evans and Becker, 2009; Skovdal et al., 2009), work in progress associated with the 'Young Carers' project (including Lane, forthcoming) and to web-based networks in which issues relating to care-giving children are discussed (www.caregivingchildren.org; www.youngcarers.org.za).

For the purposes of this report, I offer reflections on the literature on children who live with, or care for, sick adults, which tends to focus on three broad questions:

1. What are the implications of adult caregiver illness (disability, mental illness or substance abuse) for child well-being, in particular their mental health?
2. For whom do children care in the event of adult (caregiver) illness and what does such care involve?
3. What is the spectrum of short and long term effects of (living with, and) caring for, a chronically ill adult, and how do gender, age, birth order or personal attributes affect these?

A bird's eye view of the literature indicates relatively scarce enquiry that grapples with the meaning of what we term 'care' in children's lives and those of the adults around them. While culturally defined understandings of care are recognised as salient (Becker & Evans, other refs), their investigation tends not to be given the same priority, perhaps owing to the challenges of understanding evolving cultural values and social realities in sufficient depth. An opportunity for in-depth qualitative work enabled us to add the two further questions, about which the literature speaks more softly:

- To what extent do children in a particular cultural community experience their care duties as an accepted part of their responsibilities around the home?
- How do these responsibilities change depending on current circumstances in the household and community?

Literature review

Here, as a means of foregrounding the processes we engage in as researchers, I look quickly at the main strands of our enquiry and the methodologies used by the research community to respond to the questions listed above. Later in the report I relate the process and findings of this study to these reflections.

1) How do we understand the implications of adult caregiver illness for child well-being?

Research to investigate the ways in which children are made vulnerable by HIV or AIDS is increasing in momentum and diversity as practitioners seek to understand how best to channel resources. Therein, one small but rapidly growing body of work in the global north and south examines the implications for child well-being of living with an AIDS-sick parent or caregiver. Much of this, as explained below, is precipitated by intent to understand how the caring that children do for sick adults affects their well-being. But the implications for well-being, perhaps the most serious ones, are often found to be outside the realm of ‘caring’, at least as the term is used to describe the activity of ‘looking after someone’. As a result, a broader lens is required to consider the spectrum of ways adult illness can impinge on child well-being. The call for care is one that arises within a web of relationships and a system of praxis, of ‘how things are done’. For example, the increasing frailty of one adult may, or may not, affect the division of labour at home or the way income and other resources are distributed.

A similar need for breadth, and length, of perspective is one of the lessons learned from multiple studies on the impact of orphanhood on children where compromises to well-being are found to begin long before parental death, and may not have direct relationship to parental illness.

Of the small number of studies in sub-Saharan Africa that have measured outcomes for children in households with a sick adult, findings indicate higher child mortality, morbidity and malnutrition (Mishra et al., 2005), incomplete immunisation, and school absence (Gray et al., 2006). Because these studies are of very young children, there is the possibility that their own HIV infection through vertical transmission explains some of negative outcomes. There is also the possibility that households with a sick adult have been more fragile, and less able to provide for children for some time – as would be indicated by high malnutrition for example. Adult sickness, in other words, accompanies relative poverty or marginalisation in some way (cf Ross, 2009).

There is some evidence from the developing world that child health risks may be independently associated with caregiver sickness. A trial of antiretroviral treatment in Kenya showed that HIV positive caregiver access to medication resulted in improved nutrition and growth amongst their children (Graff Zivin et al., 2006). Mothers in South Africa who are HIV positive showed higher depression and compromises in their care of infants (Stein et al., 2005). That said, there is other evidence of elevated post natal depression in some South African studies independent of HIV status. The strongest independent predictors of postnatal depression were exposure to extreme societal stressors (witnessing a violent crime/danger of being killed) and reporting difficulties with their partner (Ramchandani et al., 2009).

The link that AIDS-sick mothers in another South Africa study identify between their physical health, their mental health and their ability to care is also observable through psychological assessment

(Brandt, 2007), and through children's behaviour (Bray and Brandt, 2007). A large-scale study of over 1000 orphans and vulnerable youth found that caregiver sickness mediated levels of psychopathology in young people (Cluver et al., 2009)

It is now widely recognised that orphanhood is a mark in time (construed by researchers, and perhaps shared by children and their families) within a much longer process, rather than a discrete event or status (Meintjes and Giese, 2006). By the same logic, we can expect that periods of vulnerability in a child's life prior to adult sickness or death stand to shape their responses to these events (refs). Moreover, amongst families where children are historically most vulnerable, adult illness is more likely and often one amongst several intrusions that are experienced by adults and children alike as stressful, demanding of multiple resources and beyond personal control.

In South Africa, for example, loss of income, eviction and domestic or neighbourhood violence may be as much part of the everyday scenario as sickness (Ward, 2007). Psychologists interested in identifying the effects of multiple challenges that are layered on the lives of individuals, as well as families or communities, have developed approaches to identify the cumulative impacts of adversities.

One suggestion arising from this body of work is that risk rises markedly with the accumulation of multiple stressors (Rutter, 2000). The onus on the layering of experience is consistent with understandings of resilience as a process rather than a trait (see for example Ward et al. 2007 pp166-7; Luthar, 2000).

Research thus far indicates that adult caregiver illness has a detrimental effect on child well-being through three general mechanisms. The first is an increased possibility that a child is exposed to a range of inter-connected social and physical disadvantages, including compromises to education, financial insecurity at home, hunger and malnutrition that severely limit her future potential. The second mechanism, and one that has attracted most research, is the long term psychological damage thought to arise from children's exposure to suffering, plus their own anxiety and grief. And the final mechanism is the undermining of self-esteem and social status that may occur when an adult caregiver is very ill. This small body of work tends to focus on how AIDS-related stigma reduces social support from communities and extended family who refuse to offer help, and how this effects the bullying of children or their stigmatisation when engaging in public tasks such as fetching water (Evans and Becker, 2009). More recently it has extended into processes of identity formation and recognition (Skovdal and Andreouli, 2011).

The gathering momentum of research activity around children and AIDS is not only in response to the scale of the epidemic, but also to an understanding that AIDS stands to have distinct impacts related to the taboos, fears and silences that surround it in any particular context. Much work has been done in southern Africa, and particularly South Africa, towards understanding the dynamics of knowledge, power and morality that underpin the fears of stigma, or drive behaviour that stigmatises or excludes (Maughan-Brown, 2010). What emerges from existing literature is that experiences of stigma (amongst adults), both at a personal and neighbourhood level, are highly uneven and vary considerably between and within urban and rural contexts, yet are rising even in the context of greater access to antiretroviral therapy (*ibid.*).

Does AIDS-related sickness increase children's perception of personal danger entailed in living with and caring for an ill adult? In contexts where biomedical explanations for HIV transmission are part of common parlance, those of any age who care for AIDS-sick people are likely to be aware of the personal risks entailed, their fears around which will depend on what sources of protection are available. But in contexts where disease of the kind associated with HIV is explained in multiple ways, personal sense of vulnerability to infection or the fear of moral 'pollution' may or may not be a factor in influencing the well-being of those giving care (Henderson, 2012).

What may be of greater salience is fear of social pollution, in other words the potential for knowledge about, or the naming of, a sickness to pollute the family. Such fears may impinge directly on child well-being through more tightly maintained silences (leaving children to guess what might be happening) or greater demands for confidentiality. And their indirect effects may include heightened mental stress levels amongst other adults in the home that compromises their care of children, an association identified in other ethnographic work in peri-urban South African contexts (Bray and Brandt, 2007).

Further insight into the way the presence or knowledge of socially unacceptable maladies, or their associated behaviours, in adults can affect child of the household may be found in research from the global North looking at the implications for children of adult mental illness, disability or substance use.

Large-scale qualitative studies in the UK amongst children caring for parents who are ill, disabled or have on-going mental health problems find that children frequently miss school and experience emotional distress (Dearden and Becker, 2000; Aldridge, 2006). Given that a high proportion of HIV infected persons in the North are likely to have become so due to needle sharing and such practices, it is likely that these children are coping with parental HIV status in addition to other challenges that are socially unacceptable, for example substance abuse or alcoholism.

Research in the global North has also tended to investigate the negative outcomes of caring roles played by children, although in a more diverse set of adult illness scenarios including diabetes, HIV/AIDS, cancer and mental disorders (Aldridge and Becker, 1999; Bauman *et al.*, 2009; Cooklin, 2006; Gates and Lackey, 1998; Jacobson and Wood, 2004). Findings identified as significant by Skovdal and Andreouli (2011) include increased likelihood that caregiving children live in poverty and social exclusion (Dearden and Becker, 2000), have emotional difficulties (Dearden and Becker, 1995, 1998, 2004) and suffer impaired mental health (Bauman and Germann, 2005; Cree, 2003; Shifren, 2009). The data also point to ill health and restricted opportunities for developing friendships and social networking, including taking part in leisure activities. Some studies describe these children as having limited visions of the future (Aldridge and Becker, 1993; Dearden and Becker, 2000) and difficulties with education (Dearden and Becker, 1998).

Analysis of the positive implications of a caring role for child well-being is scarce. One study amongst children caring for HIV positive parents in New York and Zimbabwe found that children considered themselves more capable than their peers and were judged so by their parents (Baumann *et al.*, 2006). Research into children's perspectives on their domestic and agricultural working roles reveals pride in assisting their kin and in making a contribution to the home, plus an understanding of skills acquisition (Bray, 2003; Dawes *et al.*, 2011). These studies did not probe whether or how adult illness, or the social acceptability thereof, may have affected children's perspectives.

2) What kinds of 'care' do children in southern Africa engage in and what results from their participation?

When this suite of studies was planned, it was recognised that nothing conclusive could be offered to theory or policy development within the small body of available evidence of both negative and positive impact of caring roles, as well as of children's interpretations of their roles (Cluver, application to ESRC). In many ways, the panel survey and qualitative enquiry were motivated by the call to expand understanding in this area: "...research is needed into the impacts, *both negative and positive*, that caring has on children, the needs of children as caregivers, and the ways in which disruptions to schooling can be minimised" (Foster & Williamson 2000:S278 quoted in Evans & Becker 2009:24, *emphasis mine*).

The image produced by much of the earlier work, particularly in the global South is of a pair of scales, where children's livelihoods hang off balance because the burdens outweigh the advantages. The language of 'burden' found in the literature on children's caring resonates with concerns about child work and labour that took root internationally during the 1990s and have continued to dominate debate (Dawes et al., 2011; Dorman, 2008; Duncan and Bowman, 2008; Levine, 2006; Whetten et al., 2011; Woodhead, 2004). This concern may be proven valid should research show care-related activities that harm children, or which they experience as beyond their capacities. But because it arises from Western notions of a normal childhood that is dependent and carefree, there is a danger that research unwittingly sets out to look for such evidence, and misses the nuances around what is appropriate and manageable for children.

Sensitive to these possibilities, some recent qualitative work has tried to document the varied ways in which children experience the caring role (Clacherty, 2008), and to use these insights to unpick or refine definitions of 'care' that are being incorporated into policy and practice (see for example resources under development by REPSI).

African studies of this nature, while scattered and small in scale, show a combination of costs and benefits to current child well-being associated with the children's caring roles (Clacherty, 2008; Donald and Clacherty, 2004). Some document reports by children of emotional distress, educational shortfalls and abuse (Robson, 2000 in Zimbabwe; Bauman et al., 2006 in Zimbabwe; Evans and Becker, 2009 in Tanzania). The majority (80%) of children in Mutare studied by Bauman et al. (ibid.) said that they had too much responsibility, and could participate to a lesser degree in after-school and peer activities. At the same time, they considered themselves to be more capable owing to their caring responsibilities. Other benefits to being involved in caring for an adult identified elsewhere are about qualities of relationship and internal resourcefulness, such as a sense of closeness with family members, plus a sense of positive responsibility and of capacity to contribute to the household (Dearden and Becker, 2004; Donald and Clacherty, 2004; Robson, 2000).

The study by Bauman and colleagues in Zimbabwe (2006) suggests that these potential positives are reliant on qualities of the child's social nexus. Such qualities are the protective factors built over time that establish resilience of the kind referred to earlier in this review. Another example is Henderson's (2006) ethnographic study of rural orphans in South Africa which describes the way ties are made and sustained between children, their family members and wider community. Such work points to the need to look within and beyond the household to understand how children are resourceful in their extended families and neighbourhoods in ways that influence their long-term well-being.

With the exception of Henderson's work (2006, 2012), studies exploring care by children rarely continue long enough to give us a picture of its impact on long-term well-being. Some findings suggest both short and long-term compromises to well-being, and raise questions about lines of causality operating in particular contexts. For example, two-thirds of a small sample (50) children studied in Mutare, Northern Zimbabwe, had depression scores in the clinically significant range as measured by the Children's Depression Inventory (developed by Kovacs; 1985, 1992). This proportion is extremely high. The reasons are not clear as there was no association between caregiving roles and child depression. The children were drawn from very vulnerable households in which maternal health was very compromised, so the elevated scores may be a function of their very challenging circumstances rather than caring *per se*. It may also be the case that the Kovacs test (which is not standardised on Shona children), produced false positives for cultural reasons. Nonetheless the findings are of concern.

Without a longitudinal perspective, we cannot tell whether short term positive outcomes such as increased competencies are masking negative long-term effects (Bray and Brandt, 2007). Studies with the potential to shed light on such relationships are more expansive in their focus, aiming to understand how the broader social dynamic shifts in response to increasing prevalence of adult AIDS illness (see for example Henderson (2012) and on-going work by Lindsey Reynolds, situated in different rural districts of Kwa Zulu Natal, South Africa).

As noted earlier, another potentially fruitful avenue of exploration is a process-orientated approach to resilience, such as that developed by Ward et al. (2007) and Luthar (2000). Becker (2007), writing about global perspectives on young caregiving supports such a direction on the basis that “researchers may be better equipped analytically to explain *differences* in experiences and outcomes *between* young carers within and across countries” (p. 40). In other words, why is it that some children do well despite living with severe adult illness, while some flounder? A number of scholars looking at child caring are working with this concept (e.g. Daniel in Botswana, Skovdal in Kenya). Such work is very useful in countering the bias in enquiry that can result from a model of child vulnerability (Becker 2007 citing Evans, 2005; Newman, 2002), because it prioritises an understanding of *how* children manage their responsibilities in ways that protect their well-being, and what is available to them in the family and neighbourhood

Resilience is taking centre stage in global enquiry around childhood adversity (see for example Ungar, 2012), and is entering popular discourse through efforts to educate the general public about how children cope with challenges such as caring for AIDS-sick adults, in very different socio-cultural settings. In a press release for a London exhibition of artwork by children generated in research in Kenya, Morten Skovdal, the lead researcher is quoted as follows:

“Our research points to the struggles and coping strategies of young carers in sub-Saharan Africa. One of the more important lessons was the significance of including children's voices in research. By incorporating their perspectives, a different story emerged – one that highlighted children's contribution to dealing with the Aids epidemic and their ability to cope with hardship, dismissing the idea that they are passive victims and a burden to their families.” (www.caregivingchildren.org website for the International Network for Caregiving Children, 2011)

Inherent in attempts like this to rectify an historical bias is a danger that the pendulum swings in the opposite direction and, where attention was on ‘vulnerability’, it now shifts to ‘resilience’. Even without our intention, ‘resilience’ can come to define the children being researched. Descriptors become neat labels because we are called to simplify complex realities, especially when working with the general public or policy makers. It is much messier, and more difficult, to work with co-existent threads of vulnerability and resilience. But the danger is that we proceed without a deeper understanding of the underlying social processes and structures that bolster or undermine children’s wellbeing. And the practical consequence of such a course is that categories of vulnerable child begin to drive a discourse of separated targeted responses based on the construct created by the researcher. The forces that render these, and potentially many more, children vulnerable can be squeezed out of the discussion and the possibilities of holistic responses decrease.

3) What is the spectrum of short and long term effects of living with, and caring for, a chronically ill adult?

As outlined above (in section one of the literature review), questions about impacts on child well-being make sense only when placing adult illness in the historical trajectory of both child and family, and as one of many current reasons why individuals, and groups, are called to dig deep into their physical, mental and emotional resources. What becomes 'burdensome' for some – whether judged by those in that situation or by scientific criteria – may not be so for children whose trajectories have been different. These observations do not render enquiry into child well-being one of futile relativity, but they remind us of the number of variables at play. It is not enough to measure only the range of activities or responsibilities undertaken by the child. A sense of what these mean to children now and in the context of their developmental trajectory (what is available, what is on their horizons) is also required. Mediating factors will include their age and developmental stage, plus their age and gender-related status within the family, and the manner in which responsibilities are distributed in the family. Each of these, and the interactions between them, stand to influence a child's emotional, mental and even physical health, as well as their engagement with external institutions such as schools.

Recent endeavours to extend understanding of relationships such as these have used a framework of resilience to explore the counterfactual (see for example Skovdal & Daniel, 2011). In other words, to ask what needs to be in place within the home or community for children to be able to make sense of a serious adult illness, or adult death, in ways that do not cause lasting problems.

Much of this work is based very broadly on Bronfenbrenner's (1986) eco-systemic model for understanding the direct and indirect influences of children's environments on their well-being. How significant adults in the family relate to others in the neighbourhood, or the school, can be shown to promote or undermine children's well-being by building strengths, or widening fractures, over time.

Increasing attention is being paid to factors within the individual child's current biological make-up and social status, plus the net effect of the interaction between them, to understand how these may enhance resilience. Personality, temperament, history of illness, gender, age and birth order all become salient. [Four chapters within Ungar's 2012 edited volume on resilience are devoted to the individual (in context)].

An eco-systemic approach helps situate the roll of the family, long-considered the primary buffer zone and protector of child well-being, within the structure and sociality of neighbourhoods and society. Research cited earlier and conducted in two very different contexts (the town of Mutare in northern Zimbabwe and New York), found that "the most important predictor of child mental health was a strong parent-child relationship" (Baumann, 2006:68). This study uses a suite of questionnaires linked to psychological instruments so does not investigate the many facets of parent-child relationships in each context, nor can it explain particular qualities of those relationship that sustain children's mental health, that may or may not include dependability, intimacy or mutual care.

