

Developing a child-friendly Young Carers Questionnaire: A pilot study

Jenny Back

Department of Psychology

University of Cape Town

Supervisor: Lauren Wild

Word Count:

Abstract: [261]

Main Body: [9764]

**ABSTRACT**

A minimal amount of research has been conducted on the role of young carers in South Africa. Young carers are defined as children below 18 years of age who perform caring tasks for their ill parent(s) or guardian(s) which exceed the routine, household tasks expected to be performed by most children. These tasks range from medicating and bathing their parent to attending to their siblings. A team of researchers from Oxford University in England has designed the Young Carers Questionnaire to assess the social, health and educational impact on young carers managing parental illness. This will allow for the exploration of potential causal mechanisms concerning child well-being which may in the future be relevant for policy. The purpose of this study was to determine whether the questionnaire, interviewer behaviour and interview experience required refinement with the aim of increasing the validity of the overall questionnaire and the interview process in the South African context. This was determined through piloting the questionnaire. The sample included 10 male and female young carers between the ages of 12 and 18 from a township outside Paarl. Participants were recruited through referrals from the Stellenbosch Hospice and the Klapmuts Primary School. Cognitive interviewing was used to access feedback from the participants on the questionnaire. Their responses were analysed using thematic analysis. The results indicated a number of ways in which the format, wording and content of the questionnaire, the overall interview experience and the interviewer behaviour could be improved. The results were then presented to the parent study as recommendations for refining or improving the questionnaire.

**Keywords:** cognitive interviewing; parental illness; South African pilot study; thematic analysis; young carers, Young Carers Questionnaire.

The declining health status of a large sector of South African society has resulted in an increase in the number of young carers. This status is largely as a consequence of the HIV/AIDS pandemic the country is faced with. Health subsidies made available by the government in African countries are limited. More often than not they are unable to address the needs of those suffering (Akintola, 2008). Clinics remain understaffed and ill-equipped. Children are being required to care for their ill parent(s) due to the nature of their environment (Akintola, 2008; Cluver, 2008). The child is thus transformed into a young carer. Young carers are defined as children under the age of 18 who perform caring tasks for their ill parents beyond that which is considered routine (Aldridge, 2008). Due to co-residency, location and lack of resources there is an enormous degree of dependence on children to provide care for their ill parents (Aldridge, 2008; Cluver, 2008).

International research suggests that being a young carer has a number of detrimental consequences for children, although there may also be positive outcomes (Evans & Becker, 2007). However, there is a dearth of research on the experiences and adjustment problems of being a young carer in the South African context (Cluver, 2008). One of the reasons for this is that there are a number of challenges involved in conducting research with this group, including a lack of measuring instruments that have been developed or validated for use with children in South Africa. Therefore, careful development, piloting and a refinement of the measurement tools to be used in research with young carers is essential.

The scenario presented above has resulted in the establishment of the Young Carers Project and a research team dedicated to studying this group of individuals. Preliminary research has been conducted with young carers in order to develop a questionnaire which will assess the social, health and educational impacts on this group of children caring for their ill parent(s). The results from the questionnaire will determine what structures and support services are necessary to lessen the risk factors and increase the protective factors for young carers in order to protect their overall wellbeing. These findings will ultimately inform policy. However, before this questionnaire is administered, it was necessary to pilot it. This was the focus of the current research project. Piloting the questionnaire ensured that the overall questionnaire design and interview experience are suitable, given the sample of participants (young carers) it targeted and the context in which it will be administered (urban and rural townships in the Western Cape, Mpumalanga and KwaZulu-Natal). The results of the pilot study were drafted in the form of recommendations for the refinement and improvement of the questionnaire. These recommendations were then presented to the research team conducting the parent study.

### **The impact of being a ‘young carer’ on children**

The role of children as young carers has recently caught the attention of researchers and policy makers (Earley, Cushway, & Cassidy, 2007). Previously, little focus was placed on this group and thus progress in determining the impact on their social, educational and health status has been slow. Furthermore, the literature is sparse with regard to studies of young carers within the South African context (Cluver, 2008).

International studies suggest that children may experience varying outcomes as a result of caring from a young age (Aldridge, 2008). The majority of these outcomes are negative. Children’s mental health may be affected as a result of providing intimate personal care to an ill parent, potentially resulting in emotional exhaustion, anxiety or possibly depression (Earley et al., 2007). Their physical health may be compromised as a result of performing tasks inappropriate to their age (e.g., lifting of parents). Educational problems may result due to their caring responsibilities conflicting with their school attendance (Banks, Cogan, & Riddell, 2002). Lastly, the stigma attached to the parental illness often results in children being bullied or treated differently and in turn becoming socially withdrawn (Roberts, Bernard, Misca, & Head, 2008).

