

Understanding norms and practices around care and illness:

Where do children fit?

Report from qualitative research amongst 'young carers' in Grabouw, Western Cape, South Africa

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The purpose of this short report is to give policy makers and practitioners insight into the social and cultural dynamics of family care practices. Grasping a sense of local understandings of both appropriate and problematic caring roles for children is essential to designing effective supports to families in neighbourhoods where serious sickness is prevalent.

For a policy brief and full report on the ethnographic study conducted amongst a sub-sample of the Young Carers panel participants in Grabouw (see Bray, 2012 on www.youngcarers.org.za).

Questions and method

A qualitative analysis of the 'economy of care' within households allows us to understand where and how children are expected to step in. In Grabouw, 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 drama improvisation exercise¹ was to give children open-ended prompts on the subject of care and to 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.

Findings

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.

Gender dimensions to care-roles and growing up

Adult women were marked out by children and adults as the ones who take primary responsibility 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 owing to our gender² or to perceptions that we were '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 intimate domestic relationships, we noticed a variety in their actual involvement in care for children or sick people. Other researchers have suggested this spectrum is indicative of the narrowing of possibilities for men to offer care through

¹ The purpose and use of these methods are described in the full report available on www.youngcarers.org.za.

² Research and translation assistance was ably provided by Pride Mtetseni. She and I lived in Grabouw for two periods of twelve days separated by a three month interval. Spacing the fieldwork in this way enabled us to observe changes in children's roles in response to health and other matters at home.

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

Thandiwe's³ 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 depot. 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. For Thandiwe, her father's consistent and attentive oversight of the household needs is evidence of his provisory care. She also 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 the settlement. Our only conversation with him was friendly and open, and he chose to tell us that his greatest concern is his daughter's health: "Because of her situation, she plays with everything on the ground outside including dog faeces, used condoms and such. 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, than his wife in terms of material, practical and emotional support towards the care needs of the family, and particularly his disabled daughter.

In apparent contrast, Aphelele's uncle was never at home when we visited and Aphelele did not include him in her description of household members 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 that of their neighbours, replacing tarpaulins and nailing in new roof struts. Aphelele's adult sisters explained that their uncle would work on the home, as long as they bought or acquired the materials.

Such examples of specific, yet attentive, care by men are easily overlooked yet may be pivotal in everyday household economies and to children's sense of security and provision at home.

In Grabouw, we witnessed a greater range of practical and emotional care responsibilities placed upon teenage girls when compared to their younger siblings or male peers. As evident however, was that all boys participating in the study (age range of 10 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, bringing medicines and water when needed, and massaging the feet or backs of a sick parent (the latter to bring relief in cases of TB, although children may not have known the cause of illness⁴). When younger siblings reported pain, their brothers 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)

³ All names used are pseudonyms.

⁴ The extent of children's knowledge of adult illness and the factors influencing their abilities to find information are discussed in the full report on www.youngcarers.org.

“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)

This early caring role notwithstanding, our limited experience in the eight Grabouw households suggests that when boys reach their mid or late teens something shifts in how they see themselves, and what others expect of them. And with this shift, they move 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 in the full report) 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 in their early teens, who during the first phase of fieldwork were behaving and being treated as ‘children’ within the household, began carrying themselves like young women, co-ordinating domestic activities and supervising their younger siblings in the space of only three months between the two phases of fieldwork. 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 during initial fieldwork was overseeing domestic chores and providing emotional care, had moved out by the second fieldwork phase 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.

Across many societies, caring is seen as a ‘natural role’ for women. The literature on gender and care rightly points out that one result of the feminisation of care 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 yet 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 personhood⁵) 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

⁵ I acknowledge Anna Versfeld (2012) in my use the term ‘positive personhood’ to refer to the process through which people construct themselves as recognised and valuable. Anna has studied survival and ‘coping’ amongst young men and women in Mannenberg, Cape Town, and we have had much productive debate on the conceptual underpinnings of coping in the two research sites.

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 the boys in this study (now aged 11 to 13 years) do not repeat any further years of schooling, they will be in grades 7 to 9 when they reach 15 years of age. 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 during the three months between fieldwork phases. 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, also see 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 for 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 nexus 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 the historical significance of educational opportunity (Bray et al., 2010; Maloni & van Dijk, 2011; Soudien, 2008). 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 the twenty four days of fieldwork we did not achieve these in any of the participating households: 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, their relatives clearly having waited until they were desperately anxious. Even at this point, adult family members were unable to discuss what might be wrong.

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 were witnessing during visits to her home. Zikhona 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 even 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, such as who would live with who?

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?'

Thina's inability to ask the question that troubled her illustrates a pattern in communication about illness, particularly between generations. Children in this study know that adult relatives try to protect them from the harsh realities of life-threatening illness by staying silent on the topic. There was some evidence that adult silence may exacerbate the costs of illness to children's 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. Children understand codes of respectful behaviour between generations, yet perceiving themselves as full family members drawn into caring (whether by default or design) they feel excluded when they perceive adults to be withholding information about illness that could help them. The strain on children is increased by having to maintain a front, to hide illness through silence in order to protect the small familial or neighbourly sphere of trust and belonging⁶ 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).

Conclusion

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.

Two important qualities of children's caring roles were made clear through attention to norms and practices around care used in this qualitative study:

- 1) **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'.
- 2) **Caring by children cannot be divorced from qualities of other relationships.** Attention to these dynamics assists our understanding of where, and how, a caring role may contribute to children's well-being, as well as to aspects of caring activities or emotional responsibility that may contribute to their vulnerability. While we cannot assume that the dynamics observed amongst Xhosa and Sotho families in Grabouw can speak for other areas similarly

⁶ The full report describes the role and workings of these small networks of trust and belonging in Rooidakke, tracing their significance within a growing, immigrant community comprising families from diverse backgrounds and with histories of chronic poverty and marginalisation. See www.youngcarers.org.za.

affected by HIV and other sickness, there are likely to be strong parallels with these findings as well as local specificities that deserve local research.

The Grabouw study highlights the value of time spent doing local ethnography able to dig deeper into the expectations that adults have of each other and of children, and of children's sense of where they fit in the economy of care. Questions able to illuminate these processes in other areas include;

- How have aspects of history and of contemporary social change shaped interpersonal relationships between children and adults, between adult kin and amongst neighbours.
- How 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? In communities 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?

Further discussion on the implications of these findings for our conceptual approaches to research and intervention for children in areas of high AIDS prevalence are found in the full report mentioned in the introduction, and in forthcoming publications (Bray, in process; Bray and Dawes, in preparation).

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