One important conclusion drawn in this two-site study was that child caregiving was not, in and of itself, necessarily hurtful to children (*ibid.*). The data point to "some cause for alarm in certain situations – when the child is unable to participate in usual activities including school, when the child is alone and has no adult support and when the child does not feel appreciated" (*ibid.*) all of which are shortfalls in relationship quality, and thus very open to process and change over time.

While scholars persist in the valuable exploration of the family and neighbourhood as mediators of resilience, more systematic investigation of the socio-cultural environment has now become prominent (see for example, Panter-Brick and Eggerman in Ungar 2012). Germane to such enquiry are the norms and values surrounding appropriate behaviour for men, women, girls and boys, and

the appropriate transmission of knowledge, including for example what should remain hidden and what may be made public in situations of ill health.

Where does this qualitative study fit in the bigger picture?

Few studies have widened the lens sufficiently to explore how social and cultural inflections on childhood, maturation, gender, status and the making of 'family' affect our understandings of the relationship between younger and older family members at times of illness or impending death. We know to expect variation in the activities and expectations of childhood in response to different sets of norms around maturation and the raising of children, as well as to what the surrounding environment can support. But we know much less about the manner in which these shape, or are shaped by, children's experiences of and responses to, severe adult caregiver illness. Does the slow, or rapid, intrusion of serious ill-health shift the position of children relative to those around them? Does it place new, or different, demands upon individuals and their relationships as compared to other kinds of intrusions? And if so, are these shifts specific to AIDS-driven illness? Such questions can only be explored through exploratory ethnographic work of the nature intended this qualitative study, the particular aims of which are explained in the section that follows.

Broadly speaking, the ways in which children in Africa are expected to support the family and assume responsibility are extensive and subtly shaped by local interpretations of values of communality and reciprocity, and of gendered and age-based norms. The participation of children in generalised reciprocity within African homes and communities has a long history not dissimilar to other parts of the global South. One contemporary difference is that the value of such participation has been inserted into the continent's legal and moral framework for children, namely the African Charter for the Rights and Welfare of the Child (adopted by the African Union in 1990). The charter lays out the rights, freedoms and duties of children, making plain their responsibilities as members of society in ways that are not explicit within the International Convention on the Rights of the Child.

Before proceeding to the details of research design there is one other feature of the larger universe in which this study sits that deserves explicit mention and reflection. My understanding is that all scholars conducting research on adult illness and child well-being intend to contribute to an empirical foundation upon which policy and practice can be built. The nature and extent of their direct engagement with the authors of policy or the development sector vary, but the fact remains that children are not flourishing, especially where poverty and illness are rife, and we – as a community of scholars – feel an obligation to do what we can towards improving this situation.

The consequences of this moral imperative are myriad, and too numerous to discuss here. However, my reading of the existing literature is that one such consequence is the tendency to view care and caring in instrumental terms, where actions of intent or obligation are mapped and scrutinised for their implications on individual well-being. Often the means of enquiry can fix relationships between individuals and generations in time and in space, disallowing the responsiveness of children and adults to a host of desires, hopes, fears and concerns associated with and outside the illness (see Camfield et al., 2009).

The term 'young carers' has perhaps taken root in this climate, where terms describing children endeavour to capture experience, activities or vulnerabilities (as noted earlier) that are considered qualitatively different by those looking in from the outside. Quickly adopted into popular parlance they become categories that are soon found wanting in their abilities to reflect the realities of those so-labelled (Meintjes and Giese, 2006). Their conceptual inadequacies contribute to the cyclical invention of new categories and sub-categories. AIDS orphans, were followed by OVC (orphans and vulnerable children), CABA (children affected by AIDS), and more recently MVC (most vulnerable

children) and ‘young carers’ all have places in development discourse. Once a category is created, it functions as a box that must be filled with knowledge about ‘these particular children’. The process for doing so will depend to an extent on the hegemony of the disciplines that are deployed to fill the conceptual space.

It would serve us all well to reflect upon which disciplines lead the way in researching the lives of ‘young carers’ and how their preoccupations may be shaping both study design and emerging debate. Psychology, social work and social geography are perhaps the three most prominent disciplines as I write, with medicine, anthropology, education and sociology playing more minor roles. Emphasis on behavioural change, mental health outcomes and the ‘burdens of care’ may in part be explained by the disciplinary foci of those at the forefront of research. And the current necessary and healthy debates in how evidence is mustered, and interpreted, are informed to a large degree by different - even opposing - disciplinary perspectives of those involved (an observation I expand on in the concluding discussion). It is also worth reflecting on the relative absence of history, political science, economics, law, theology and philosophy in informing the research agenda on the social dynamics of (adult) illness and (child) well-being.

Cognisance of these dynamics equips us with a framework for understanding how our efforts to generate information and build knowledge are positioned in the bigger picture, and what may be required to move the debate forward in fruitful ways. For, implicit in conversations, whether direct or indirect, between researchers and those designing policy or development resources is a set of norms surrounding how we approach, investigate, analyse and share knowledge about topic of enquiry which inevitably have a bearing on the decisions taken by state or other parties towards supporting children.

The Research Process

Study Rationale

The South African panel study titled ‘Young Carers’ defines young carers as “children and adolescents under 18 who take on substantial and significant tasks with responsibility that would normally be associated with an adult when someone, typically a relative, becomes unwell” (Becker, 2000). As data collection has progressed and evidence from elsewhere processed, scholars leading this component are seeing the need to place greater emphasis on the implications for children of living with adult illness that stretch beyond caring (Cluver, 2011, Pers. Comm), a position taken by other prominent researchers in the field:

“The term ‘young carer’ does not adequately convey the multiple meanings and experiences of these children, whose caregiving maybe only one dimension of their experience of living in a household affected by HIV/AIDS” (Evans & Becker2009:24)

The qualitative study was designed to complement the survey by investigating questions that cannot be answered through questionnaires, and using ethnography to explore local understandings held by both children and adults, of the issues under study.

The survey is a two-wave panel study designed to follow children over a period of one to two years, in which change in children’s life circumstances, their well-being and the household dynamic can be expected. Our intention was to capture change over time in the qualitative work within the limits of timeframe and budget. The qualitative fieldwork was conducted in two phases of ten days, set three months apart, amongst the same twelve children and their family members. As will become clear in the analysis to follow, our entry into and understanding of the domestic environments and familial

dynamics in which the twelve children reside varied considerably. We gathered very rich data in some cases, and only limited material in others. As is described in the findings below, challenges in recruitment proved helpful in understanding the broader socio-cultural context.

The design process was collaborative, initially involving three scholars (Dawes, Meintjes and Wild) who laid out broad conceptual parameters before I joined the planning process. Looking back, our respective backgrounds in psychology and anthropology informed the exploratory objectives, yet our early research questions were driven by a central concern in the literature around over-extensive care roles and responsibilities placed on children. Our desire was to understand these within a broader household economy of care, while their framing was still predominately instrumental, concerning the 'doing' of care:

- How does primary caregiver illness affect the whole family system within which the child is located?
- How are care responsibilities assigned amongst children and adults living with a sick adult, and are specific children marked out as carers?
- How does variation in the health and functioning of the ill caregiver over time affect the extent to which members of the household will be required to assist?
- In what ways do roles of both adults and children change once the adult caregiver becomes ill, and how do these roles change over time?

Also present in the early stages of design were questions about shifts that might occur in children's relationships within and outside the household, and in their status or reputation within the community:

- How does the transformation brought about by the long term illness of a primary caregiver (including an AIDS related illness) change (or not) children's everyday important relationships within the household, and how do these change over the course of the adult's illness?
- How does adult caregiver illness affect the public persona of the child and her social relationships in a context where the illness may not be disclosed outside the household, and when it is known to outsiders?
- How do affected children make meaning of caregiver long term illness, and how does this affect their wellbeing?

And, underlying the proposed enquiry into changes in role and relationship lay the important question of whether HIV-related illness affects children differently to other kinds of long term adult sickness. One early proposal was to group children sampled by the panel study in one site into those with AIDS-sick caregivers and those whose caregivers have other long term conditions, then to use ethnographic methods to explore similarities and difference in the well-being of the two groups. However this did not prove possible partly owing to the panel study's reliance on children either naming the adult sickness or reporting symptoms, the presence of which were used to diagnose sickness (the verbal autopsy method) and to the absence of questions about length of illness needed to lend weight to such diagnoses. In the KwaZulu Natal study sites, the same method was used but symptom reports were given by adult carers.

Research aim and objectives

The ethnographic study was conceived in order to illuminate the complexity and subtleties of adjustments made in households occasioned by caregiver illness (not simply due to AIDS but also as a result of other long term conditions) and to explore children's responses to, and perspectives on, adult illness in the home within the broad context of an AIDS epidemic.

The specific objectives were

1. To generate rich qualitative data on the caring relationships in which children participate within 6 households in one peri-urban research site (initially at least)
2. To map changes in children's experience of, and responses to, the care they undertake over a 4 month period, in the context of other changes within the household and family (economic, health, relationships, residence etc)
3. To facilitate children in building a picture of their world of responsibilities, past and present, and how these relate to their concept of their development and future aspirations. And to link such emic definitions of care and its implications with a) the measures of well-being and development being used in the broader study, and b) a realistic picture of what is possible for youth growing up in the research site and the skills or attributes needed to reach such potentials.
4. To provide insight into the dynamics and multi-faceted nature of care that can inform the interpretation of questionnaire responses, and convey children's experiences in ways not possible through the quantitative components.

Study site and sample

The qualitative study was conducted in Rooidakke, a settlement on the outskirts of the town of Grabouw, the hub of the Western Cape's apple industry. Selected by the national survey team as the province's 'rural site', the area relies heavily on farm-based employment, and has experienced very high population growth in the past ten years. Expenditure on infra-structure in the expanding informal settlements clustered around Grabouw currently accounts for approximately 85% of the Theewaterskloof municipal budget.

Rooidakke is one of four neighbourhoods on the town's periphery chosen by the survey team for their high rates of HIV, deprivation and shack fires. Residents speak Afrikaans, Sesotho or isiXhosa having moved to the area from nearby farming areas, from townships on Cape Town's periphery or from distant rural areas in the Eastern Cape or Free State.

The twelve children and adult relatives who took part in the qualitative study are from eight households in which one child had agreed to participate in the national survey and had completed the first of two interview-based questionnaires (see table 1 below). They were recruited from the large sample of survey participants through a process that prioritised similarity in household composition and socio-economic status. The aim was to work with more than one child (siblings, cousins or co-resident children), half of whom live with an AIDS-sick adult and half in homes without adult ill-health – as reflected in the sampling framework for the survey.

In practice, all twelve children were living with one or more adults who were chronically ill, or had been sick for a long period during the past year. While the nature of the illness and impact on children's lives varied considerably (as will be illustrated below), the way the survey tried to distinguish 'AIDS-affected' and 'healthy' households proved inconsistent with reality. Some background in how the survey sample was achieved is needed before considering reasons behind the blurring of these two groups.

In August 2010, research assistants on the survey team walked door-to-door through Rooidakke asking whether one or more children aged between six and seventeen years were resident, and whether there any adults in the household were sick. Using this technique, children willing to participate in the survey were selected and divided into two groups; those living with a sick adult and those in homes where adults are healthy (the control group). On the basis of children's responses to the first questionnaire (a verbal autopsy method based on validated WHO clinical criteria), the first group was then sub-divided into children living with AIDS-sick adults and those living with adults who are chronically sick from other causes. Where the questionnaire showed that adult illness reported at recruitment was minor, short-term sickness, participants were re-allocated

to the control group. Data input kept pace with recruitment to ensure large enough sample sizes in each group.

Our experiences in working with the sub-samples of two of these groups (those living with AIDS sick adults and the control group) raise questions about whether the sampling for the survey is sufficiently robust for comparative statistical analysis. For the purposes of this qualitative study, the important process of understanding who has been included (and thereby who excluded) was achievable through a cumulative understanding of the diversity and commonalities within the group. A spectrum of exposure to adult illness, only a proportion of which we know to be AIDS-related, and a range in access to resources were apparent within this group of children whose life experiences mirror those of their peers in the Xhosa-speaking families living in Rooidakke.

Pseudonyms are used throughout the report.

Table 1: Demographic details of children participating in the qualitative study

| House hold | Name | Sex | Age | Who else lives at home? | Incomes sources | Illness & death observed or reported ² |
|------------|-------------|-----|-----------------|---|---|--|
| 1 | Smangele | F | 13 | Spinster 'aunt' (approx. 45 yrs), younger aunt (30 yrs), two teenage boy cousins & 3 younger cousins | Spinster aunt's salary as domestic worker, One CSG ³ & one disability grant. | Cousin 'sister' is bedridden; drug use named & HIV status kept hidden. She died shortly after first phase of fieldwork. Her younger sister died the previous year. |
| | Thina | F | 12 | | | |
| | Xoliswa | F | 14 ⁴ | | | |
| 2 | Vuyo | M | 12 | Great aunt (67 yrs) who considers herself Vuyo's caregiver, Aunt (42 yrs) and her children (age 11 yrs and 2 yrs) | Seasonal apple packing work & occasional street cleaning. CSG for two younger children | Aunt has TB (HIV confirmed by another party). His mother died of AIDS in late 2008, and his elder brother in a shack fire in early 2009. |
| 3 | Sbusiso | M | 12 | Mother, older sister (20 yrs) | Mother and older sister's salaries (night shifts at apple packer); | Mother reported as having diabetes, no evidence of sickness during fieldwork. |
| 4 | Lungelo | M | 13 | Mother/grandmother (45 yrs), 5 cousins (under 7 years), extended visits from their mothers | One older sister has salaried farm work; other two earn occasionally, 3 CSGs | Mother to Aphelele/grandmother to Lungelo and Siyamthanda is reported to have 'high blood'. She is on monthly medication, and weak but mobile during fieldwork. |
| | Siyamthanda | M | 11 | | | |
| | Aphelele | F | 13 | | | |

² In a separate exercise, it may be instructive for the panel study analysis to distinguish between how illness was reported by the focal child in TeenTalk 1 and TeenTalk 2, and then how it was observed in the qualitative study. Such an exercise would enable consideration of why adult sickness was masked in the 'healthy' households, and how reliable the verbal autopsy might be. Time passes and ill-health arrives, raising the question of whether, for the purposes of quantitative data analysis, children are re-categorised should the verbal autopsy collected a year later in the second panel (ie TeenTalk 2) reveals a new presence (or absence) of sickness, or a different diagnosis.

³ CSG stands for Child Support Grant

⁴ Nobody in the household is sure of Xoliswa's age, but the consensus was about 14 years.

| | | | | | | |
|---|---|---|----|--|--|--|
| | | | | (Aphelele's sisters) who work elsewhere, uncle | | |
| * | Ayanda | M | 13 | Mother, aunt, uncle, elder brother, 3 younger cousins. | Uncle's work, mother's occasional street cleaning. | None observed |
| 5 | Masonwabe | M | 13 | Mother, father, younger sister and infant brother | Parents run an (unlicensed) beer shop, and keep cattle | None observed |
| 6 | Thandiwe (attended art club only three times) | F | 18 | Mother, father, brother (15 yrs), sisters (11 yrs & 4 yrs); cousins & aunt eat here. | Father is a salaried night watchman, mother packs apples. | Eleven year old sister has a mental disability, needing full-time care. |
| 7 | Lerato (did not attend art club, wrote story) | F | 16 | Mother, father, two younger brothers, and 2 young children of her deceased older sister. | 2 salaries: Mother packs apples (seasonal), father stocks fridges with ice | None observed (her elder sister died of AIDS earlier this year, her toddler is HIV positive) |
| 8 | Noluthando (attended art club once, moved away) | F | 18 | Mother, younger brother, elder sister and her infant. | Mother and her 2 daughters sell alcohol from the house (unlicensed) | Older sister is thin, wrapped in a blanket. No mention is made of her sickness. |

* Ayanda requested to join his friends at 'art club' even though he is not a participant in the Young Carers survey. We therefore did not have the background information on his household, personal history or illness within the home that are recorded in Teen Talk 1 and 2, and for these reasons elected not to observe his household through home visits and conversations with adults.

Ethical provision and responses in the field

The research plan for the ethnographic component was approved by the Faculty of Humanities Research Ethics Committee at the University of Cape Town and the Central University Research Ethics Committee (CUREC) at Oxford. Information sheets outlining the study's purpose and activities were prepared for children and for adult guardians, attached to which were consent forms. These sheets were printed in isiXhosa and English and given to prospective participants during short visits to households ten days prior to the first fieldwork phase. Following conversation with both children and adults about what the study would entail and its dissemination plan, children were asked to sign their consent to participate in daily art club activities. Adults were then asked to sign consent to their children's participation, and to the researchers visiting their home at agreed times.

On one occasion a seventeen-year-old girl questioned a statement within the information sheet, asking us "why does it say that we will not gain personally from this research?" In light of her family's precarious economic and social position in the community (the details of which we later learnt), Noluthando could not see why she should participate in something that did not bring her direct benefits. Our answer firstly pointed out the broader aim of the study to inform government and better shape policy for children and families, and secondly offered this teenager the opportunity to express her views through the study. Neither answer seemed relevant to what she was contending with at that moment in time. But neither Noluthando, nor her mother, declined consent and she arrived at art club the following day. This was her only visit. She appeared ill at ease with the other children who were at least three years younger than her, and mostly boys. Conscious of our responsibility to offer a conducive environment to her expression, we offered Noluthando the option of meeting up and taking the bus to Grabouw together. She agreed to this plan but it never materialised owing to her mother's drunken provocation of a neighbour who beat her badly. No soon as her mother was out of hospital than their family shack was flattened by the neighbour and other members of the street committee. This series of events seemed to render Noluthando and her siblings and infant nephew even more vulnerable, and prompted us to question the extent of our ethical obligations. None of these events were precipitated by the study, but we had borne witness to them and stood in positions where we could have been more pro-active in assistance. Interestingly, Noluthando never tried to garner our support in any way. She was surprisingly pragmatic (perhaps indicating emotional withdrawal), explaining that the community clearly wanted rid of them, so they would return to the township near Cape Town from whence they had recently moved.