Research from which the above findings have been drawn has primarily been based on parental reports and retrospective self-report questionnaires (Earley et al., 2007). From the above studies it became apparent that the opinions of young carers had been neglected. Their role appraisals are important to account for, as from a theoretical perspective an individual’s appraisal of their experiences and the degree to which they perceive them as stressful has been shown to be crucial in influencing psychological outcomes (Lazarus & Folkman, 1984). A shift from parent appraisal to child appraisal of care-giving activities may present researchers with a better means to assess the needs of young carers and in turn develop an appropriate intervention for these children.

In addition to providing young carers with a platform to voice their opinions, research is aiming to further raise their profile, based on the perceived impact caring has on these individuals (Earley et al., 2007). This will grow researchers’ understanding of their roles and responsibilities and consequently the risk and protective factors associated with their psychological wellbeing. This knowledge may later contribute to the establishment of policies aiming to protect their interests (Cluver & Gardner, 2007). A possible reason for the lack of research on South African young carers lies in the challenges which studying this group presents.

### **Challenges to conducting research with young carers in South Africa**

Given the nature and developmental level of a child as opposed to an adult, researchers will inevitably be faced with a number of challenges in their endeavours to conduct research with children. It is the social and cultural context in which children function that can also pose challenges to researchers.

#### *Accessing a sample*

Conducting research with young carers in South Africa involves addressing sensitive topics such as illness, bereavement, behavioural problems and school non-attendance (Cluver, 2008). The sensitive nature of such topics may make it difficult to access a sample as parents may not feel comfortable allowing their children to answer the researcher's questions, despite the principle of confidentiality having been explained (Mann & Tolfree, 2003; Valentine, 1999). Based on previous research, they may fear their children will be removed from their care or they will face difficulties with the authorities.

If research is conducted in low socioeconomic status areas where there is likely to be an emphasis on seniority, parents or guardians may exert an influence on whether their children should be allowed to participate in the study. Their involvement may thus have an influence on which 'voices' are heard (Mann & Tolfree, 2003). Furthermore, in the past the voice of the child was marginalised (Christensen & Prout, 2002), and thus not only would the researcher be challenged in terms of accessing an unbiased sample and uncovering the true story, but in fact accessing any story at all (Mann & Tolfree, 2003). This may also be the case within age-related hierarchies.

#### *Age*

In African cultures, age-related hierarchies are considered important. Older children are given priority to participate over younger children. Thus, it may be difficult to access participants from across the young carers' age continuum and the researcher may only gain access to certain opinions. However, if younger children do participate, the researcher may still struggle to access the necessary information, due to their potentially short attention span and limited ability to articulate themselves (Mann & Tolfree, 2003). Thus age may be related to the young carers' language proficiency, development and levels of education (Harden, Scott, Backett-Milburn, & Jackson, 2000).

### *Culture in relation to education and language*

Various words hold different semantic meanings for different cultures, and thus are often considered ambiguous (Tourangeau, Rips, & Rasinski, 2000). For example, the connotations associated with depression may differ across cultures (Weiten, 2004). Ambiguous words can lead participants to interpret questions in various ways. This then challenges researchers in determining the validity of their responses. Furthermore, the literature has shown that questions often presuppose that certain characteristics apply to participants. The reality is that cultural diversity denies the application of a standardised questionnaire (Tourangeau et al., 2000).

A study in Liberia illustrated that children who had higher levels of formal education were more familiar with Standard English and consequently could communicate more freely (McCauley, 2002). Moreover, research has shown that those with less formal education are often more open to the process and better able to understand and interpret the content of their peers' comments despite their lack of language skills (Mann & Tolfree, 2003). This indicates that the level of education presents both challenges as well as benefits to conducting interviews and administering questionnaires.

Existing questionnaires are inadequate in determining the impact of caring on South African young carers, as they have mostly been developed by and for the Western world (Mann & Tolfree, 2003). They do not account for the differing contexts of other countries. For example, South African young carers being assessed are typically from low socioeconomic backgrounds; they may be poorly educated; and frequently, they do not have English as their home language. The questionnaire content may therefore be irrelevant to these children or exceed their processing capacity (Tourangeau et al., 2000). The challenge here is creating a measurement tool which addresses their specific context. The communities in which young carers originate from, form a major part of this context.

### *The community's experience of participation*

In many African communities, during the apartheid era, adults themselves did not have the opportunity to contribute to society through expressing their opinions; thus allowing their children to do so, may be foreign to them (Mann & Tolfree, 2003). Additionally, cultural hierarchies often adhere to the expression 'children shall be seen and not heard' (Christensen & Prout, 2002). This stance may further prevent child participation in research.