When requested, we considered facilitating participants' access to services to be an ethical responsibility. The aunt of one child who joined the 'art club' asked us to assist her in applying for a Foster Care Grant having struggled to make progress herself, apparently owing to different surnames on the boy's birth certificate and his mother's death certificate. We accompanied the aunt, her nephew and Nozuko, (a local community social worker) to the local NGO tasked with social services to Rooidakke. There we were advised of the need of a police affidavit, so accompanied the aunt to obtain this paperwork. Our support was made more effective and sustainable because Nozuko already knew the family well and had been assisting them for some time. The reasons why I invited Nozuko to assist us with translation and facilitation during the second phase of fieldwork included her local knowledge, her professional experience and her ability to follow-up with referrals such as this.

Noticing that one girl in the art club has a squint, and reported difficulties in seeing the blackboard at school, we suggested that she have an eye test. Her family said that the nearest optician was in Caledon, too expensive for them to travel to, and too far for us to manage within the research period. We therefore referred the case to coordinators of the Young Carers study in the Cape Town Child Welfare office who are facilitating access to a sight test.

During the first 'art club' gathering, I consulted children on the question of who they wanted to hear the study findings, and how should we present these. We discussed various options including mounting their artwork on the walls, playing audio recordings of their stories, and setting audio stories to a series of photographs in a way that produces a video. They were eager to pursue the first and third of these. The photographic component of the project required us to explain to the twelve children the need for consent from individual subjects in every picture they chose to use. Once the first cut of each child's video was made, we played it to the individual only so that he or she could remove sections or change images around. At this point we sought their consent for showing all or part of the video to each of the following audiences; the rest of the art club, other residents of Rooidakke, members of the Young Carers research team, government and international policy audiences. Most did not agree to their video being shown to other residents of Rooidakke, probably because each contains that individual's short account of adult sickness in the home, and it would be impossible to disguise identities. For this reason, we decided as a group to use very short audio clips from different children and no photographs in the following week's community feedback meeting.

Ethical ethnographic research demands conscious reflection upon the researcher's position amongst her subjects and the potential impact of her particular subjectivity on the data gathered. To this end, we paid particular attention to the topics raised in our presence, as well as to the way people spoke to us about themselves and others. Try as we did to bring an open, non-judgemental attitude to our interactions, those whom we met and built relationships with in Rooidakke brought their sense of who we were and what we might expect, or think proper, to hear from them. Unhurried visiting and the sharing of tea created the spaces most adults found conducive for talking within their own home. The subjects raised, and ways in which these were framed, at least initially, are likely to reflect both care-giver priorities and the face they wanted to present to us. We were either referred to, or expected to act, as 'social workers' in several households. By being alert to turns of phrase used to describe familial relationships or illness, and tracing patterns in their use, we learnt how individuals and domestic groups – both important nodes of intimate care construct themselves – and their capacities to tackle adversity.

Methodology

The qualitative methodology was designed to deepen understandings of the interaction between adult AIDS-sickness in the home and child well-being in ways not possible in a large-scale study. Our intention was to facilitate processes through which participants could describe their experiences and perspectives, thereby generating a complementary body of knowledge to that gleaned through the directive interviews used in the survey. The methodology can best be described as an iterative, 'mosaic-approach' in which themes were explored and techniques chosen both in response to the information brought and to participants' interests in different modes of expression.

The research was conducted in two phases of ten days, three months apart, in order to achieve something of a longitudinal perspective within the time frame allotted to this component of the wider study and to coincide with school holidays.

Our aim was to work towards a rich ethnography within the restrictions of short fieldwork periods. Participant observation in homes, the community and 'art club' established for the purposes of the research formed the core upon which other methods were layered. Walking through Rooidakke, sitting chatting with families in their homes and conversing with community leaders or service providers were as important to data collection as what was expressed by children during daily 'art club'. Because the priority during the first phase of fieldwork was to build rapport and trust within the 'art club' group, we chose techniques such as collective community mapping (using wax crayons and watercolours on very large pieces of paper) that have proved effective in other ethnographic studies with children aged 10 to 14 years (Bray et al 2010). Clay modelling, story-telling and journal-making were also used as vehicles through which to explore the terrains of family and community as

experienced by children. A full description of techniques chosen to explore particular themes is provided in Appendix 2. All twelve children used isiXhosa throughout the research, and Pride Mtetseni, in her capacity as research assistant, translated for me and co-facilitated many of the art club activities.

Not until the second phase of fieldwork did we introduce techniques to purposively elicit children's experiences of adult illness and the nuances of their caring roles. Sensing the importance of an individual process and an 'end product' to both the individual children and to the research, we invited 'art club' members to make a short video about their lives based primarily on audio recordings and photographs. Their enthusiasm led to an intense six day period of drawing, directed photography, clay modelling, dramatic improvisation, audio and video recording. Time did not permit children's participation in the editing, but their responses to the production process and viewing of the first cut steered our editorial decisions and yielded valuable insights.

Findings

The study findings are broken down into three sections as follows:

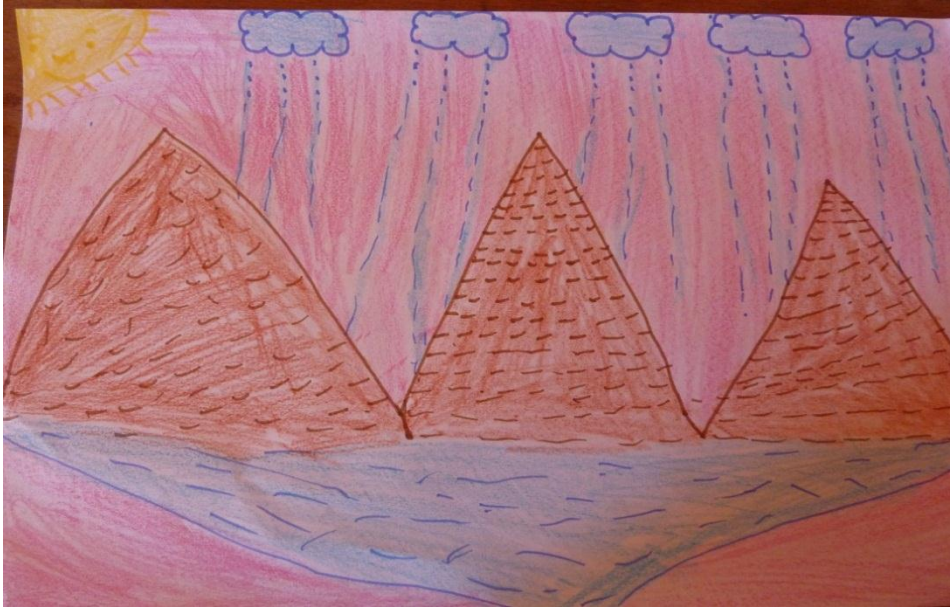
- The stage on which illness plays...
- Norms and practices around care and illness
- Children's responses to adult sickness: an alternative lens on well-being

In any analysis of the impact of illness, HIV-related or otherwise, on children's lives, it is recognised that context plays a large part in mediating the nature and levels of such impacts (refs). When analysing the large and varied data set gathered in this study, I was struck by the need to go beyond acknowledging context to understanding the nature of children's and adult's life experiences, and current realities, before assessing whether and how illness driven by AIDS makes different kinds of impressions on their lives. Thus, I begin by evoking the textures of environment and everyday life into which illness creeps, sometimes slowly and sometimes suddenly.

The stage on which illness plays...

Characteristics of the physical environment and the social and economic affordances that influence children's lives most keenly are best expressed through images. The photo montage that follows is a selection of children's drawings and the photographs they choreographed during production of the videos.

Mountains, water and waste



Aphelele, like her peers in art club, often drew pictures of water streaming off the mountains behind Roidakke, explaining that it runs in front, behind and into their homes, carrying disease and making life very uncomfortable.

“We all have to go to the toilet in the bush, there are some people who come and do their business right near our home. As you can see there are bushes above my home, and people just go into these bushes to do their business. And the toilets that the government have built are not nice.”



She wanted us to take the picture above to record how much rubbish flows down the mountain with the water, and the narrow bridge that she and other children must cross when they go to the communal tap.



And in relation to the picture above, she explained:

“And at my home, you can see it in the picture there in the corner, people go and throw their rubbish just above our place. It is not right because they even put dead dogs on that rubbish pile. The smell of the dead dog comes into our home. And it could make us sick because it is not right. It is wrong. My uncle, the one who is a drunkard, went to report this. But the committee just ignored him, and what he did was to buried the dead dog. What makes me angry is that they don't throw the dead dogs there during the day, they do it at night while we are sleeping.”

Provision for children and families



Rooidakke's two play parks, each with a couple of rusted climbing frames and broken swings, as well as the 'soccer pitch' (a sand surface) are enjoyed by children as spaces to meet friends, get exercise and play 'three tins'. Highlights of their year are annual carnival at a one of the local schools, soccer tournaments and the occasional beauty pageants.

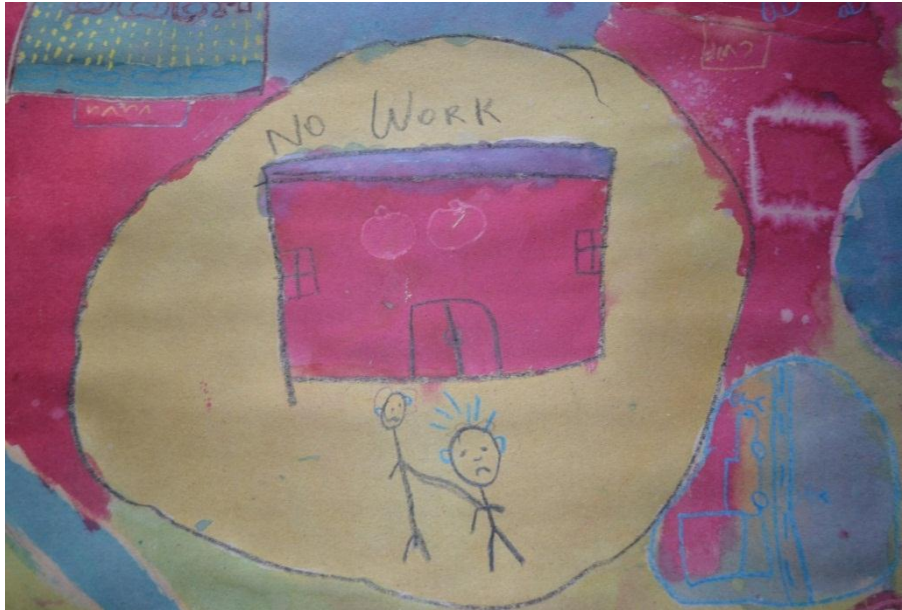


Sbusiso wanted us to take his picture standing on the steps of 'Vivien's Multi-Purpose Centre' because he considers the crèche that operates there to be important (one of only two in Rooidakke), as is the weekly medicine collection service. We ran 'art club' in this centre. The clinic, Department of Home Affairs and NGO offering medical and social support are located in neighbouring settlements approximately three kilometres away.

Earning opportunities



None of the children wished to include pictures of the scrapyard (above) in their videos, preferring not to be associated with the activities that occur there; selling metal, smoking and drug-taking. It is a source of income for boys, that they consider attractive, even tempting, but are put off by the possibility of being drawn into drug use or being mugged when walking home with new earnings.



The largest source of employment in the vicinity of Grabouw is on apple farms or in fruit packing factories. A few adults we met had permanent jobs, but the vast majority work only during the apple season (January to June). The picture above was drawn by members of the art club on the first day of our second period of fieldwork when we asked what had changed in the neighbourhood since our previous visit. The adult and child outside the closed factory are sad because no work means no clothes for Christmas, and perhaps hunger. Out of fruit season, some adults were working two days a week as 'Community Development Workers', cleaning the streets. Depending on their roles, they earned R50 or R90 per day. Some children felt that this work was not a viable option because "it pays too little money".

Change and continuity in housing



The physical environment of Rooidakke was changing rapidly during the fieldwork period. New government housing was at various stages of completion and even those homes without running water or electricity were being occupied. The shacks from which new home-owners had come were marked with a red cross, in order to prevent re-occupation. (We were told that the government wished them to be destroyed, but this rarely happened). The families of five of the twelve participants in this study gained access to a house during the study period, of which they were very proud.



When preparing material for their videos, several children chose to be photographed in front of their homes or with a domestic item of particular significance to them (see above). However when asked to shape 'something important in my life' during a clay modelling exercise, none modelled the structure of a house. Their models pointed to the comfort and security found in certain material items: tables with food on being shared with family members, watching television from an armchair,

a cell-phone, a grandfather's kraal in the Eastern Cape, riding an uncle's horse and traditional cooking pots.



Shack fires are feared by children because they occur very frequently in Rooidakke and neighbouring settlements. They spread very quickly, endangering people's lives and destroying possessions (including identity documents and clinic cards needed for grant applications, banking and school enrolment). One participant lost his older brother to a shack fire, and three others (siblings and cousins) missed a year of schooling when their documents were destroyed.

The images above convey some important connections between the physical environment and the inter-personal dimensions of neighbourhood and family life that affect children. Other characteristics of community, especially the nature of sociality in Rooidakke, became evident through our analysis of children's verbal descriptions of events and possibilities, their interaction within the art-club space, and the improvisation exercises we facilitated during a day of drama.

Rooidakke, agreed the children attending daily art club workshops, has few basic resources but is "safer and friendlier than the other areas around here". Some spoke from personal experience having moved from one of the neighbouring informal settlements, while others pass through these on route to school and hear reports of fire and theft from relatives and friends. The positive gloss they give to the neighbourhood they share is all the more striking in the context of the physical and social violence apparent in their drawing and writing, and in the conversations circulating through the neighbourhood about the recent rapes and deaths of two young girls, and the rape of an elderly man by two teenage boys.

Regardless of age, children showed an acute awareness of living amidst many dangers including shack fires, electrocution, traffic accidents and drunken knife-fights. Whether or not objective evidence would support it, their definition of Rooidakke as a relatively safe and friendly area conveys an engagement with the risks around them and with the possibilities for protection. For the duration of our study, the police were conspicuous by their absence from both the streets of Rooidakke and the drawings and accounts of children. Two children wrote about not knowing where to get help or find safety when faced with sudden threats, such as rampant fire or being pursued by masked men with intent to rape. But the remainder identified individuals in the community to whom they would turn in situations of crisis or to resolve conflict. One spoke of an uncle on the street committee,

another of a local shop keeper with influence, but most frequently mentioned was the local councillor, a woman, who was referred to by her first name or as 'the mayor'. For the children in this study, having a local leader who they find listens to, and acts upon, the grievances of residents, including children, was something that distinguishes Rooidakke from the neighbouring settlements:

"What I love about Rooidakke is that if someone has done wrong, we call a meeting and we have a mayor. People who are doing wrong in Rooidakke they are not from here, because people from here, they know, that we will call the mayor." (Thina, 12 years)

Thina's projection of blame onto those from 'outside' the area mirrors the positive gloss put on Rooidakke by the rest of the group when discussing the neighbouring informal settlements. Such responses are likely to reflect a defensive positioning that denies intra-community problems because children need to affirm their own community as positive in order to feel secure. Nevertheless, adult family members corroborated children's analysis of the local councillor's willingness to act on residents' behalf, although the extent to which they called upon, or saw themselves having access to, her support varied between families. Some families had forged particularly strong relationships that facilitated the calling of favours, including sourcing medicines from her sister who worked at the local clinic. Others – unsurprisingly – regarded her as partisan. But her attention to the immediate practical needs of children was what marked her as more effective than other local institutions:

"If [adult illness at home] is a big problem, usually Vuyiswa will help. Before she became mayor she had a committee that children could go to and she would give help, like providing a car to take the person to the hospital, or calling an ambulance. Children can still ask for help in this way" (63 year-old aunt and principal carer of Vuyo, boy aged 12).

School and community

By contrast, school was conspicuously absent from children's conversations and depictions of their worlds through art and narrative. Our presence in Rooidakke during the school holidays may partly explain this absence, and precluded us from observing the schools first-hand. But aside from the expected assertions by children and adults of the necessity of schooling for success, there was no evidence that either generation engaged with the school as a community or even a productive learning environment.

The large combined primary and high school serving the majority of Xhosa and Sotho speaking children in informal settlements west of Grabouw was often described as failing in its principal job of educating children. According to one parent "You can spend all day just visiting this school, rather than learning, because the teachers sit and gossip and eat cookies". Teachers arrive each morning from a distant Cape Town suburb, and are seen as disconnected from, and disinterested in, the local neighbourhood and the families of their pupils.

A minority of the children in the study attend an Afrikaans-medium primary school that costs a little more, and is generally regarded as providing good tuition. Several children spoke highly of their particular teachers. But parents and children alike find that both schools are out of touch with problems experienced by children at home as well as in the classroom. Negative assessments of schooling are likely to derive, in part, from the sense of alienation parents feel from the school system. Its inadequacies were being tolerated through non-participation. Family histories of movement between distant rural areas, townships nearer Cape Town and the Grabouw area, have no doubt contributed to this detachment from schools. Such mobility, plus childhood illness or the destruction of documents in shack fires, has also meant that all twelve children in our small sample had missed periods of schooling, and were two to three years 'behind' in relation to their age.

A number of children who attend the 'better' Afrikaans-medium school spoke about being one of the few Xhosa-speakers in the class, and of discriminatory treatment by both teachers and pupils. Their representations of the dynamic in school resonated with comments by adult family members about being 'at the bottom of the pile' as a Xhosa-speaking resident of Rooidakke. It was frequently asserted that Afrikaans-speaking 'coloured people' had greater access to jobs and services, and that Sotho-speakers had pulled each other up the housing list. Such self-identification can be a strategic move to gain empathy, or explain shortfalls in children's care as beyond the power of the family. However there was other evidence that the Xhosa-speakers are the least well organised or represented in community structures and that the neighbourhood is fractured along language and cultural lines, at least in terms of the way adults perceive, and relate towards, each other. These differences, plus the tendency of all groups to 'look after their homeys' are what residents say prevent the community from co-operating and engaging state authorities on matters such as sanitation and water supply that affect everyone, particularly shack-dwellers.

Children comment on adult protection

In a number of different (written and oral) contexts children pointed to the actual, or potential, abilities of adults to act in ways that would better protect them. Often these served to identify the failures of adult relatives with whom they now live, to contain or resolve problems encountered by children that are rife in the neighbourhood:

"One thing that I don't like [about Rooidakke] is people who are leaving their children with the paraffin stove on. That is why we have the shack fires, because children will go and play with that stove. And there is rape. The mothers must start buying panties for their children, so the children don't wear skirts only, but must wear panties also." (Vuvu, girl, 9 years)

"There are lots of children who joined this thing of smoking, they even stopped going to school. Then more copy them, thinking it is right. Allowing children to go and buy beer and cigarettes, this must stop. Some parents are allowing this, but others are not." (Thina, 12 years)

Working in clay, Sbusiso modelled a man holding a knife and standing over a cow, lying on its back with its legs tied. Nearby stand three smaller figures; they are children. Once everyone in the art club had completed their models, an audio recorder was passed around for each child to speak about what they had formed:

I like our culture [*isiko*] because most children have a problem of wetting their beds and it is important for the adults to slaughter some cows for their children, in order to solve the problem. Even when you beat other children they do this ritual, they slaughter some cows, and you become OK. Even if you are bad at school, they do the ritual and you become OK. [Sbusiso, boy 12 years]

Sbusiso's model depicts another potential source of protection that lies in the hands of adults, this time from on-going problematic behaviour children may display, which may have its roots in violence within the home or neighbourhood. He explained that this ritual is not performed in Rooidakke, and one reading of his choice to model it as 'my most important moment' is an expression of adult ineffectiveness in resolving problems experienced by children here and now in Rooidakke. His sense of entitlement to – if not access to – this culturally prescribed mechanism was not expressed by others in the group, but the salience of his account was recognised by his peers.

Rural-urban connections

Sbusiso's household was one of only two amongst the eight in which we detected strong connections with a rural home and a set of cultural practices originating there. In his case, the

connections were strongly symbolic despite no visits to the Eastern Cape for the last five years. In the second, they were physical and economic: Masonwabe's father transfers assets accumulated through his liquor sales in Rooidakke to the Eastern Cape, and raises cattle from his rural home in a kraal he has built near his shop in Rooidakke. For those in the group born in villages far from Rooidakke, early childhood recollections contain time tending gardens or herding cattle with a loved grandfather and these remain powerful anchor-points in their sense of self. Subsequent problems accessing school, or persistent childhood illness that could not be cured locally, prompted their move to Grabouw's periphery. Five of the twelve children recalled serious, chronic infections in early childhood that had caused them to miss long periods of school, often resulting in their repeating one or more years, and in some cases a move to relatives in urban areas for access to better health care.

Hearing children's accounts of why they and their relatives moved to Grabouw gave us insight into the set of adult expectations that accompanied the move, and how these may shape children's sense of access to what it takes to 'do well in life', achieve overall well-being and positive personhood⁵. These expectations are associated with access to the resources and services that are scarce in deep rural areas, such as health care, effective schooling, jobs and housing. While associated with urban 'modernity', these resources are also known to be in high demand (and perhaps short supply) in densely populated townships on city fringes. Grabouw is attractive because the settlements are new and growing, giving physical and social space for immigrants to come and stake a claim, whether this is by building on common land, adding one's name to the housing list and/or starting a new business.

In reality, rapidly established community norms and government rules mean that there are fewer openings than anticipated, a scenario that raises questions about how children's lives are affected when the move fails to meet adults' expectations towards improved quality of life. Even brick houses, longed-for by so many for very good reasons, were described as a disappointment: "People think that when they move into a brick house all their problems will be solved. Then they realise that the problems come with them, into the house." None of the adults we spoke to spoke of the positive aspects of previous homes that they had left behind, as was implicit in children's clay modelling described above. But they consistently expressed anxiety about child safety in Rooidakke.

Raising children and deflecting danger

Mothers and aunts in particular spoke about the hazards that children are exposed to in Rooidakke, welcoming the prospect of art club because their children would be busy and protected. Boys explained that their mothers asked them to run errands to the local spaza store because it is not safe for their sisters to go, especially in the evening. We heard repeated statements of frustration by adults who see greater need to protect their children but feel less and less able to do so. Their assessment of the danger and feelings of disempowerment were consistent with children's appeals to adults to do what is possible towards protecting them from harm (described above).

Over time, we began to understand that concern for the safety of teenage girls explained some of the challenges we experienced during recruitment for this qualitative component of the study. In three cases, our first conversations with teenage girls were met with enthusiasm to join the art club from the girls and yielded both verbal and written consent from their mothers.

In one case, the mother immediately alerted us of her conditions around her 17 year-old daughter's participation; she could attend art club if she was not needed to cook at home and the session did

⁵ I acknowledge Anna Versfeld in my use the term 'positive personhood' to refer to the process through which people construct themselves as recognised and valuable. Anna is currently writing a Masters in Anthropology about survival and 'coping' amongst young men and women in Mannenberg, Cape Town, and we have shared ideas on the conceptual underpinnings of coping in the two research sites.

not clash with church-related activities. Thandiwe was away at a church camp for young leaders in a nearby town for the bulk of our first period of research. During the second period, the combination of church and domestic commitments meant that she came to art club only twice. The family were continued to welcome us in their home and were not trying to pull Thandiwe away from the research activities. But it was clear that her mother, and Thandiwe herself, prioritised church above the activities offered through the research. Usually at work, and emotionally distant when at home, Thandiwe's mother was not available to discuss the role of church in their lives. Some of the reasons for allocating Thandiwe's precious free time to church seemed obvious to us: unlike the art club, it is a lasting institution that offers a guiding moral framework and a broad social support network. These qualities become especially valuable in a setting where the risks of physical violence and infection – both of illness and 'social pollution' – are high. Chatting to Thandiwe upon her return from the camp shed light on certain specific protective benefits of church membership:

RB/PM: "What do you like about church or being on camp with church friends?"

Thandiwe: "I like it that they encourage you by saying 'You don't have to have a boyfriend until you get married'. When I apply that rule to my life, it makes me feel free. I also like singing and dancing."

RB/PM: "Do people at church help families out when they are struggling, and if so, how?"

Thandiwe: "If someone is very sick at home, then the church members are always there to come over and pray. They will do the same if someone dies at home. And if you have to bury the person far away, they accompany you to that place"

In the other two cases initial parental consent was effectively retracted. Endeavouring to understand why the teenage daughters in both households were prevented from participating shed light on notions of risk and parenting dynamics in the neighbourhood. We were cautious in our follow up, wishing to respect the right to non-participation and seeking only to ensure that both parent and child had the necessary information to make an informed decision. One mother was friendly on the telephone, telling us that she did not mind her daughter participating and we must sort it out with her. As she hurriedly passed the phone to her daughter we heard her irritation at our request being directed at her daughter, who then hung up. After this conversation, we left voice and text messages on her daughter's phone explaining her right to non-participation, and asking if she wanted to meet us to discuss anything. These interactions and the silence that followed our subsequent messages to the daughter told us that the invitation to participate was uncomfortable, even threatening, to the parent-child relationship.

The second, Lerato's mother, repeatedly asserted her intention to re-arrange her work shifts or make baby-sitting arrangements so that her daughter – now looking after her toddler niece and baby brother – could attend. None of these plans materialised and, in light of our subsequent conversations and interactions, we saw that in assigning her daughter with long days of childcare she was able to keep Lerato within the safe confines of home.

Lerato's mother was unlike other parents in her ready articulation of the events surrounding the sudden (AIDS-related) death of her 22-year-old daughter earlier in the year, and her understanding of the current dilemmas facing parents. Without prompt, and in workable English (unusual in Rooidakke), she spoke of her daughter's decision to go to Durban in order to train in computing, of the rumours she then heard of her daughter spending time with foreigners who had money (conveying to us her understanding that her daughter was selling sexual favours), of her own sister's negligence in caring for her daughter and of her daughter's death from AIDS a few weeks after returning to Rooidakke.

According to Lerato's mother, recent changes in the way children and adults relate to each other result in greater risk for children, particularly daughters.

"Since freedom came, African children want to Westernise; they want to be like the whites without really knowing about their true background. They want to be like what they imagine white people are such as assertive in the way they speak, having lots of material things, leaving home at eighteen and having the freedom to do what they want. I know after 25 years of domestic work, what is actually happening in white households and it is not like the TV shows – things like arguments happen there too...So now we are in a situation in which children do what they want. If they feel that it is right for them, then they will do it. If children don't listen to their parents, then the result is a very big problem such as getting into alcohol or drugs like dagga or tik"

Like other parents we spoke to, Lerato's mother alludes to the difficulties presented to parents in an era where corporal punishment is no longer legal, and the absence of something effective to take its place. Unlike others however, she went on to acknowledge that parents need to understand and adapt to these changes:

"I need to trust Lerato. If she is saying that she wants to go to school and work hard, I need to believe that she is sincere. Rather than shouting at her and giving her rules, I need to sit with her and listen to her and hear her when she says "I like this but I don't like this".

Yet her stated intent to follow a more 'modern' route, to discuss the issues with Lerato, and allow her to influence decisions, is not what transpires at home. We saw how deftly she curtailed Lerato's movements by leaving her at home with the infants, even on days she was not working, and she later told us "I don't like Lerato to have lots of friends. If she leaves the house she must go straight to her brother's house". Through the stories that Lerato wrote at home as a means of participating in the research, we subsequently learnt that she is roaming much more widely than her mother believes her to be, and would want her to. And that Lerato has been in serious danger when doing so.

In Rooidakke we heard reference, and some resistance, to 'modern' ways of raising children in which corporal punishment is no longer a legitimate option and the notion of 'children's rights' something to contend with. Within this climate, adults express confusion regarding how to relate effectively with children who they perceive to be in danger (boys approaching adolescence and girls from around eight years upwards but particularly in their teens). Parents and caregivers use familiar means to try to protect such children, yet at the same time acknowledge they are failing. The elderly aunt of twelve-year-old Vuyo described herself as his caregiver since the death of his mother two years ago. Vuyo's older brother, to whom he was very close, died in a shack fire six weeks after their mother passed away. The reason he died, explained their aunt, was that the fourteen-year old brother and his friend "liked to wander", and got involved in drugs. "He slept out at his friend's place when the adults were away and could not wake up when the shack was burning". We, like his peers in art club, observed how frequently Vuyo was out and about, allegedly in the scapyard making sales or repaying debts. Although his aunt did not speak of these specifics, she is acutely aware of the possibility that Vuyo's tendency to 'wander' will put him in grave danger, but is at a loss as to what to do about it:

"I am very worried about Vuyo. Before we were in a shack, but we are in this new brick house now. It is a nice place, there is enough food here plus all the things he needs like clothes etc. But he does not stay at home. He likes to be out and about with friends."

For Vuyo's aunt, the 'art club' represented a safer alternative to the scrapyard but she did not press Vuyo to attend (for reasons I explore in the final section of findings). The mothers of some older teenage girls (described above), seem to have perceived our presence and the 'art club' very differently. Our understanding is that it represented a space into which we would bring different, more 'modern' ways of engaging with children, of understanding the world and the choices available to young people, and that this was an unattractive, even threatening, prospect for these mothers.

Keeping girls attentive to their domestic duties is partly about ensuring the smooth running of the household when mothers are working. It also functions as a socially acceptable mechanism to sustain parental authority, through which parents endeavour to protect their children. Perhaps mothers feared that their daughters' participation in art club would lead to their challenging maternal authority in ways mothers felt ill-equipped to respond to?

In this first section, I have described aspects of the landscape into which adult illness enters that stand to affect the influence of such illness, alongside other kinds of pressure, the manner in which children are called upon to respond and the effects of their involvement on their well-being. The quality of neighbourhood interactions, family and individual histories of movement, connectivity to a cultural home and frame of reference for raising children that lie outside Grabouw are each in themselves dynamic, and it is in the interaction between these that the resource base for children (and supporting adults) is found.

And when, as illustrated above, children (and/or adults) acknowledge that these systems are not working as they should, questions arise around how children source what they need to sustain their development when family members are in 'good health', as compared to their abilities to do so when an adult caregiver falls seriously ill.

Norms and practices around care and illness

Core to our intentions when planning this study was to explore the 'economy of care' within households as a means to understand where and how children are expected to step in. We wanted to know how care is distributed, given and received in the home, and against such a backdrop, how adult sickness is experienced by others sharing the home. Is care the prerogative of a particular person, gender or age group? And in particular, to what extent does adult sickness and death become the business of children?

The ideal method for exploring these questions is observation. But the obvious challenges in witnessing the entire spectrum of care given and received in the household called for additional techniques. The purpose of the journal, graffiti poster and improvisation exercise was to give children open-ended prompts on the subject of care and observe their responses. Our concern was not to count or compare care experiences but to document the kinds of care children engage in, and the meanings they derive from their activities.

Gender, age and birth order (or 'seniority' within the home) were presented as the three greatest influences on the distribution of care responsibilities in the eight households studied. Adult women were marked out by children and adults as the ones who take primary responsibilities in caring for the sick.

On the few occasions when men were at home, or returned during our visit, our interaction was usually brief and cursory. Perhaps because we were regarded as 'social workers' of some kind, boys in their late teens or older men who answered the door usually brought us into the company of women and then disappeared. But on the rare opportunities we had to discuss, or observe, male involvement in care for children or sick people, we noticed a variety in actual involvement that other research has suggested is indicative of the narrowing of possibilities for men to offer care through

traditional provisory roles (Wilson, 2006) and a masking of other forms of care that men may try, even in limited ways, to sustain (Brandt and Bray, 2007).

Thandiwe's father was the only co-resident adult male relative of the children in the study who had salaried employment. He is a night watchman and his wife, Thandiwe's mother, does day shifts in the apple packing factory. According to Thandiwe, her father budgets at the end of every month when his salary arrives in his bank account, and her parents budget together each fortnight to ensure they have money for groceries and other daily expenses. Thandiwe explained that she and her father take turns in walking her younger, mentally disabled sister to and from the school for children with special needs on the other side of Roodakke. Our only conversation with him was friendly and open, and he chose to tell us that his biggest concern is his daughter's health: "Because of her situation, she plays with everything on the ground outside including dog faeces, used condoms etc. I would like the municipality to give us a brick house to deal with this situation. It must be a single story home because she cannot manage stairs. I have been to get a note from the doctor to show the municipality that we qualify for a house." Thandiwe's father clearly sees a strategic opportunity to claim a house, and does not attempt to hide his daughter's disability. From the glimpses available to us, he was doing as much, if not more, in terms of material, practical and emotional support towards the care needs of the family, and particularly his disabled daughter.

Aphelele's uncle was never at home when we visited, and Aphelele did not include him in her description of her household in the survey questionnaires. We were alerted to his presence by the empty beer bottles under the wooden bench early in the morning. Over time we learnt that he slept in the family home, a three-roomed shack, but did not eat there. According to Aphelele and her nephews, all three of whom participated in our study, when their mother and sisters challenged the uncle about his drinking, he retorted with 'It is my money that I am spending, not yours. I can do what I like with my money'. Although opting out of the household pot appeared to let him off financial contributions, he had not relinquished all responsibilities. We witnessed him and his nephews on the roof of their shack, as well as the neighbours, replacing tarpaulins and nailing in new roof struts. Aphelele's sisters explained that their uncle would work on the home if they bought the materials.

The greater range of practical and emotional care responsibilities placed upon teenage girls, as compared to their younger siblings or male peers, was amply evident. But what also became evident through art, drama and conversation during 'art club' was that all the boys, their ages ranging from 10 years to 14 years, regard themselves as having a significant part to play in caring for younger siblings and adults when they fall sick. They reported cooking, cleaning the house, massaging the backs or feet of a sick parent, and bringing medicines and water when needed. When younger siblings reported pain, they used pocket money earned by running errands for neighbours to buy them an aspirin. In this age cohort, the boys express pride in their caring role and seem no less troubled by it than the girls of their age:

"I feel happy because I know that by doing these things [for my sick aunt], she will feel better" (Boy, age 13 years, written entry in journal)

"I am content to care for my little brothers and sisters. It only becomes too much when I want to go and play soccer at the pitch and my grandmother asks me to stay at home to watch them" (Boy, age 13 years, written entry in journal)

"I saw that I should cook because my aunt and the other adults were too busy looking after my mum. That was OK. My brother and I took turns... But I am not alright [inside] because my mum is sick. She had TB" (boy age 12 years, verbal account and written entry in journal)

But our limited experience in these eight households suggests that when boys reach their mid to late teens something shifts in how they see themselves, and what others expect of them, that pushes them to the edge of, or outside, the sphere of familial care. While the difficulties we had in recruiting older teenage girls for this study (explained above) appear related to inter-generational tensions around appropriate environments for girls of this age, the possibilities for recruiting boys over fifteen were negligible. In the three households where we met boys of this age, they were reticent to talk to us. Perhaps shy, or perhaps unwilling, their shrinking back from the 'female world' of care was palpable. Exercising greater independence is consistent with Xhosa cultural scripts for emerging manhood and doing things associated with women may attract ridicule from peers.

What we observed could be described as an age and 'stage' of maturation marking a junction in the life-path, such that girls must take one direction; that of accelerated maturity and involvement in the practical and emotional health of the household, and boys must take another; one where they pull (and are nudged) away from domestic concerns and towards more independent living.