### *Gender*

In many cultures girls are not allowed to openly express their views, especially in the company of men (Mann & Tolfree, 2003). Thus the sample accessed may be biased towards male participants. Furthermore, an awareness of the effects of interviewer gender on the participant is important. The literature has shown that individuals tend to prefer working with same-sex researchers (Padfield & Procter, 1996). A number of participants tend to feel uncomfortable when being interviewed by a researcher of the opposite sex, and consequently share less openly. Additionally, parents may not be comfortable with male researchers interviewing their daughters as this may cross gender-based boundaries in that the girl moves out of the traditional context of her domestic duties to that of becoming a research informant (Mann & Tolfree, 2003).

The challenges discussed above suggest that careful piloting of questionnaires aimed at young carers in the South African context is essential. Although the importance of conducting rigorous pilot studies is often overlooked, the literature does suggest some possible approaches.

### **Methods to pilot questionnaires**

One of the main objectives of piloting is to determine whether the validity and reliability of the questionnaire is acceptable (Cox & Cox, 2008). This provides the opportunity to refine the questionnaire before officially administering it to the participants (Lancaster, Dodd, & Williamson, 2004). Literature regarding pilot studies generally involves direct piloting of the questionnaire in order to check the validity and reliability of the results (Simon, 2008). Direct piloting involves administering the questionnaire to participants and statistically analysing the results using quantitative methods.

While there has been minimal research demonstrating the use of alternative methods to pilot questionnaires with the inclusion of participant involvement, the literature has shown that greater emphasis should be placed on acknowledging the voices of young carers through allowing them to contribute to the research process (Aldridge, 2008; Davis, 1998). Their involvement enables the researcher to gauge their feelings about the research setting, the interview process and the content of the questionnaire (Davis, 1998).

The alternative methods which do exist, originate from cognitive psychology (Jobe & Mingay, 1989). Methods which have been used in previous research include the cognitive interviewing technique and recording.

The cognitive interviewing technique involves participants communicating their thoughts regarding the questionnaire. This is done either concurrently or retrospectively (Jobe & Mingay, 1989; Tourangeau et al., 2000). Each of these approaches has its limitations. The former method may break the flow of the questionnaire, consequently influencing the participant's answers, while the latter could result in failure to recall related thoughts due to memory lapse (Hammell & Carpenter, 2004). The advantages of both methods however offset their limitations. In addition to testing the questionnaire, the researcher receives feedback on it while the use of prompts allows for the development of a dialogue between the researcher and the participant (Jobe & Mingay, 1989). The concurrent method further allows for observation of the participant's responses to the questions and is appropriate for recruiting participants who are available for short time periods only.

In addition to deciding to conduct the interview either concurrently or retrospectively, the interviewer can choose between two methods of cognitive interviewing (Beatty & Willis, 2007). The first method involves the interviewer proactively guiding the interaction with the participant through the use of follow-up prompts. The second method involves the interviewer generally encouraging participants to verbalise their thoughts; that is, to think-aloud while completing the questionnaire (Rebok et al., 2001). Ultimately, both methods allow the researcher to access how participants interpret, perceive and answer questions, in order to evaluate the effectiveness and the validity of the questionnaire and interview experience (Beatty & Willis, 2007; Yorkston et al., 2008).

A study conducted by Vivier (2006) has demonstrated that recording an interview can improve the efficiency of the cognitive interviewing technique. This recording allows the researcher to re-experience any comments made by participants regarding the questionnaire. This provides further opportunity to detect factors which may have been missed during the actual interview and which consequently may contribute to questionnaire refinement. These factors include the participant's line of thought, the meaning behind these thoughts (often in the form of unintentional explanations) and the preferred terminology. These examples support the notion of accounting for the participants' voice and acknowledging their comments through using them to improve the questionnaire (Vivier, 2006).

The major advantage of recording is to save the researcher valuable time, as the material recorded does not have to be transcribed nor does the researcher need to take notes during the interview. However, it does have its limitations in that the identification of problems requires a spontaneous expression from the participants (Vivier, 2006). Further, recording the interview may influence the participants' willingness to converse and the



content of their feedback. Thus this method may work best as an optional addition to the cognitive interviewing technique.

### **Aims of the current study**

Piloting the Young Carers Questionnaire stemmed from the necessity of having a measuring instrument which was able to address the challenges which studying young carers in South Africa presented. The pilot was conducted independently of the parent study and thus offered an objective view of the Young Carers Questionnaire and Project as a whole.