Several girls, who during July behaved and were regarded as 'children' within the household, were in October carrying themselves like young women, co-ordinating domestic activities and supervising their younger siblings. It was difficult to tell whether they 'grew into' this expanded role and different demeanour, or whether they were shunted into a more mature, responsible position by changing care needs and resources in the home. In the case of two girl cousins who live in the same house, we noticed that one of the two resident aunts, who in July was overseeing domestic chores and providing emotional care, had moved out by October to live with her boyfriend. The two girls, aged 13 and 14 years, appeared to have assumed many of her roles and responsibilities. It is likely that this aunt stayed in the home during the rapid decline in her cousin's health and then her death, moving out once this intense period of care was over. Observing the two girls stepping up to at least a portion of her role suggests that they would undertake to meet some of the practical and emotional needs of younger and older family members should the second aunt fall ill, even if the wider family considers them 'too young' and brings in another adult woman to assist.

The literature on gender and care rightly points out that one result of caring being regarded as a 'natural feminine role' in many societies is that vast amounts of demanding care responsibilities not only fall on women and girls, but their impacts remain invisible (see Bray, 2009). The patterns we describe above suggest that boys experience an exclusion from care, the impact of which on their well-being is not fully understood. Do boys entering their mid to late teens, and entering a phase we could describe as 'early manhood', struggle to retain a sense of their own value and integrity (positive personhood) having been seen by others, and regarding themselves, as a key player in care for a sick relative? Assuming that they gained satisfaction or reassurance from being effective carers, in whatever respect, from where can they draw equivalent meaning and satisfaction once they have made this transition? Where are they expected to invest their time and energies, and with what expected outcome?

Assuming that they do not repeat any further years of schooling, the boys in this study (now aged 11 to 13 years) will be in grades 7 to 9 when they reach the age of fifteen. This means that the transitions described above are likely to occur in their critical years of high schooling. Of the three girls who were making a transition into women of the home, two had stopped attending school between July and October. One intends to re-start in her former school in the Eastern Cape. The third girl is in grade 4, and both she and her family intend her to continue in school, despite the extent to which she contributes to domestic chores and cares for her five young nieces and nephews, plus her mother when her illness worsens.

There are (at least) two dimensions of well-being at stake here. One is educational outcomes and the other is the ability to construct a sense of self as effective within a web of interpersonal relationships, and as valued by others (the 'positive personhood' I referred to earlier; see also Lerner

et al, 2000). The second, while much less easily tracked or measured, stands to have lasting impact on young people's immediate, and longer term, recourse to strategies of managing difficulties. In general, the patterns described above imply that girls may be more readily detached from schooling, in part because practical demands on their time and energy increase at home and in part because their role is being demarcated, and validated, in this sphere. The effect of being positioned more overtly as 'carer' stands to have positive impacts on their sense of self as valued, when within a cultural environment that validates femininity in this manner. Boys, on the other hand, are not drawn away from school by familial expectations (in fact, there may be pressure to invest and succeed there) but no longer have the source of validation within the home that they have been accustomed to, and must look to other identities from which to build a sense of self as having status and value. This shift begs the question of what possible alternative identities exist for boys in their late teens in Rooidakke?

Despite very small proportions of school graduates entering training or work, the identity 'school student' remains attractive to adolescent boys in very poor, urban neighbourhoods in South Africa owing partly to its historical significance (Bray et al., 2010; Maloni and van Dijk, 2011; Soudien, 2007). Our impression is that this identity is short-lived for most older boys in Rooidakke who did not appear to derive meaning from their schooling or to be socially or emotionally invested in the institution. We did not enquire into potentially toxic aspects of being at school, whether rooted in personal history, the home, school setting or neighbourhood. But given that all twelve of the children in our sample are already over age for their school grade, they are very likely to fall further behind in performance and fail to garner the family support needed to catch up. We can therefore expect older boys to shift their sense of self from a 'school pupil' identity to something that carries social value and reaps personal benefits in the short term.

Other identities more consistent with reality, and which provide both status and a cash income, quickly become attractive. But few of these available to youth in low-income settlements are legal or socially acceptable. Engaging with other teens and young men who are earning and becoming known in illicit trading becomes a more fulfilling and interesting path – even if it is thought to be a negative trajectory. Perhaps it is through these associations that a positive though socially 'deviant' identity is constructed?

Do adults 'see' how children respond to sickness, or value children's caring roles?

One afternoon, we spent two hours sitting at the bedside of the 28-year-old cousin of three of our participants who, at the time, were downstairs playing a game of cards. Their aunt – who runs the household – returned home while we were there, and it was the first opportunity we had had to talk to her more generally about raising children. Knowing we had very little time, we launched in by asking her whether she thinks it appropriate for children to be involved in care for the sick or whether it is best that they are shielded from such concerns. She replied:

"It is important for children to know because when they are older they'll need to know how to treat a sick person".

Her reply implied that care of the kind required by very sick people is an adult activity. Children's involvement in care may be masked to the wider world in similar ways to caring by men, including a discrepancy between the articulation of gendered and age-defined care roles, and what occurs in practice. A further reason why caring by children (and perhaps also by men) can remain hidden is that it often functions to fill in the gaps where adult female carers are physically, or emotionally, unable to attend to a sick relative.

But does a lack of acknowledgement of children's caring roles mean that their contributions are not seen, or valued, by the adults for whom they care? Answers to this question are more difficult to

find because they require conversations in which the intimate details of the sickness and responses to it are revealed. In none of the households did we achieve these: For the most-part, the adult sickness reported by children during the survey was not an open topic of conversation. And in one home where the mother's on-going sickness was not concealed, to have probed about who was caring for her and how she felt about it, would have been wholly inappropriate.

In all likelihood, a longer period in the field building trust may have enabled the gradual opening of such conversations (see for example Henderson, 2012). Our experiences are useful in their testimony to the face of 'health' (not illness) presented by families, at least until the point in which a person is utterly debilitated. Nothemba, a volunteer for a community based organisation supporting families affected by HIV, recounted the many times in which she had been called to a home to find somebody bed-ridden and extremely sick, yet no-one broached the topic of what might be wrong.

Against the backdrop described above, adult sickness does not quickly or directly become one person's prerogative. There may be differences in care-related expectations placed on co-resident adults and children based on gender, age, birth-order or 'status' within the family (defined by ability to earn, aptitudes, or force of personality), but the actual conduct of care-related activities is likely to be shared across the domestic group. The exception here is that men may be excluded, or exclude themselves, from the arena of care.

When we gave 13-year-old Thina opportunity to recount her experiences of serious illness at home, she spoke lucidly about the sickness of her elder cousin, Zikhona, aspects of which we witnessed. She died shortly after the first phase of fieldwork. Our questions to Thina, designed to explore her knowledge of what was happening, elicited responses that shed light on the reaction of a young man to the severity of the situation, Thina's bewilderment at his response, and her inability to question it at the time.

Researcher: Did anyone talk to you about what would happen if sis Zikhona was to get very serious and to pass away?

Thina: Yes, it was Yamkela's step-father who said that sis Zikhona is very sick and then told Yamkela 'you must take care of your 'sister' [his mother], because she is going to die'.

Researcher: Did the person talking to you about might happen, mention what could happen afterwards, who would live with who and that sort of thing?

Thina: Yes, Yamkela's stepfather did.

Researcher: Is there anything that you wanted to ask that you felt you couldn't ask?

Thina: Yes, I wanted to ask the question: 'why did he say to a child that a child should take care of his mother and that she is going to die?'

How do children understand adult illness to have entered the home?

The detailed account by each child of a recent episode of adult sickness showed that such illness, in their experience, enters the home through one of the following means:

- A familiar pain that worsens and confines a person to bed for several weeks;
- A sickness that is named and 'known' but does not get better;
- A conflict in which another party uses malevolence to make a person sick;
- A calling by the ancestors to become a Sangoma;
- The return of a young woman, in three cases a sister or cousin, who has been living in a distant town for several years and whose health deteriorates quickly.

Only the last of these scenarios led to the deaths of the women concerned, an event experienced in two of the eight households and thus by four of the children in the study. In one other household, the young woman was visibly very unwell, but no allusion was made to her sickness.

How does adult illness shift the balance of care needs and provision?

Several children spoke about the focused attention of adults, both co-resident and those who had come to assist, on the ill person, and their inability to cover the other care needs, including those of children:

“When sis Zikhona got sick my aunt Mpumi was not working. On some days we went to bed with no food because she just had to watch Zikhona and miss her work.” (Thina, girl, 13 years)

“There was a change at home [when my aunt got sick]. It became busy and we didn’t have anyone to talk to because everyone was focusing on the sick person.” (Ayanda, boy, 13 years)

Periods of perceived neglect seemed to have been short-lived, and the increasing care demands were often met by a relative or neighbour coming to stay, or popping into the home with food each day. None of the children in the study mentioned receiving a food parcel from an institution, despite the fact that an NGO providing this service is located in the neighbouring settlement. Our impression was, that unless the family took the step to self-refer (entailing the public acknowledgement of chronic sickness), the organisation was unlikely to identify them amidst a very large population of homes with similar trajectories.

In homes with very young or otherwise dependent children, or where a number of people are sick, it is possible that care needs compete, and may cause greater stress on children and adults living there. Within the very limited exposure we had to this scenario, there is some evidence that members of the household – including even the sick adult herself – arrange on-going care roles in such a way that adult sickness does not undermine existing provision for children:

The high blood pressure and other (AIDS-like) symptoms suffered by her mother mentioned by 17 year-old Thandiwe in the first survey questionnaire were never mentioned by anyone in the household, nor seemed to be affecting her mother’s abilities to work over the four month period of our study. Thandiwe’s reported her mother to have high blood pressure only in the second questionnaire during this period. We do not know whether her illness was, or continues to be serious, nor whether it was AIDS-related. Thandiwe’s mother was hardly ever at home and did not invite our conversation. In exploring with Thandiwe how the considerable care demands posed by her ten year-old sister’s disability were met, it became clear that daily monitoring, meals and bathing are done by Thandiwe and other children in the home, their father and their aunt (in whose shack she has slept for the last five years since her mother had another baby). Thandiwe’s mother works during the day and helps with her middle daughter’s care when Thandiwe is busy. We were struck by the fact that this arrangement is one that could be sustained without seriously compromising the disabled daughter’s care should Thandiwe’s mother fall ill again.

The emotional impact of adult illness on children appears to be increased when the health of the person with primary responsibilities in sustaining the household is physically unwell or ‘stressed’, perhaps by the illnesses of other adults (see also Cluver et al., 2012b).

The following excerpt is from our conversation with 13 year old Thina in which we prompted her to describe her recollections of her elder cousin's recent illness and death (caused by a combination of drug use and HIV):

Researcher: Sometimes the person caring for the sick person can feel tired or sad. Did you notice that sis Mpumi had some different feelings or some stress?

Thina: Yes we saw some of that... like when my aunt Mpumi got fed up and told Zikhona 'I am tired of someone who is killing herself' because sis Zikhona was still smoking pills and my aunt told her she must stop smoking, because the smoking killed Zintle.

Researcher: Can you tell us how the feelings and the stress were affecting the other children?

Thina: We were hurting because aunty Mpumi must not talk too much because she is so stressed.

How does AIDS enter the family consciousness and children's understanding?

In only one of the eight homes was the presence of AIDS openly acknowledged to us. In two others, we were told in private that the sick adult was HIV positive, once by a member of the household and once by a friend who is community social-worker. Only in this first household can we be sure that the child participating in the study knew the cause of her elder sister's death because she was present during the conversation. [We noted that this sixteen-year-old girl had been placed in the 'control group' of non-AIDS affected children because her primary caregivers (in this case her parents) were not sick. More research is needed on the impacts of having a sick younger or adult sibling].

It is highly likely that in the case of the boy whose mother died two years ago, the social worker's involvement in his family has made him aware that AIDS caused her death.

But in other cases, we cannot be confident in what children know. We can only look for clues in their narratives and behaviour. Neither of the two girls from the family in which two sisters in their early twenties have died within the past year made any allusions to their positive status, which we were told about. Instead, they blamed drug use and/or food poisoning. It is possible, but unlikely in the context of their openness in all other regards, that they saw fit to conceal their knowledge that AIDS was in the mix from us.

Aphelele's consistent explanation for her mother's chronic but currently mild sickness is 'high blood'. She speaks openly of the medications that her mother collects monthly from the nearby community centre, wanting to photograph these and the vitamin supplements bought by her mother, for her video. The medication is for a heart condition related to high blood pressure, and she makes no explicit reference to possibility that HIV may be involved. However, when we returned to Rooidakke for the second phase of fieldwork and visited her home, Aphelele was both delighted to see us, and uncharacteristically withdrawn, even cagey. As her nephew, who is also a member of the art club, entered the shack, she pulled him roughly into the bedroom and pinned him against a bed whispering something urgent in his ear. This very swift interaction may have been an instruction on her part to keep something secret from us. In the day of drama towards the end of the second research period, Aphelele played the sick adult. As the improvisation unfolded, a 'neighbour' stated that this sick person was HIV positive. Aphelele responded in her role by going to the police and demanding that the neighbour be reprimanded for false accusations: "It is my right to disclose my own status" she said "I am not HIV positive, I have high blood".

We cannot know for sure whether Aphelele and her nephew understand her mother (his grandmother) to be HIV positive, or indeed whether she is. However her behaviour, plus the

whispered 'shushings' by children round the table at Art Club when one mentioned Ithemba Care, the local AIDS hospice, told us that AIDS is seen as shameful and often concealed.

Sitting with the local councillor, in the privacy of her home, we listened to her speaking frankly about the schisms and challenges in the neighbourhood, one of which was rising illness and death owing to 'the sickness'. Her unwillingness to name AIDS caused Pride to choose similarly circuitous references. And in response to my more directive questioning, the councillor replied "People don't use the terms HIV or AIDS. Lots of different words are used as ways to disguise its presence". Before considering the nature and impact of these modes of reference, it is important to explore other arenas in which care is taken to conceal particularities.

Only in one, very obvious, case of impairment was children's mental health discussed openly. Adult family members told us that certain children "get the disability grant", sometimes warning us off including them in art club activities because "they are not quick like their siblings". No openings were offered to discuss the sources or implications of mild learning difficulties, nor the supports they may benefit from. Discretion around when, and to whom, one shares information about children ceasing to attend school, about earning money through selling alcohol, and about a relative who keeps cattle or generates his own electricity. The potential to be identified, and punished, by the authorities is one factor motivating concealment. But there is a sense of caution around marking oneself out as different, or as seeking recourse to alternative ways of managing the challenges of life. Resourcefulness that deviates from the script of what is proper is best kept hidden.

The deft handling of these different kinds of knowledge by children in this study – a skill that kept us guessing – indicates a level of understanding about why and how one manages the sharing of information with others very carefully. In response to the prompt 'the responsibilities of care entrusted to me' in the graffiti poster exercise, Sbusiso wrote: "keeping something confidential". The following excerpts from our conversation about his experience of adult sickness at home demonstrate how he exercises this responsibility, even when no-one but the two researchers are in earshot, and reveal the sustaining of confidentiality to be one aspect of 'good care':

Researcher: What kinds of thing were people talking about when your mother fell ill?

Sbusiso: They were gossiping about my mom and having meetings about her, and wanting her not to get well.

Researcher: Was it all hush hush, some things you couldn't talk about?

Sbusiso: Yes,

Researcher: Can you tell us?

Sbusiso: No, I can't.

...

Researcher: When people are sick, we don't always know what is going on. Would you tell us a bit about what you knew about the sickness?

Sbusiso: At first, I was not worried because she does get sick sometimes. I thought it was the usual things.

Researcher: Can you tell us how you worked it out?

Sbusiso: I dreamt that my mother was sick then I asked her, 'what is wrong with you?', and she told me 'I've got this and this and this',

Pride: what is this and this and this?

Sbusiso: Let's just leave it.

While children may be good at guarding the possible entry points to deeper levels of knowledge, they may have little choice but to do so (where participation in this endeavour is invited by adults, while children are excluded from other arena of knowledge), and may not know precisely what is being concealed nor the gravity of its implications. As a result, in recounting their own explanations for why some illness persists, or proves fatal, while others do not, they may encounter a gap in the chain of logic they have used thus far to understand cause and offer (themselves and us) an alternative explanation.

[Sis Zintle] died because she ate pork. I don't know why, perhaps they put poison on the pork. Sis Zikhona also ate the pork. The next day they had diarrhoea and sis Zintle got worse, and Sis Zikhona didn't get anything, just a bad tummy for one day. Sis Zintle and sis Zikhona smoked tik together.

(Xoliswa, girl of 14 years, from narrative about adult illness recorded for her video)

We interpreted such questioning of cause and effect in the midst of narratives about adult illness to imply a desire to know more that had, until this point, been stifled by their own participation in careful concealment.

Thina, age 13, was one of the few who stated her own interpretation of the situation and her reason for wanting to know more than she was being told:

When Sis Zikhona got sick, I could tell straight away because she couldn't even speak. Even in her eyes, you would see that she is sick... I wanted to know why she was sick because maybe the things she was doing were wrong, and we should not do them. (Thina, girl 13 years, conversational interview following narrative for mini-movie)

Aphelele, another 13 year-old girl with recent experience in looking after a sick relative, spoke of the way in which adults try to prevent children from knowing about certain topics and, like Thina, claimed that she saw the truth of the matter despite their efforts:

Researcher: How much do children know when the parent or the adult is sick? Do the children know everything that is going on, or are there some things that the adults try to hide?

Aphelele: Yes, there are things that children are not supposed to know, like 'big things' (*into zinkhulu*) or important matters of the house that they don't need to hear. So adults lie to us and tell us some other things, when we know that they are not telling us the truth.

Pride: How is that you can tell that they are lying?

Aphelele: Ahahh (giggle), because, because, because...you can see what your mother is sick with, this or that. You can see what is really the problem. But some other children don't see it.

Researcher: Do adults talk about what happens after someone dies, about inheritance and things?

No, they don't tell us those kinds of things.

Researcher: If it is difficult to talk about these things in the family, where can you talk about it?

Aphelele: The parents of some children do tell them 'my child, I am sick with this and that', that is why they know these things. But some others, they are being lied to, and that is why these children don't talk about death. The adults will always say 'your mum is going to get better'.

Children's responses to adult sickness: an alternative lens on well-being

In this final section reporting the study's findings I explore the ways in which children respond to the implications of adult sickness, and understand its effect on their lives. The purpose of the analysis is to provide another lens on the question of 'well-being' than is offered through measures of psychological impact of the kind used in the survey.

The evidence base from which I draw consists of our observation and reflection by children on personal experience. We observed children in their homes and the art club setting, noting the nature of their interactions with others and the way they presented themselves. A number of the art club exercises facilitated children's own judgements of their capacities to cope and the factors that underpin their happiness, one important aspect of their well-being. These data, like the psychological instruments, do not provide a complete picture in and of themselves, but can offer clues to the ways children engage with, and interpret, adult illness and how such processes may affect their well-being.

When recounting their experiences of living with a sick adult, children list giving medicines, massaging painful limbs and helping the sick adult to the toilet within the general array of care-related tasks, such as cooking, cleaning and bringing water for washing and drinking. Half the group who did the 'graffiti wall' brainstorm around care wrote about giving medicines or 'treatment' in response to the prompt 'Responsibilities of care entrusted to me'. These more medical aspects of care are not distinguished by children as being more onerous in terms of time or energy, but some said that giving a sick adult their pills can be 'difficult' at an emotional level:

"Giving people medicine [is a responsibility of care entrusted to me]. Sometimes it is good, but sometimes you are just not up to it." (Vuvu, girl age 9 years)

At this juncture, I provide three of the ten accounts given by individual children which were recorded for the purposes of data collection, and to insert into each mini-movie (and thereby to be retained by each child for future listening). The topic of each account is what happened at home when an adult fell ill. The content and texture of the narratives give insight into the way illness is understood, and responded to, as well as children's particular involvement. We used silhouette figures and clay modelling as a means for children to begin identifying people in their families who had received long term care.

Aphelele picked out two silhouette figures as having been very sick in the past; her elder sister who fell ill when Aphelele was seven, and then her mother who is still unwell.

RB/PM Aphelele, are you ready to tell us the story of what happened when your sister got sick?

Aphelele: My sister got sick when we were living on the farm. My sister had an argument with another lady. This 'sisi' ('sister' referring to woman of similar age to her own sister) was on the side of a man. She hit my brother, so my sister went to her to ask why she did that. That's when they started fighting. Every day they were beating each other. Many old people they were on the lady's side. After they found out that the lady lied, and that she had started the fight, some left. The lady also left and she had an argument with her husband. And then my sister got sick that day. She was so sick that we told her to go outside and get some fresh air. It got so bad that she couldn't breathe. We took her outside. It was at night and she nearly died. And then we had to call someone so that they could find a car for us, and they took her to St John's. They gave her 'iswash' (a cleansing medicine) to wash her body with, and the other thing that made her sick. They told her that it is not the lady who she argued with who made her sick, it's her school teacher. The teacher didn't want my sister to be educated, so she gave her something like a bad *muti* (medicine), so that if she came to school she would get sick, but if she stayed at home, she would be fine. So that's what made her sick and she stopped going to school.

Masonwabe spoke candidly and succinctly about his mother's illness, pointing to the part he and others played in caring for her different needs and his ambivalent feelings when doing so. His mother was mobile and apparently healthy during both periods of fieldwork.

My name is Masonwabe. I live here in Rooidakke and I live in house number ****. At that time when my aunt was sick it was (emotionally) painful (*hlungu*) for me. And I couldn't go anywhere. I was always taking her to the clinic and cooking for her. And then she couldn't even wake up from the bed when she was sleeping. She would go to bed and then the next morning she couldn't wake up.

OK, thank you. Did anything change at home, in terms of who was living there?

Nothing changed

Was it busy at home or was it quiet?

It was always busy because she sick, people are bringing her medicines. And some are going to town to the chemist to buy her medicine.

Sometimes we need to do extra things when someone is sick. Did you need to do new or different things to help care for her?

Yes, I used to wash her feet and rub her back.

How did you feel about doing those new things?

Sometimes I was sad, but sometimes I was happy.

And what about the others in your family did they have to do some new, different things.

My father used to take her to the clinic, and to the chemist to get medicines. And my younger sister used to fetch water (from the community tap).

Other children were much more expansive in their stories of adult illness, recounting their understanding of the series of events and accompanying interactions that they recall to have marked a period of serious illness. Here Thina describes what preceded the death of her cousin, sis Zikhona, whose HIV status had been diagnosed two weeks prior to her death. This knowledge was shared with us in private by one of Thina's aunts (sis T) but was not spoken about at home as far as we could tell.

I am Thina... I live in Rooidakke, I am 12. [Pointing to silhouette figures] This is sis M (her aunt and primary caregiver), sis T (young aunt), and sis Zikhona (young aunt), and this is brother Y (son of Zikhona). The one who was sick is sis Zikhona. Sis Zikhona was smoking drugs but she didn't tell us

that she was smoking drugs. We didn't know. One day they told me I must go and fetch an empty bowl from her room, and when I arrived in her room, she said I must take her sniffing tobacco from under the pillow then I saw a bottle head. I just took the bowl and left the bottle head. And at home at that time they were talking about why she was thin and she said 'why are you asking me that question?' And at home we asked her 'we heard that you are smoking mandrax tabs (*pilis*), is this true?' She said 'no' and aunt Mpumis said 'Time will tell' (*uza zibona*). After that sis Mpumi told her 'the mandrax will make you bed-ridden, you won't be able to move. And she denied it again, 'I'm not using mandrax'. I saw her, she was with another lady called Sis Leti and they were in the shacks and when they entered the shack, and the other lady left but sis Zikhona was still inside. Then for the 3rd time aunt Mpumi asked 'Are you using Zikhona?' and she said 'no' and then I took the bottle-head and showed it to aunt Mpumi. And my aunt asked sis Zikhona, 'what is this?' and she said 'it is not mine, it is L's thing' (Thina's older brother). My aunt said 'ok, I will see'

The next day sis Zikhona started complaining of headaches and dizziness, We called the mother of V [the local councillor] as she couldn't even walk. V's mom gave her tablets that were brown. And then she became better and she was getting out of bed a bit. Aunt said 'I told you that this thing will make you bed ridden (*lala phantsi*)'

Sis Zikhona was going up and down, staying with us sometimes, and then sometimes staying in the shack (previous home before the new house). And cousin X and aunt M went to fetch her when she got sick again. And aunty took care of her at home, she used to bathe her and dress her. One night Sis Zikhona couldn't stand up. Her body was stiff. She could talk. But her tongue was tough and aunt called the ambulance. It was about 10 o'clock at night. The ambulance arrived. But we couldn't even get her down the stairs, and the ambulance people took her to hospital. In the ambulance they put her on a drip, and sis Zikhona refused and they told her it will help you. But she kept on taking these things out.

In a study such as this one, designed to enquire into the particular dynamics between AIDS and child-well-being, care is required to assess the total body of evidence pertaining to well-being in adults and children. Perhaps owing to the emotive, private nature of the subject matter, there is a tendency for (relatively scarce) material in which direct links between adult illness and a child's vulnerability are intimated to trump data on well-being more generally. For example, in reading the narratives cited above, there is an inherent danger of assuming that coping with adult illness has been, and will always be, the most pressing concern and source of anxiety amongst the children recounting their experiences. The accounts are powerful because they carry the force of a first telling, and when bewilderment is evident in their articulation we read this as confusion and/or high levels of associated emotion (that may have rarely been expressed). Many speak of profound experiences, mostly relating to new knowledge or capacities they were called to bring forth and exhibit at a time of sickness. But none of the accounts are told in ways that foreground this particular set of experiences as defining their own lives, or prospective opportunities.

The narratives, and the changes of role and demeanour we observed amongst the children (described in an earlier section), point to indirect ways in which adults illness affects children. When an adult is sick, they become dependent and demand more emotional, physical, mental and financial resources from the household. There is often less of each for children, and we were told that when the main caregiver has to focus on the sick individual she becomes "stressed" and must be treated gently, and not demanded upon in other ways. In such contexts, children can perceive themselves as receiving less nurture but often consider the allocation of care to be appropriate. A transition that does seem to occur at this juncture is that children try to fill gaps in the usual care routine, for example getting on with the cooking when they see that no-one else is able to think about it. Our data suggest that boys and girls do this, but for girls in their early teens such activities may catalyse the transition into a caring role that is equivalent to that of an adult woman, including for example monitoring younger children and taking charge of domestic chores, some of which are done by

younger children. Earlier in the document I wrote about the gendered transitions into maturity that we observed in Rooidakke, and the long-term care demands of a chronically sick adult appear to play a part in stimulating these processes. None of the girls who made this shift expressed regret or resentment regarding their increasing responsibilities, and which gave them greater status in the home.

Status and recognition for one's domestic role, including caring, has been one of the positive outcomes of living with a sick adult identified in studies elsewhere (Bauman et al., 2006; Skovdal and Aleandreouli, 2011). What is not so clear is whether this shift into a more mature position is beneficial to children, girls in particular, in the long term. As teenage girls become more central to the workings of the home, can the neighbourhood offer what is required for personal development in other directions than domestic expertise? Two girls in our study stopped attending school; it took too much time and its content bore little relevance to their lives. In Rooidakke, there is no compelling evidence that remaining at school would enhance well-being in the long term. Apart from school, there are few institutions within the neighbourhood that offer adolescent girls, and boys, legitimate ways to develop positive personhood or make tangible steps towards future economic security.

There is no doubt that physical illness, and the mental and emotional frailties that accompany it, weakens adult abilities to protect and care for children. But so too do adult efforts to 'cope' in the face of highly challenging histories and the social nexus that is Rooidakke. Turning to drugs or alcohol, earning through illegal or 'improper' means, and withdrawing from engagement with the social and political structures (such as schools), are strategies to survive taken by those with parental responsibilities, and young adults trying to get further in life than their elders. They may generate some short term benefits (cash, status, 'coping' of a kind that holds a family together) but children in this study pointed clearly to the long term costs to their protection, general well-being and sense of personhood. At the same time, parental figures watched their daughters and sons stumble into infection or crime, often with life-threatening consequences. The threat to well-being comes from two directions; in undermining care of children and in rendering pathways for the future dangerous and fearful.

For these reasons, certain routes adults take cannot be described as 'coping', from the points of view of children. Reflecting on these phenomena, we have to ask what possibilities exist for adults to 'cope' in the true sense of the word? In highly impoverished and marginal communities like Rooidakke, personal faith, religious institutions and traditional practice are three of the most prominent sources of support to adults. Two families in our sample spoke of, and demonstrated, their regular commitment to a church or to traditional healing rituals. Their children were included in the institutional connection and understood its importance to the family's well-being. But other avenues for finding relief and garnering support – including those more 'modern' such as education and social services – appear difficult to access in Rooidakke. Many struggle to step beyond the confines of roles cast by poverty and gender.

It is in this context that 'wandering', as described in an earlier section, comes to the fore as a means in which children (and adults) may escape from the grief and demands of illness or death. Used frequently, the term acts as a metaphor for recourse to non-sanctioned, 'unacceptable' and dangerous ways of coping. It signals a resourcefulness that deviates from the modern script of good living, and is therefore shameful and hidden behind an apparently neutral word 'wandering'.

Wandering can refer to time away from home or beyond the watchful eyes of mothers or other (adult female) protectors in the home, to the tendency to 'hang out' in places known for illicit and

dangerous activities, or even acting in ways that are self-oriented, such as spending money allocated to children's needs on new clothes.

Neighbourhood deprivation, violence and their accompanying social sanctions are ever-present realities that are more readily verbalised by children as threatening to their well-being than adult illness. Three boys in the art club told us that they wanted to be policemen when they were older; "to arrest drunkards", "to catch people who do wrong things", and "to help people when they are short of money". Three children, girls and boys, said that they intended to become doctors "to heal people", to "help those who are sick", and "to earn nice money". Like their peers in poor neighbourhoods in many parts of South Africa, their aspiration to high status professions are likely to reflect a moment in time when educational aspirations are related more closely to the possibilities associated with the 'new' South Africa, than with personal experience (Bray et al., 2010; de Lannoy, 2008). But they also speak to arenas of life these children regard as needing to be put right, and roles in which they could act legitimately and effectively towards reducing harm.

The ebb and flow of adult illness, regardless of cause, is something that can on the one hand be contained within the family realm of care, but on the other hand remains mysterious or partially understood, associated with neighbourhood malevolence and beyond familial control. Being unable to know the pathway of the illness, or to treat confidently, appears to be one major stressor for children. The other is the potential finality; that death – while rarely spoken of at home – is a real possibility. Fear that a loved one might die was the greatest concern of the children who recounted their experiences of serious adult illness at home.

RB/PM: Ahh, so you want to become a doctor. Are there things you fear might get in the way of you becoming one?

Aphelele: Yes, that my parents will die, and I will not know who will look after me
[NB her father died of a stroke three years ago, and she consistently describes her mother's chronic illness as 'high blood']

How do children judge their caring roles to affect their well-being?

At no point did children convey that they find caring, as a broad set of activities one does within the home, to be inappropriate or an unfair imposition on their time. When compared to their other routine domestic tasks of cleaning, cooking and doing laundry, caring for a sick person was quickly identified as more pleasurable, owing to the satisfaction gained by doing something that helps a loved one feel better. Worry and sadness were felt to be possible accompaniments to this kind of care, should the sickness persist or worsen, and children not know how to help. The graffiti poster exercise gave us some insights into children's perceptions of personal benefit from providing care. In response to the prompt 'the richness you find from caring for others', one boy wrote 'you get even greater riches' and another 'you get a spirit, strength and courage'. How far these relate to their own experiences of caring for a sick adult is not clear, nor can we be sure that the sickness was AIDS-related or whether they knew it was so. A third boy identified the sick person's recovery as the condition under which caring can be emotionally rewarding; 'it is the happiness you feel when you know the person is well again'. The implicit flip-side of this emotional investment is the likely sense of failure and inadequacy when someone does not recover.

In response to the same prompt, Thina, who was involved in caring for her cousin until her death involving both drug use and AIDS, wrote "I am healthy, but not that healthy because there is a sick

person in my house". Her words imply that her own observable 'good health' is diminished by the presence of sickness in the family home, as if one cannot feel fully well when a loved one is suffering sickness of this nature.

For the most part, children considered themselves appropriate care-givers, indicating that they had the knowledge and resources to know how to meet the sick person's needs. The only time when they expressed a clear preference for an adult to be present, was when a person is nearing death and about to breath their last words. Their greatest concern in looking after someone very sick was the cost of transport to the hospital, should their worsening condition require it. They were not as worried about accessing the transport; all knew which neighbours to run to who had a car, or could make a phone call. Anxiety about cost may be heightened by the possibility of making a premature judgement of the need for hospital care, and thus incurring unnecessary costs to the family.

Support sought by children at times of adult sickness

In Rooidakke serious illness is managed within the home, often guardedly so, and adults in the vicinity are largely unwilling or unable to talk to children about the sickness and its implications. It is perhaps for these reasons that children in our study rely heavily on their siblings, cousins or other co-resident children, and are keenly aware of which individuals in the neighbourhood could give them practical help when needed.

During home visits and interaction within 'art club', we noticed very close relationships between thirteen year old Aphelele and her two nephews Lungelo and Siyamthanda, brothers aged thirteen and eleven respectively. They share a three-roomed shack with Aphelele's mother – whom Aphelele has reported as unwell in the survey – and five children under six years, the cousins of Lungelo and Siyamthanda. Aphelele's two elder sisters, one of whom is mother to the two boys, return to the home periodically between work stints on a farm, and in Johannesburg. Her uncle sleeps in the shack but is scarce in the daytime, his only contribution being assistance with structural repairs. For much of the time, the home is run by Aphelele, her mother, and less visibly, by Lungelo. Aphelele does a large amount of cooking, cleaning, laundry plus feeding and bathing little children. She is a mother figure to the small children, as well as to Siyamthanda and Lungelo, who rely on her to provide for their daily needs and identify her as dependable and caring. She is the one they talked to when worried about one of their cousins who fell ill, perhaps because their mother's mobility and grandmother's ill health renders them less available, physically and emotionally.

The two boys are always found together, often with a younger cousin or some friends. Siyamthanda relies on Lungelo as a playmate, as well as for protection and advice. Although Lungelo considers himself junior to Aphelele, who has greater authority in household affairs, he appears to be taking on some aspects of the provisory, protective male role in relation to the other children, Aphelele included. Usually a mild-mannered, easy-going boy, we were surprised to read in his journal; "I am able to beat people very hard". In conversation he described how his temper can flare when teased and how he has no qualms in using a large stick to retaliate or protect his brother, cousins or (aunt) Aphelele. When his young cousins complain of body pain, he buys an aspirin and gives it to them, seeing no need to discuss this with an adult. Should he not have money, he passes the message on to his grandmother asking her to buy the tablet. Aphelele's caring role is much more obvious and time-consuming, but Lungelo's may entail as great a sense of responsibility.

In only one other household did we work with a group of siblings and cousins. There it was difficult to tell the extent to which they spoke to each other about their elder cousin's deteriorating health, or offered each other advice or specific support. What was readily apparent was their sticking together as a group, sharing domestic tasks and playing cards downstairs while their aunts sat by their sick cousin.

The children in this study frequently run errands between their home and relatives or neighbours, some of whom live in the same street and others on the other side of Rooidakke. Taking messages, fetching items or buying groceries from the spaza store are what children do on a daily basis, and enable them to know where their potential supports reside. They are aware of which 'aunties', 'uncles' or 'grandmas' in the neighbourhood (who may or may not be blood relatives) have close relationships with the adults with whom they live. Some children distinguished particular individuals who they can call upon, who they know to have the kind of 'strength' that enables children to become strong in their presence, even when their parent or carer is very sick. As explained in the first section of the findings, children source support from certain institutions in the community such as the councillor, and certain members of the street committee. Some of this support is not instrumental, but comes in the form of reassurance in the knowledge that the clinic is accessible, and that the community centre can supply monthly medicines to a sick parent. Children's ready recourse, or at least statements around, neighbourly support implies more positive, trusting relationships with others in the community than adults reported amongst themselves.