The pilot ensured that the content, wording and format of the questionnaire, in addition to the interviewer behaviour and interview process, addressed these challenges. Piloting the questionnaire allowed for areas identified by the participants as problematic to be refined, improved on or changed before officially administering it to the participants of the parent study.

Thus the initial aim of the pilot study was to access young carers' opinions on the Young Carers Questionnaire. The following questions were asked:

- (1) What are the young carers' opinions on the format, wording and content of the questionnaire?
- (2) What are the young carers' opinions on the overall interview experience?
- (3) What are the young carers' opinions on the behaviour of the interviewer?

Ultimately, the main aim was to transform the results from the above research questions into a set of recommendations for refinement and/or improvement of the questionnaire. These recommendations were then presented to the research team of the Young Carers Project.

## **METHOD**

### **Design**

A qualitative design was used for this study. This design allows for research to be conducted using a variety of different methods. These methods are designed to gain an understanding of the nature of the particular field through the analysis of an assortment of texts (Babbie & Mouton, 2006). In this case the text is verbal, as the young carers communicated their opinions to the researcher while completing the questionnaire. Nevertheless, the existence of non-verbal texts, for example facial expressions and body language, were not overlooked.

The data collected and analysed were expressed in the form of words rather than as numbers. Statistics derived from the numerical data would not allow the researcher to discern

any nuances in the young carers' opinions. This is an indication that the qualitative paradigm lends itself to the collection of rich data and in-depth description (Babbie & Mouton, 2006). It is these features, along with conducting the pilot study in the participants' natural environment, which allowed the researcher to make sense of their opinions in the given context.

This type of research design was thus well suited for the proposed study, as it went beyond that which quantitative designs could offer. The face-to-face interview allowed young carers to express their opinions in a space which encouraged the exploration of meaning, while allowing the researcher to account for their individual effect on the overall research process (Parker, 2005).

### **Participants**

Six males and four females who met the criteria for the role of young carer were selected to participate in this study. The participants were between the ages of 12 and 18 years. The sample size was determined on the basis of the average sample size of previous studies using similar methodologies (Yorkston et al., 2008). The participants were selected using purposive sampling. This involved specifically seeking out participants who met the pilot study's criteria for young carers (Trochim, 2006). They were found to be performing caring tasks for their ill parent(s) or guardian(s) which exceeded the routine, household tasks expected to be performed by most children. The illness of the parent(s) or guardian(s) for which the child was caring was not stringently defined, provided that the child met the above criteria. Thus participants were seen to care for parents with diseases which included HIV, arthritis, dementia and tuberculosis.

In order for the sample in the pilot study to be as representative as possible of the parent study population, participants were recruited from urban and rural townships. The participants originated from low socioeconomic backgrounds, with a relatively low level of education. Six of the 10 participants were isiXhosa-speaking, while the remaining four were Afrikaans-speaking. All the participants had Afrikaans as either their first or second language and thus the use of a translator was unnecessary given the researcher's fluency in this language.

## Materials

The Young Carers Questionnaire, which has been designed specifically for young carers in South Africa, was the instrument used in the pilot study (see Appendix A). The purpose of this questionnaire is to assess the social, educational and health impact on young carers who are caring for their ill parents (Cluver et al., 2009).

The questionnaire comprised two sets of measures and constructs. The first addressed child outcomes, while the second dealt with risk and protective factors. The child outcomes included mental, sexual and physical health, and education, each of which was assessed using a variety of measuring instruments (see Appendix B, Table B1).

Mental health was assessed by having the participant complete selected items from the Child Depression Inventory (Kovacs, 1992), Children's Manifest Anxiety Scale (Gerard & Reynolds, 1999), Child PTSD Checklist (Amaya-Jackson, 1995), Mini International Psychiatric Interview for Children and Adolescents (Sheehan et al., 1997), Child Behavior Checklist (Achenbach, 1992), Strengths and Difficulties Questionnaire (Goodman, 1997), National Primary Schools Violence Survey (Burton, 2008) and the National Survey of HIV and Risk Behaviour amongst Young South Africans (Reproductive Health Research Unit & Lovelife, 2005). Items from the National Survey of HIV and Risk Behaviour amongst Young South Africans (Reproductive Health Research Unit & Lovelife, 2005) and the South African Demographic and Health Survey (Department of Health & Medical Research Council, 2007) were used to measure sexual health outcomes. Physical health outcomes were measured by the use of items from the South African Demographic and Health Survey (Department of Health & Medical Research Council, 2007) and Researching Equitable Access to Healthcare (REACH; Pillay, Nyathikazi, Bismilla & Bromfield, 2008). Lastly, items from the Young Lives Study (Boydon & Dercon, 2008) were used to measure education outcomes.

The second section of the questionnaire addressed factors that might influence the psychological wellbeing of the young carer (e.g., bullying, stigma, social support and so on; see Appendix B, Table B2). These factors were measured using the following instruments: Young Carers Tasks and Outcomes Questionnaire (Becker, 2009), Road of Life (Cluver & Gardner, 2007), Household Map (Israel, Eng, Schulz, & Edith, 2005), items from the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (WHO, 2003), Verbal Autopsy Questionnaire (Lopman et al., 2006), items from the Demographic and Health Survey, 2003 (Department of Health and Medical Research Council, 2007), the Health Systems Trust Annual Review (Health Systems Trust, 2007), items from the REACH study (Pillay et al., 2008), items from the South African Census

(Statistics South Africa, 2001), National Survey of HIV and Risk Behaviour amongst Young South Africans (Reproductive Health Research Unit & Lovelife, 2005) and the South African National Food Consumption Survey (Labadarios et al., 2003). Furthermore, the Social Support Scale (Adolescent Pathways Project, 1992), Stigma-by-Association Scale (Mason, Berger, Ferrans, Sultzman, & Fendrich, 2008), Social and Health Assessment Peer Victimization Scale (Mynard & Joseph, 2000), UNICEF measures for national-level monitoring of orphans and other vulnerable children (Snider & Dawes, 2006), National Primary Schools Violence Survey 2007 (Burton, 2008), Child Exposure to Community Violence Checklist (Van der Merwe & Dawes, 2000) and the Alabama Parenting Questionnaire (Elgar, Waschbusch, Dadds, & Sigvaldason, 2007) were used.

These scales from which items were taken, and the particular items that were selected, were chosen based on a number of factors. These factors included strong psychometric properties (such as good internal validity, test-retest reliability and promising alpha scores), standardised scales, cross-cultural validity and items considered successful in a previous questionnaire designed for AIDS orphans (Cluver, 2008). The tables in Appendix B list the psychometric properties of each scale/questionnaire. Furthermore, findings from the workshops conducted with a Teen Advisory Group of AIDS-affected children helped to inform the inclusion of certain scales, questionnaires and items.

## **Procedure**

This pilot study followed the guidelines for research with human subjects, as outlined by the University of Cape Town. Ethical approval was obtained from the Research Ethics Committee of the Department of Psychology. Ethical approval for the parent study was obtained from the Oxford University Research Ethics Committee and the Cape Town Child Welfare.

Participants were recruited through contacts held by the headmaster of a school in Klapmuts. The headmaster referred the researcher to key community leaders and hospice workers operating in Klapmuts. Based on their knowledge of the families within the community, these individuals assisted the researcher in identifying children who met the young carers' profile. Those families willing to allow their child to participate in the project were then introduced to the researcher, who was subsequently able to confirm participation and finalise arrangements.

The interviews were conducted in the staff room at a school in Klapmuts. The venue was prearranged with the school administrator before each interview took place. This location was convenient and comfortable for the participants and accessible to the researcher.

The interviewer introduced herself to the participants and their parents and explained the requirements of the research process. Before asking the parent(s) and child to sign the consent and assent forms respectively, she read through the information sheet with them. This sheet highlighted that participation was voluntary and that the child could withdraw at any point during the interview and that all information collected from the study would be kept confidential. Participants were informed that if the researcher had any concerns during the interview relating to the child's wellbeing, confidentiality may be broken. Lastly, the researcher made it clear to those involved that there were no overt risks or benefits attached to participation in the study (see Appendix C and D). Once consent/assent was obtained, the researcher asked the child's parent(s) to leave the venue and proceeded to spend five to ten minutes informally talking to the participants in order to develop rapport with them.

The cognitive interviewing technique was used to pilot the questionnaire. This study used a combination of the two cognitive interviewing methods; the direct technique and the think-aloud technique. The emphasis placed on each method was determined by the participant's developmental level. Through the use of questions and probes, participant feedback was accessed across three distinct topic areas. The probes which were used were distinguished according to four dimensions. They were either proactive (searching in nature) or reactive (responsive in nature) and were standardised (determined prior to the interview) or non-standardised (determined during the interview) (Beatty & Willis, 2007).

Two interviews were conducted with each participant. The first interview involved the administration of the questionnaire, while the second interview required the participant to provide feedback on the questionnaire itself, interviewer behaviour and the overall interview experience. Before administration of the questionnaire, the participant was asked to think about these three topics throughout the first interview. The second interview was conducted the following day, so as to allow the participant time to reflect on their experience before being required to provide feedback to the researcher.