Certain qualities of the way relationships are conducted in Rooidakke appear to be the primary forces working against children's abilities to garner support from their neighbourhood. Understanding contexts in which such relationships evolve is critical in further study of child caring at times of adult ill-health, and the ecological models drawing from Bronfenbrenner's early work are helpful in this regard. It is possible that research conducted in communities where there is much greater cohesion may find that children have greater opportunities for supportive and protective engagement available to them.

Children's commentary witnessed in this study contain instances of suspicion, mockery, denigration and conflict as a means of addressing problems. The interactions between the twelve children during art club also contained these qualities, and a relaxed conversation could turn in an instant to a verbal or physical fight. Each child (with one notable exception), when discussing their experiences and associated feelings, was able to identify the ways they would like to have behaved, for their own and others good, as well as what triggers their anger. Interestingly, it was often after such an open conversation that an individual demonstrated the force of their anger, almost as if he now had license to do so. Some warned us in the early days, saying 'you must know that I have a very quick temper' and describing the kinds of mockery and denigration that makes them lash out. One or two individuals (boys and girls) stood out as apparently unruffled by the persistent taunting and name-calling. One such boy was described by his mother as '*lulamile*' or 'humble'; someone who quietly gets on with his own thing and keeps his head down, a quality that she understood to underpin his well-being, and we grew to see why. The identification of personal traits that capitulate to, or resist, the way things are generally done alerts us to an awareness in children of the potential to act differently, to possess agency, even in this highly pressurised environment, and suggested that children have as much (perhaps more?) capacity to do so as adults. Moreover, the prominence of neighbourhood sociality – or style of interaction – in shaping the parameters of behaviour amongst the children points to the significance of context. Research conducted in communities where there is

much greater cohesion might find different scripts of interaction, including greater opportunities for supportive and protective engagement.

But it has nothing to do with the presence of adult illness *per se*....Recourse to verbal and physical violence as a means of personal defence, or maintaining social status, is something that is part and parcel of children's lives in Rooidakke – just as it is part of adult life – and there is no indication that it is specifically related to living with adult illness. Anxiety about the possible death of a sick loved one is something that children identify as making them upset, which could then be internalised or externalised through conflictual behaviour.

The climate of neighbourly sociality and ways relationships are sustained, or undermined, become even more important to child well-being in periods when intimacy and support are unavailable from adults at home. Earlier in the report (first section of findings), I described Vuyo's aunt's concern about his increasing 'wandering' and the 'wandering' that led to the death of his older brother in a shack fire. Below, I expand on these observations to show how Vuyo's vulnerabilities may persist, or even increase, even in a setting where an adult states their intention to care.

Vuyo initially kept his distance from us, dropping in and out of art club and using wise-crack jokes to deflect the attention of his peers. His ready smile was a thin veneer over considerable pain; willing to tell the story of his mother's illness for inclusion in his own movie, his tears flowed freely as we began and silenced him. He knew that we knew of his mother's and brother's deaths, yet despite his sense of a 'safe space' he could not reconnect with and speak about those times, or at least in the way made available through art club. Vuyo's behaviour suggests the on-going emotional effects of grief and loss, which appear to be fuelling his desires to 'wander'. The neat, new brick house of which he is proud is not one that he experiences as intimate or nurturing. The relationship between Vuyo and his great aunt, who defined herself as his caregiver, was observably distant: He spent little time at home, expressed no affection for her (although has clear affection for her grandson, his two-year-old cousin), and intimated to Nozuko that he did not want her to claim his foster care grant. For her part, his aunt mentioned signs of Vuyo's grief following the deaths of his mother and brother, yet appeared passive in its presence, apparently uncertain as to how to respond. Our engagement with these past events and Vuyo's well-being seemed to strike a chord with her sense of his needs and her stated desire to care for him. Perhaps unable or unwilling to accompany him in his grief, she made no moves to connect with the local NGO offering psychosocial support and drew on our presence only with regard to the potential for financial support through the foster care grant application.

Conclusion and Recommendations

The suite of studies under the umbrella 'Young Carers' was initiated to fill critical gaps in knowledge about children's caring roles in contexts of adult sickness and their impacts on well-being, and to guide policy and programming within South Africa.

The particular contribution of this ethnographic study is to illuminate the context in which care by children is undertaken and their implications both for individual well-being and the sustenance of social networks that serve to protect children and families. By interrogating 'care' as understood and experienced by children and their families, the ethnography sheds light on what is considered appropriate by and for children in a given situation (something often lacking in studies examining 'child caring' in southern and eastern Africa, see Bray, 2009).

What can be learnt from this ethnography?

Exploring the nature and distribution of caring roles and responsibilities within families provides a picture of change triggered by adult sickness, and challenges any assumptions we might have about an absence of vulnerability (whether care-related or otherwise) amongst children living homes where there is currently no discernible illness. The child-centred analysis contained in this report points to the persistent presence of adult illness or its ramifications, as well as to children's extended sense of responsibility and the reasons for their attentive knowledge management in a context of limited information, even when adults are mobile and active. Such findings suggest that comparative analyses of child well-being according to whether they reside in 'healthy' or 'sick' households may mask a range of pervasive, concealed, current or imminent ill-health in adults with care responsibilities for children, the threats from which arise as much from economic and political marginalisation as they do from illness itself. Therefore this distinction is not a good basis for targeting intervention.

By tracing children's social networks and exploring the quality of specific, important relationships, the research shows what exists to support the younger generation growing up in Rooidakke when caring for sick adults, and where the gaps lie. It cannot comment on the extent to which these patterns exist in other impoverished settings with high rates of HIV, other than to observe likely parallels in the structural constraints on adults abilities to provide nurture and security to their children, and the possibility of similar reliance by both adults and children on small networks of neighbourhood support, concealment and incomplete information in their efforts to care.

Summary of key findings

The most pressing problems children experience do not result from caring or adult sickness per se:

The absence of food security, quality schooling, sanitation, water and safety in the neighbourhood has greater bearing on children's immediate well-being – and many of the predictable facets of their long-term well-being – than caring, or living with a sick adult. This is partly because they make everyday living difficult and distressing (knowing that medicines must be taken with food when there is none available, trying to assist a sick person with toileting or to clean up body fluids when one cannot access a private toilet or clean water). It is also because hunger, seasonal employment (lasting half the year), histories of dislocation, neighbourhood violence and the behaviour people have adopted to cope with these hardships in Rooidakke all contrive to pull adult energy towards survival, and away from nurturing such relationship qualities. Another general problem affecting children is the scarcity of adults in the neighbourhood who were both willing to take children's opinions and experiences seriously, and had the power (money and status) to act in their best interests.

Children's caring is relational and not limited to the 'doing' of care tasks: Five of the twelve children who recalled periods of recent parental sickness and various care responsibilities were not engaged in these particular activities during the entire four month research period. However they continued to 'care' at an emotional level, and saw themselves as poised to care in practical ways should the need arise owing to on-going intimacy with these adults and the relational nature of care. When adult symptoms appear and recede periodically (as is often the case in chronic illness including that caused by AIDS), children's anxiety and uncertainty about cause or prognosis may persist, even when they are not actively 'caring'.

Adult efforts to protect children through silence may exacerbate costs to individual well-being: Not knowing exactly what is going on when an adult is sick is frustrating for children because they do not know how best to care for that person, nor can they anticipate likely future events. They are aware that adults often know more than they are prepared to articulate in children's earshot. And, while

understanding this practice to be widespread and historically rooted, children feel uncomfortable about being partially included. They are drawn into the intimate sphere of care whether by default or design, yet not party to significant details about the illness. And the strain is increased by having to maintain a front, to stay silent in order to protect the small familial or neighbourly sphere of trust and belonging that is critical to survival. While children do not struggle to keep secrets, concealing realities means being unable to seek, or take, the opportunity to talk for fear of betrayal and of violating local norms. Inadequate inclusion in conversation about illness or death was one of the difficult characteristics of social interaction identified by children participating in a radio project in Ingwavuma, where HIV rates are some of the highest in South Africa (Meintjes, 2011). There, children expressed a preference for information and inclusion rather than any form of psycho-social support. Psycho-social support initiatives tend to be based on the presumption that talking is good and that by expressing oneself openly one avoids repressed anxiety, yet these associations may not relate to children's everyday experiences of seeking and receiving value within home, family and peers.

The possibility of AIDS may count as much as its presence: The findings suggest that children's adversities spring not so much from living with and caring for someone who is known to be AIDS sick, as much as from living with someone whose sickness *could* be AIDS-related (and would demand a different kind of care, for example keeping secrets, plus living with the fear of loss). In other words it is as much (or perhaps more) about living in a neighbourhood where there is fear of identifying sickness, because it contributes to the fragility of a family's social status and internal coherence.

Caring by children cannot be divorced from qualities of other relationships: This study shows that any attempt to assess the implications for children of accompanying an adult through illness and even to death must expect to grapple with aspects of history and of contemporary social change that shape interpersonal relationships between children and adults, between adult kin and amongst neighbours. How, for example, have past or on-going experiences of social, economic and political marginalisation impinged on relationship qualities? What narratives, traditions or new possibilities do children and adults draw upon to achieve the kind of nurture they desire to give and receive? In order to understand where 'young caring' starts to rub against normal practice, researchers must seek points of connection between children's experiences of relationships they define as high quality in their everyday lives, and those that adult carers at this juncture in time and in this physical space are able to provide themselves, or to enable through others in the community. It is only through such a lens that sensible questions about the benefits and costs of caring can be asked, for example when and why does intimate time with a sick adult counts for more than attending school? Where most families and individuals therein have moved frequently in recent years, how robust are cultural systems for protecting children from violence in the neighbourhood, and from the effects of their own distress and grief?

The term 'young carer' has no utility in Rooidakke for residents, researchers or practitioners: For the reasons outlined above, the term 'young carers' could be applied to no-one (in the sense that none of the children regarded themselves as different in their caring), and everyone (because almost all children were in some fashion accompanying sick or dependent relatives). There was no evidence in this small qualitative study that the construct 'young carers' would be of benefit to participating children or their families, thereby begging the question of whether it has value in neighbourhoods with different demographics. There is the possibility that its chief (or only) purpose is to provide an

artificial means for policy makers and practitioners to identify and target resources towards a small portion of the vast population of children whose survival and development are compromised by poverty and illness.

Implications for policy and practice

Knowing that children want and feel able to offer care to sick relatives, yet experience limits to their capacities, demands very careful responses. Policies and intervention must protect the small familial and neighbourly spheres of belonging and support that children have formed, and tackle the factors that undermine the abilities of adults within those spheres to provide what children need.

Children's anxiety stems from both fear for a loved one's survival and the knowledge that they cannot provide appropriate care in acute situations. Interventions best able to support children living with sick adults, regardless of the cause or stage of illness, include some health-specific provisions, some attention to replicating and nurturing reciprocal, respectful relationships between children and adults with influence, yet must focus largely on investment in infra-structure, the local economy and broad-based services.

Adult access to health services: Knowing that a sick relative has access to medical care, even if they do not have money, is important to children because specialist, emergency care is beyond their capacity. The weekly distribution of medicines on repeat prescriptions from the local community centre (within ten minutes' walk for all residents) greatly reduced the risk that a sick relative went without critical medicines otherwise available from the clinic (a visit typically means a 45 minute walk and several hours queuing). Most relied on a trusted relative or neighbour to whom they could run who would listen (see below) and had a reliable phone connection should they need to call an ambulance. Some worried about the expense that such a call-out might incur to their families.

Adults who listen to children and respond to their insights. Children often rely on adults outside their own families for access to services (e.g. an ambulance) or to meet basic needs (food, clothing), especially when a new stressor (job loss, rapid decline in health) renders adult well-being at home even more fragile. Children repeatedly asserted the importance of knowing at least one adult within walking distance who will firstly listen carefully and not dismiss their words as 'childish' (i.e. inconsequential), and secondly who could take the required actions to meet a specific immediate need. The important criteria here are the availability of such adults, and their non-specificity (they are not deployed to 'listen to vulnerable children') which allows children to choose who they turn to when.

Income security and neighbourhood safety to enable relationships to thrive: Most important to children's well-being in the presence of adult illness are high quality interpersonal relationships within families and the wider community. Children actively seek access to socio-cultural resources such as stories passed down over generations, healing rituals and faith communities, both to bolster their own well-being and because they know that these support other adults in the home who, in turn, nurture them. They desire that the family sits down together to share food and talk about what needs to be done, and that an adult will be present if a sick person is about to breathe their last. For these qualities to persist, or to re-emerge, within family and neighbourly interaction, certain conditions are necessary for example food security, a wider employment base and a safe neighbourhood.

Locating care and services in hubs accessible to all children and families: Because AIDS and other chronic, debilitating diseases affecting adults amplify the effects of poverty and marginalisation in families, those members able to provide aspects of care do so in ways they perceive to best protect the familial integrity as well as the health of an individual. As explained in the report, children's

careful attention to who knows what about the family is integral to such care, meaning that they too sustain silence around illness (especially when AIDS-related or mental) and conceal its presence at home. In this context, using services that are specifically directed towards AIDS-affected, 'at-risk' or highly impoverished families entails the risk that people know too much, and the fear of gossip or exclusion. If children, and adults, are to sustain the small spheres of belonging and support that they have created within a highly challenging and critical environment, and to have the option to draw on these when adult health declines severely, then intervention must avoid undermining such networks through targeted, individualised support. Instead, children stand to gain from services that are accessible and available to all children through well-used, community hubs with long opening hours (civic centres, libraries, community halls). With attention to the qualities of relationships valued by children, creative ways may be found of offering specific medical, economic, educational or psycho-social support within these more generalised hubs. A suggestion arising from this study and ethnographic work in Manenberg (where poverty, violence and illness are also pervasive; see Versfeld, 2012) is for Community Centres now under the auspices of the Department of Sports and Recreation to be run by a partnership between this body and the Department of Social Development, thereby allowing a broader suite of services to exist in these hubs.

Lessons for further study of caring and youth in AIDS-affected areas

Ensure that qualitative research accompanies survey investigation: Even within a limited time-frame, the qualitative study in Rooidakke produced extensive insight into the dynamics surrounding children's caring and the mechanisms through adult sickness and other local factors impact their well-being. The learning gained in this study suggests that veracity requires triangulation, in other words data collection and analysis that relies on three methodological pillars. These pillars are a time-series investigation of a large data set (achieved through a panel study), close observation of children in their familial and neighbourly contexts, and a suite of creative techniques able to draw out perceptions and experience, that are both appropriate to children's interests and capacities, and appealing to their desire to experiment, perform or learn new skills. Often, short-term qualitative work relies heavily on the last pillar without a sound basis in observation, compromising veracity and insight. Narratives captured through stories, drawing or drama provide insight through their content, but cannot be properly interpreted without attention to how these are expressed in the context of broader local dynamics between children, and with adults.

Consider what is kept beyond reach of researchers: The territory of ill-health, AIDS, loss and grief is sensitive and difficult for the reasons illustrated in this report, the implications of which include bodies of experience and perspective, of both children and adults, that remain out of bounds and unknowable to researchers. Preparing to further knowledge of how children chart this terrain must include acknowledging some serious limits to data collection in that certain information will be concealed simply because it is too difficult for people to articulate, and probing would compromise ethical principles of dignity and respect.

Know that reliable evidence requires investing in time: Our experience in conducting and analysing this ethnographic study is that it only just achieved its goal. With more time, we are confident that more trusting relationships would have been possible with certain children and adults who were hardest to reach, and hence better insight into the nature and implications of their extreme vulnerabilities. Sustained and repeated periods of fieldwork also allow researchers to be present in the community in ways that offer greater insight into its social dynamics and turn 'community feedback' into a more meaningful, embedded experience. At the end of the second period of fieldwork in Rooidakke, we hosted a two hour evening meeting in a community centre (the hall of a

school for children with disabilities run by an NGO) attended by all participants (children and their family members), ward councillors, street committee members and social workers from local NGOs. There were about 90 people in the room and there was lively dialogue after we shared findings through children's audio, pictures and our analysis thereof. The immediate questions and concerns were recorded and inform our analysis, but we know nothing of whether this conversation led to action by any who attended.

Consider tracking the legacy of the research project: Although this study was never intended to be an intervention, it remains the case that researcher involvement through data collection and our personal or 'ethical' responses to situations met in the field, mean that we do leave a footprint. Little is known about whether qualitative studies of this nature (that are often shorter than ideal owing to funding constraints) are purely extractive or whether the research process, as a short but embedded process, can be a vehicle or catalyst for change in local institutions.

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Appendix Two: How fieldwork was conducted

a) Art Club techniques and process used in first fieldwork period (10 am to 3pm, daily, 27th June to 5th July, 2011)

Art Workshop Process

Day 1: Mapping Grabouw from children's point of view (5 children)

Ice-breaker Games: "shake shake banana" + wool web/trust game (both enjoyed)

Explained project and handed out info sheets, asked for Questions, got consent signatures

Snack break (cheese & jam sandwiches, naartjies, hot choc)

RB demonstrated the wax resist technique (food colouring as paint) & children practised

RB asked children if they would like to work together or in 2 groups (girls/boys), and they chose 'together'

Large piece of brown card covering central table,

Activity introduced as making a children's map of Grabouw, the places that are important for children. First we brainstormed (writing children's suggestions on rough paper so we'd remember to capture them all), then children chose what they'd like to draw/paint and worked on a specific area of the paper.