In the second interview, the content, format and wording of the questionnaire and its individual items/scales were first addressed. This was to ensure that the questions within the questionnaire were unambiguous and comprehensible to the participants (Yorkston et al., 2008). Furthermore, feedback obtained from the participants assisted the researcher in assessing whether the questionnaire was relevant in terms of the context in which it was

being administered. In order to address the above issues, the participants were prompted through the use of questions, such as: “Would you prefer things to look different?”; “Is there anything missing from this section?”; “How do you feel about this wording?” and “What would make more sense to you?” This illustrates proactive and non-standardised probing (Beatty & Willis, 2007).

Secondly, the behaviour of the interviewer was addressed. Questions related to the manner in which the interview was conducted (for example the tone of voice used by the interviewer). Questions such as: “What would your ideal interviewer be like?” and “What sort of personal characteristics should they have?” were asked. Proactive and standardised probing was considered to be more appropriate in this case (Beatty & Willis, 2007).

Lastly, the overall interview process was assessed. The purpose of this was to gauge whether the medium and process through which the participants are engaged was appropriate. Questions such as: “What environment would you like to be interviewed in?” and “Is there anything you would change about the process or the setting?” were asked. These are examples of standardised and responsive probing (Beatty & Willis, 2007).

Throughout the second interview, the participant was encouraged to make notes on the questionnaire itself, whilst informing the researcher of his/her thoughts. The researcher engaged in note taking in a subtle manner, so as not to unnecessarily disturb the process (Babbie & Mouton, 2006).

The interview was closed with a debriefing session and thanking the participant for his/her feedback. As a token of appreciation, each participant was presented with a young carer’s certificate (see Appendix E).

The interviews were conducted in the form of one-on-one, face-to-face meetings. All the interviews were conducted by the same researcher so as to ensure consistency of approach across all the participants (Babbie & Mouton, 2006). The first interview lasted approximately 3 hours, while the second interview lasted 1.5 hours. The interview schedule was kept flexible, in that it could be adjusted according to the participants’ needs. The participants were offered fruit and biscuits throughout the above process. Lastly, the majority of the interviews were conducted in Afrikaans. Given the researcher’s level of fluency in both English and Afrikaans, she was able to use a level of language appropriate to the age and developmental level of the participant. This level was assessed upon meeting the child.

## **Data Analysis**

The interview data were analysed using thematic analysis. This method allows patterns found within the data to be identified, analysed and reported. Furthermore, it organises the interview data in great detail. It is important to note that thematic analysis is not a linear but a recursive process (Aronson, 1994; Braun & Clarke, 2006). Thus throughout the analysis, the researcher was able to move back and forth between the data set. This ensured that all the themes were included and relevant to the research question. The analysis involved the following steps:

- (1) The field notes made by the interviewer and the notes made by the participants on the questionnaire were collated into three separate sections defined according to the aforementioned research questions. The researcher familiarised herself with this data. She read and re-read the collated data noting down possible themes arising and why they would be of interest for the pilot study.
- (2) Initial codes were generated for the data. The data was coded in a thorough and systematic fashion.
- (3) The researcher searched for themes relating to the opinions expressed by the participants. Codes were collated into potential themes and the data were then organised within each theme.
- (4) The themes were reviewed. The researcher checked to see if they related to one another and to the entire data set.
- (5) Once the main themes were decided upon they were named and defined.
- (6) Using the established themes, an argument was made in relation to the research questions. Recommendations were then formulated from these findings.

## **Reflexivity**

Qualitative research requires that the researcher be reflexive throughout the process (Rosenthal & Rosnow, 2009). The researcher's demographics (white, upper class, attending tertiary education) and her cultural and political positioning may have affected her response and behaviour towards the participants based on the clear distinction between them.

The researcher was consciously aware that throughout the 10 interviews conducted, she endeavored to minimise the inherent effect of the difference between herself and the participants with the purpose of putting them at ease. She attempted to achieve this through speaking in non-academic terms and using conversational, colloquial language. This difference was further mitigated by the researcher's fluency in Afrikaans which was the

language spoken by the majority of the participants. She felt that this style of communication would result in a greater level of participant cooperation.

The setting in which the researcher conducted the interviews was familiar to her in that she had grown up in the area and had volunteered in similar locations (townships surrounding Cape Town) to the one in which she interviewed the participants (Klapmuts). Thus, she felt comfortable conducting research in the given setting. Her previous exposure contributed to her ability to interact with those with a different demographic profile to her own, and to do this with relative ease. She felt that this ability resulted in the participants being able to openly share their opinions with her. However, despite this level of comfort, she remained aware of these differences and how they might potentially have affected the content and nature of her responses to the participants and consequently their behaviour towards her.