Snacks: Cheese sandwiches, jam sandwiches, fruit & hot chocolate

Day 2: (6 children but 2 new)

Games: Children wanted to do the same ones as yesterday to teach the newcomers. Wool web game used to introduce study and explain importance of consent, confidentiality & trust

Return to the map; went round the group asking each artist to explain what they had drawn and tell us why it was important for children (some chose important in negative sense, some in positive sense)

Brainstorm about what is missing? Three more suggestions made, and they worked in pairs to fill in gaps with these other important things

Snacks at end: noodles, hot choc, cookies

Day 3: (10 children; 5 new)

Games: fly fly clap clap 'mosquito fly' (leader tries to trick others into clapping when a non-flying thing mentioned) & fruit salad with chairs

Back to table: explain study to newcomers; hand out info and consent forms (making times to visit families)

ACTIVITY ONE: A1 piece of parcel paper in middle, and RB explains we're doing a 'speed map' of Rooidakke and the different areas around it, as there are many small neighbourhoods within Grabouw. We take turns to pass the pens round to 'scribe', beginning with me and Pride. I draw a circle in middle for Rooidakke and ask children to tell me what is there that is important for children, then I ask for nearby community and we do the same for 3 others (Iraq, Pineview, Council), then use this visual to discuss which areas are better to live (for children) and why some families have moved from pineview to rooidakke.

ACTIVITY TWO: To think of an important moment or event in your life, and make a sculpture that you can use to tell us a story about that moment. RB quickly demonstrated the rolling, coiling, thumb pot techniques (but no real need to!). Lumps of red clay (about 2 adult fistfuls) handed out to each child. *Children took to it with enthusiasm and concentration, happy banter around the table (giggling included), and some beautiful, vivid pieces made quite readily. Apparently a more accessible method than drawing?*

Snacks at end: Soup with salami pieces, 2 slices bread, hot chocolate & cookies

Day 4: Stories of significant moments or events

Game: broken telephone

ACTIVITY ONE: Unveil the sculptures and gently group them into indiv work. Comment on the beauty and variety, and what a lot of stories they contain. Explain that we need to be able to hear those stories, and to do so with gentleness, quietness & respect. Seek permission to use audio recorder

Create a sacred space (Waldorf style): Everyone sitting in circle (preferably on mats/cushions)

One person elects to begin, and candle is placed in front of them, lit by RB, and story is told 'what happened and why it was a significant moment, how it affects my life now'

If your sculpture is about something different then tell us what you made, and why, then tell us a story about a special or important moment in your life

Snacks at end: Bread, polony, apple & ricoffee/rooibos

RB: photograph the sculptures against white background

Day 5: Silhouette figures to probe 'what we do at home'

ACTIVITY ONE: Children make up their 'home-families' from silhouette figures (*decided against*: drawing their home large enough to fit everyone in), with lots of room around. Use large piece of brown card

Write the people's names beneath the figures (and share the figures around, not enough young children to go round!!)

Look at your family and think about 'who is there in the morning before you go to school to help you get ready?' 'who is there in the afternoon when you get back from school?'

Who does the budgeting at home, ie deciding how the money is spent?

ACTIVITY TWO: Roles at home: Find your own name (some had to add themselves as had left themselves out) and write underneath the things you do at home, then look at the others at home and write underneath the things they do at home from day to day, to make everything happen well.

Think about a person, or people who do not stay in your home but offer you and your family help or support? Write or draw them in and how they support you

Who cares for you (emotionally) at home? Put a red sticker near that person/people

Who do you give (emotional) care to at home? Put a blue sticker by these people. Write or draw how you care for that person near the sticker.

Day 6: Stones & shells in the basket

Warm up activity one: Think about your name and draw a picture about its meaning, or how you feel about the name. Introduce book-making aims and plans, that this drawing can be included.

Activity two: Brainstorm 'things we do at home': Long list (girls only column, boys only column, both column)

- What are the things we enjoy doing? (smiley faces drawn nearby)
- What do we do that is just 'part of everyday life', and we don't really think about them (neutral face)
- What do we do that we really don't like? (sad face)
- What do we do that makes us worry? (worried face)

Choose shells to represent the enjoyable/neutral tasks (mark them with masking tape). Then choose stones to represent the last two, size according to how horrid or worrying the things are, and label with masking tape. Put each one in basket once labelled.

Take them out one by one and ask the questions:

- i. Is this a task that is done alone or shared? With whom? Why is the shell/stone this big, rather than this big?
- ii. Have the shells or stones (including the pleasures, mundane tasks, worrying jobs, burdens) changed at all? How were they a year ago? Over weekend what do the shells and stones look like? What do they look like when you live in the EC or anywhere else?
- iii. When can a shell become a stone? Or vice versa? What do you feel and do when this happens? Who else shares this with you?
- iv. What would be needed to take the stones out of the basket (ie children's lives)? Or turn them into shells? (Instead, we asked: 'What would be needed to make the stones smaller and lighter...less troublesome?')

Pizza-making! Shared meal round the table, and spoke about whether we wanted a name for our art workshop group. One suggested the 'national team', others liked it...

Day 7: Begin making book covers & 'this is who I am' group input to drawing

- 1) Draw a picture, anything you like, to go on your front cover. Crayon then food colouring paint over the top (Most drew SA flags)
- 2) 'This is who I am' group activity: Sitting around the table, each person with A4 paper (including facilitators) draws a fist-sized picture of themselves, or something they identify themselves with (quick simple outlines). Then we all pass the paper to the person on our right, and receive one from the left. Thinking about the person whose paper it is, we write one word in Xhosa or English that sums up what we value in that person. Keep passing round until each paper has input from all round the table. Food colouring used to paint over and make the words stand out.

Day 8: Complete books, library visit & round-off workshop

Make inside front covers: choose coloured paper and stick on your photo of your clay sculpture.

Make a back cover using your drawings about your name, and the 'this is who I am' picture

Make the book by stringing the 10 blank pages headed with questions to the back cover, and front cover.

Questions used were:

- 1) What is happening in my family / at home?
- 2) What is happening at school?
- 3) What is happening among my friends or in the community?
- 4) What makes me happy?
- 5) Who am I caring for now?
- 6) What am I doing for that person?
- 7) How do I feel about doing those things to care for that person?
- 8) What makes me sad, worried or angry?

Trip to the library to familiarise everyone with the space, the intention being to talk about the book process and make a start in the library, and to leave a tub of crayons behind the desk for access over the coming months.

Sat in a circle in the main hall, talked about the book being special and unique to each person, that it is about 'my life'. We worked through the questions heading each page, answered queries, talked about the kind of thing one might want to draw or write about.

Logistics question of where/how they could work on these. Library was suggested but all children were very keen that they keep their books at home, asserting that they would be able to work on them and keep them safe if they had a plastic cover and a pencil (these were quickly bought and attached)

Return to Vicky's Multipurpose for fruit, hot choccy and cake, and rounding off the workshops. Round the table evaluation of what worked for all children participating, and what they'd prefer for next time.

b) Timetable of Art Club techniques and process used in second fieldwork period (10 am to 3pm, daily, 3rd to 8th October, 2011)

See below

Saturday 1st October, arrive Grabouw.

Sunday 2nd October– Visit all families and children: Catch up on news, Seek verbal consent for art club and its timings (children & guardians) and audio work (children); Please bring books of ‘my life’ tomorrow morning. Share plan for community feedback with household members. Ask: What timing suits? Who else should we invite?

Pride and Rachel work out the pairing of children for story-work, Go through prompt questions for ‘experiences of sickness in home’⁶.

| Date | 8.30 – 9.45 | Morning Art club 10-12 | Kit | Afternoon: 1pm to 3pm | Kit | evening |
|---------------------|--|--|--|--|--|--|
| Mon 3 rd | Set up in Viv’s multi-purpose centre Go over methods and process. | What has changed for children in Roodakke since July? Stretch a large piece of brown card over the entire table; children gather round and draw or write in wax crayon about important happenings, new things, difficult things, good things, Paint over with food colouring. Pass round audio recorder to practice Take turns to talk about items drawn | Roll of brown paper, 2 sets of: pastels, wax crayons, food colouring, brushes Audio | Introduce Chichi & Nozuko (using games), wool, Fruit salad, human knot Talk about our projects & our roles: a) Telling a story b) Making a picture story (photos of places, special things at home, in n’hood, things we’ve drawn or made etc) <i>(Show clip from Ch’s radio project)</i> Talk about the options for community feedback, telling adults about children’s lives; one of these is making mini-movies, | Wool Name badges PC, speakers and CD rom | Mary and Pride look over prompts for pairwork on sickness, check vocab Chichi, pride, Rachel talk through |

⁶ The purpose of this activity was to elicit individual accounts of living with ‘adult sickness’. While one child worked with clay to form something associated with a time when there was sickness at home, the other spoke with us. To encourage them in non-threatening ways, we used silhouette figures, from which they selected family members and described who was at home when the illness occurred. All were comfortable with the audio recorder and keen to record their stories except one who began to cry (at which point we stopped to give him space and comfort). Once children had told as much of a ‘story’ as they wished, we continued with conversational questions to explore their experiences of what helped most, how support was given to the sick person, what they did towards care, their knowledge about the sickness and its implications, and what kept them positive etc.

| | | | | | | |
|-----------------------|--|---|---|--|---------------------------------------|---|
| | | and written. RB PM intro our topic for this week's work: what happens when people get sick... | recorder | IF they are keen, divide group into pairs for neighbourhood photography with Chichi & Nozuko | Camera Audio recorder, notebook | photo work content & ethics |
| Tues 4 th | Rachel & Pride: 1st Pair for exps of sickness work | Exploring Care in Xhosa thru Graffiti wall, Then: Support circles (me/us in centre, supports/things that work for us in next circle out, challenges next, then what we have / need to meet challenges (in pairs, 2 colours) +/OR Map different kinds of care onto the circles, arrows for multiple directions of care received or given, | Large roll of paper, masking tape, lots colours of kokis, flip chart paper Lamp Audio recorder? | 2nd pair with Rachel and Pride for personal exps of living with sick adult ChiChi and Nozuko 1 st pair walk & photograph what ch think important to them / for their story (stop off at home, take pics of important things at home, keepsakes, clothing, handmade items, photos) | Clay, 2 nd audio recorder | Editing audio & translating Downloading photos; editing into tracks for shorts |
| Wed 5 th | Rachel & Pride 3 rd Pair for exps of sickness ChiChi and Nozuko ; 2 nd pair walk & photograph | Rachel & Pride 4 th pair for exps of sickness ChiChi and Nozuko ; 3 rd pair walk & photograph | | 5th pair with Pride and Rachel for personal exps of living with sick adult Chichi and Nozuko 4 th and 5 th pairs photo walk | Clay, 2 nd audio recorder | Produce and edit mini-movie for each child using audio and the photographs they have authored |
| Thurs 6 th | View/listen to 'shorts' as they are now (as group if they consent to open viewing) | | | Chichi departs | | |

| | | | | | |
|-----------------------|--|---|--|--|----------------------------------|
| | Children comment, suggest additions or changes | | Pride and Rachel visit community leaders (councillor, social worker local teachers? Pastors? ACVV). Invite them to community feedback. | | |
| Fri 7 th | | DAY OFF | | DAY OFF | |
| Sat 8 th | | Look at the journal books kept by children between July and October; talk about the entries made and probe context and meanings | | Visits to homes, (additional photos? Or audio with consenting family, older sibs, parents, other guardians) | |
| Sun 9 th | | Art club: Notions of the future; talk about aspirations, why these? Interim goals, who they follow, what needs to be in place | | Visits to homes, explore notions of future with parents and guardians; aspirations, stepping stones, what may trip up...what is known, what is unknown | |
| Mon 10 | | Prepare community feedback. What do we children want to say to their family, neighbours / street committees and community leaders? | | Community feedback? At library? | PC, big screen? Cables? speakers |
| Tues 11 th | | Last Art Club Talk about what enjoyed and what could be improved. Read story 'Jake and Tuffy' and talk about its meaning. Hand out photos, CDs & gifts | 10 CDs with movies; gifts = notebook & coloured pencils | Depart Grabouw | |

Appendix Three: Material presented at Community Feedback Meeting

Roidakke, 10/10/2011

What we did in our research: Art club with 12 children: mapping, drawing, movie making, interviewing about experiences of illness at home, drama. Then we also did lots of home visiting, having conversations with adult family members, and others we met in the community.

What we found:

WHAT CHILDREN DO AT HOME WHEN ADULTS ARE SICK

Some of the jobs we do are....cooking, bringing food, bringing water and medicines, reminding sick parents to take medicines. Taking them to the toilet, accompanying them to the clinic.

Children like to be involved in caring for people who are sick at home. It makes them happy to be able to do things that make a difference, even little things that help someone to feel better.

When we asked children what will keep them strong and positive and hopeful even in times of sickness, they replied 'we the children should be involved in the care'

They should help the sick person by bringing tablets and water." Lihle

And the things that they used to do, the older people, we did them, while they were looking after my aunt...I decided to cook because I saw that people were hungry and no-one was cooking. I just had to cook. Lereko

But sometimes caring at home can become too much of a burden, either

- a) Because they do not have time to do their school work or play
- b) Because it is emotionally painful and they feel lonely and powerless to help

When we ASKED THE CHILDREN....What kind of caring do you think that children can do at home, but what kind of care is too difficult for children?

AND THEY REPLIED..... "It is not difficult for me to care for my mom, like doing the cooking, cleaning, giving her coffee, and her medicine with clean water... You just need to remember not to play far away when your mum is sick. You can just play outside near the door. You need to look after her, especially when she is sick."

They like it when there is a family conversation about sharing tasks when someone is sick:

"We need to sit down and chat about what tasks need to be done when there is someone sick."
(Lihle)

But it gets difficult when the adult gets severely ill and they don't know what to do to help them. They don't want to be alone with a very very sick person;

"There must always be another older person at home because the sick person can breathe their last breath at any time" Siyabulela

WHERE DO THEY GET HELP FROM?

- Neighbours (e.g. asking them to phone for an ambulance)
- Trusted street committee members
- Vuyiswa, the councillor
- The police are seen as potential helpers but not accessible to children (do not seem to be around very much??)

HOW ADULT ILLNESS AFFECTS OUR LIVES

1) SCHOOLWORK

We asked the children: Is there anything else you would like to share with us adults, to help people in government and NGOs to know how illness affects children?

These children feel unhappy when their parents are sick, especially those who are going to school because they might be disturbed and unable to concentrate when their mother is sick.

Especially when your mum is really sick, because you won't know who will take care of you. It will be even more disturbing when you are writing your exams. Asamahle

2) THE EXTRA STRESS FELT BY ADULTS CARING FOR SICK PEOPLE

When aunties, mothers or grandmothers have a LOT of responsibilities, and then someone gets very sick at home, children see them getting unwell also from all the worry. They worry that they might lose another loved family member who cares for them too.

3) WORRY OF NOT HAVING ENOUGH FOOD

If a parent is too sick to work, then there will not be money to buy food. They understand that there are not many jobs available, and that most are seasonal or part-time and low-paid. They know this is a major problem all the time for poor families. But when someone is sick, it can get more difficult:

One child said: "I would advise the government to support children who have a sick parent by giving them food because that parent won't be able to work."

A) NOT KNOWING WHAT IS WRONG WITH THE PARENTS, OR WHAT COULD HAPPEN

Children told us that caring for someone sick is not always difficult. What IS very difficult is not knowing what is going on....

Yes, there are things that children are not supposed to know, like 'big things' (*into zinkhulu*) / important matters of the house that they don't need to hear and they lie to us and tell us some other things, when we know that they are not telling us the truth. Asamahle

Children often know more than we realise, and usually guess the truth. They want adults to be open with them rather than covering up difficult things. The children say 'When adults are open, it helps us cope and stay hopeful'.

B) NOT KNOWING WHO WOULD TAKE CARE OF THEM SHOULD THEIR PARENTS PASS AWAY

They understand that older sisters, aunties, and other family will make a plan to care for them, BUT they do not know WHO they will be living with, what will happen to the home, what they will inherit etc.

TALKING ABOUT ILLNESS

Children told us that it is difficult to talk about illness in the family, because adults are shy to speak the truth with them.

One child told us:....“The parents of some children do tell them ‘my child, I am sick with this and that’, that is why they know these things, and it helps them to understand what is going on. But some other children are being lied to by their parents, so they don’t talk about serious sickness or death. The adults will always say ‘your mum is going to get better’. “

Then we asked them where else can they talk about it?

Close friends and trusted neighbours are the only people children can talk to, or get help from.

None of the children in our group have ever talked to teachers, or social workers.

But they would like to talk to someone because having someone sick at home is painful. They would go to a person who:

- 1) Knows the different kinds of sickness and what can happen
- 2) Who is good at listening to them, and ‘takes their words seriously’, taking on board their concerns
“A person who is nice and good-hearted, and who can listen to what we are saying and take it on board (lit = put it into her or his mind (*fakwe ngqodweni*)). She mustn’t take what we’re saying like a child would. It must be someone good (‘right’)”
- 3) Does not gossip and spread your confidential information .

The children suggested that someone from outside Rooidakke might be a better person to talk to. But that person must also understand their everyday lives and be a Xhosa-speaking African person.

WHAT CAN WE DO ABOUT IT?

We have been in Rooidakke for quite a short time (10 days in June, 10 days in October) so we know we cannot have the full picture. But our research is showing consistent findings from what both adults and children are telling us, and what we see.

Our job here is to share with you what **children have been sharing with us through their artwork, their drama, their accounts of illness in the home, and their support networks.**

What are **children's suggestions** of changes in Rooidakke that would help them when adults are sick at home:

- 1) Health services that are nearer: The clinic is very far away when you have to walk with a sick person. Transport to the hospital is expensive.
- 2) Clean water: We have taps but they are very far away for us to walk with heavy containers.
- 3) Rubbish collection: Children see rubbish piles near their homes and worry about infection, especially when rainwater washes through the rotting rubbish (including dead dogs), and they see little children playing in the water.
- 4) Build more toilets; when people use the bush for toileting, the water is made dirty and the infections can travel into our homes. "We understand that houses take time. But we really need clean water and toilets. The existing cement toilets are often locked and only a few people can access them".
- 5) Encourage more talking about illness between adults and children at home
- 6) Keep supporting each other as neighbours
- 7) Listen to children when they have questions, and involve them in conversation about illness or any other issue troubling their lives
- 8) Find trusted adults to listen to children who have had a tough time at home through parents' illness or death, to help children to grieve and heal.