## **RESULTS**

There data retrieved in the second interview were analysed according to three themes. These were drawn from the aforementioned research questions. They included: (1) the format, wording and content of the questionnaire, (2) the overall interview experience, and (3) the interviewer behaviour.

### **Format, wording and content of the questionnaire**

#### *Front cover*

On the whole, the participants found the cover of the questionnaire attractive. Six out of the 10 participants proposed that the picture of Beyoncé and those within the questionnaire (such as Rihanna and Sean Kingston) be changed to reflect inspirational South African figures, such as Nelson Mandela, Desmond Tutu or popular sports stars. The younger participants (ages 12-14, of which there were four) did not favour this change. All 10 participants felt choosing a pseudonym to ensure that their identity remained private was a good idea. A further proposal was made by five of the participants that TEEN TALK be printed in multicolours.

#### *Consent form*

The participants were disinclined to read the information sheet and consent form. They suggested the interviewer should summarise the main points of each before asking the participant to sign. However, six of the participants recommended that the researcher ensure that they and their parent(s) or guardian(s) had the necessary contact details in case of any



problems. One of the participants suggested that the information sheet be given to the participants. However the remaining nine felt this would serve no purpose, as the children would either lose it or throw it away. Four of the 10 participants indicated a desire to understand the various emblems below the consent form on page 3.

#### *Specific pages in the questionnaire*

Seven of the 10 participants were reluctant to draw the pictures of their caregiver on page 4 and 15. However, four of them indicated they would be more forthcoming if coloured crayons, as opposed to black pens, were provided for drawing.

On page 4 in the 'My day' block, five of the participants suggested having a section for 'other', while four of the participants felt that there should be an additional block in which they could write about their daily burdens. This would allow the researcher to understand their living circumstances in greater detail. This comment relates to a suggestion made by five of the participants, to increase the level of detail in the 'People I live with' activity on page 5. These young carers said that although they felt slightly embarrassed about drawing their homes (based on their minimalistic nature) they felt it would enable the researcher to better understand their living conditions. For example, details such as: 'How many individuals share a bed and who sleeps on the floor' should be requested from the participants.

The majority of participants (seven) found that it would make greater sense to have the sections regarding 'school' and 'other teens and me' found on pages 7, 13 and 15 follow one another. Furthermore, all participants suggested a section on bullying be included on page 7. In addition to combining the above pages, the seven participants suggested joining the sections on food and provisions found on pages 18 and 23 and the information pertaining to the home, including the activities on page 4 (My house), 5 (People I live with), and 18 (Stuff at home).

The feedback offered regarding 'My road of life' on pages 10 and 11 reflected the participants' desire to have another 'road', including how they had felt at the various stages in their life. They suggested this road be called 'feelings'. They wanted the opportunity to indicate in which years they felt happy, sad, challenged, alone and suchlike.

The four younger participants (ages 12-14) indicated they found it difficult to indicate how long it took them to complete the helping tasks at home found on page 12 of the questionnaire. They could however indicate whether or not they had completed them.

Six of the 10 participants proposed that there should be an additional question included on page 14 relating to the section on ‘arguments’. If participants indicated that arguments did frequently occur in the home, the question should enquire as to the content of these arguments and how they affected the young carer.

Five of the participants suggested the inclusion of a religious figure on page 18 regarding the activity relating to the kinds of support they received. This could include a minister or a pastor.

Many of the participants were initially reluctant to draw a picture of or write to their parents in the assigned block on page 20. They felt uncomfortable completing this activity, as their parents had passed away. However, three of them felt that it was an opportunity to express the sadness which they had withheld for a long time.

Three of the older participants (ages 17-18) suggested there should be an additional question on page 21 enquiring as to young carers’ knowledge on HIV/AIDS: what it is and how it can be contracted. They felt that the HIV/AIDS education which they had received at school was limited and that by adding a question of this nature, researchers would be able to determine whether this was to be a focus area for future policy.

Participants further reported that they found the picture of the Simpsons on page 22 to diminish the weight of the issues being addressed in the blocks: those of drug and alcohol abuse. They suggested a realistic photograph should replace the cartoon-like picture.

Lastly, all the participants proposed that a whole page be provided for the ‘President of the day’ activity. It was recommended that this page should end with an uplifting message or an inspirational quote.

#### *Non-specific features of the questionnaire*

All 10 participants suggested that the questionnaire be printed in colour. However, based on the expense attached to this suggestion, they suggested printing every fifth page in colour with the purpose of making the questionnaire more attractive. The participants expressed their desire to have the questionnaire printed in their own language, as this would reduce potential language barriers, enabling them to answer the questions to the best of their ability. Furthermore, they suggested additional pictures be included to explain the content of each section of the questionnaire in more detail. This suggestion was unanimous among the participants, but was greatly emphasised by the four younger participants. The results from the second interview further indicated that the participants liked the concept of using a real life example, such as that of ‘Buntu and Lindiwe’ on page 14 of the questionnaire. It reduced

their uncertainty relating to what answer was required and offered them a level of comfort in that they could relate to another child's experience.

### **Overall interview experience**

Eight out of the 10 participants indicated a preference for being interviewed one-on-one, in a neutral, private and quiet environment such as a classroom or an office. They felt that being interviewed at home would be distracting, due to the small size of their houses and the ongoing communication and movement of individuals within their homes. However, despite the potential for interruptions, five of the above eight participants indicated that their homes would be the most convenient location to conduct the interview in, given their limited means of communication with the researcher (no telephone) and being unable to afford transport to the research venue. Two of the participants suggested the questionnaire be completed in a classroom setting, where the researcher would resemble a teacher who would give instructions on what was required. This would allow for a level of privacy which they felt would not be possible if the researcher was involved in their completion of the questionnaire. All the participants indicated they would prefer to complete the questionnaire at a desk or table, rather than sitting on chairs, a bed or a couch.

Four of the participants reported that they themselves would like to complete the questionnaire, rather than having the interviewer write or circle their answers on the questionnaire for them. They felt this would give them a greater level of independence and autonomy in the process. The remaining six participants however, preferred the interviewer to be more active in the physical completion of the questionnaire due to insecurity about their reading and writing skills. All participants indicated that they would like the option to use coloured pens to complete the questionnaire.

The four younger participants found the interview to be too long, consequently they became restless, losing their focus at some points. To overcome this, they recommended having short breaks (in which to stretch and have some fresh air) after completing 5 pages of the questionnaire. The older participants (ages 15-18) were content with the length of the questionnaire and found it manageable. All the participants, however, enjoyed the biscuits and apples which were provided by the researcher, indicating this gave them the energy to concentrate all their efforts on the questionnaire.

Overall, the results from the second interview indicated that all the participants enjoyed the experience of being interviewed and offering feedback on the questionnaire. They felt the experience to be therapeutic in nature which encouraged their openness to the

process. The majority of the participants felt the researcher fulfilled the role of a counsellor in whom they felt they could confide on issues which otherwise would remain undisclosed. This provided them with a huge sense of relief. However, knowing that the interview would be a once-off interaction dampened their spirits, influencing their views relating to the capability of the researchers and the government to provide the necessary resources and services for young carers.

### **Interviewer behaviour**

Results from the second interview suggested that all 10 participants held a similar view in terms of the way in which the researcher should behave and conduct the interview. All the participants felt it was important that the researcher should establish rapport with them before conducting the interview. They indicated that this could be achieved through asking about their likes and dislikes, telling a joke and generally asking how they were. They felt that this would establish a comfortable basis from which to begin the process.

Eight of the 10 participants wanted the interviewer to sit next to them, as opposed to opposite them. They all reported that consistent eye contact, a friendly face and a gentle tone of voice were conducive to feeling able to honestly provide feedback. Five of the 10 participants indicated that they were uncomfortable with the researcher hugging them when they became emotional during the interview. They suggested that the researcher show care through verbal means and first ask if it would be appropriate to provide them with physical affection, such as a hug or a pat on the back. Furthermore, six of the participants indicated that if they did not understand the question, the interviewer should attempt to rephrase the question as clearly and directly as possible, potentially providing them with a real-life example corresponding to the question. The four younger participants required a greater level of assistance from the interviewer in understanding the questions.

## **DISCUSSION**

Framed by the parent study's interest in ensuring the Young Carers Questionnaire is both valid and appropriate given the context in which it will be administered and the sample it will target, the results from the current pilot study assisted in providing a clear set of recommendations for the improvement and the refinement of this questionnaire. The feedback obtained from the second of the two interviews conducted, provided the basis for achieving the initial aims as outlined. However, the process of interviewing and accessing this feedback was not without its challenges. These challenges stemmed from a variety of

sources, largely relating to the broader issues of conducting research with children as well as interviewing this group of individuals on topics of a sensitive nature.

### **The challenges**

Conducting research with children brings with it a variety of challenges, especially when interviewing on topics of a sensitive nature. In addition to being a child, it is the role of young carer (the impact of this role and the child's level of vulnerability), which added to the above challenges. In order to assess and make sense of these challenges within the young carers' context, a comparison with previous literature on conducting research with children was made.

#### *Accessing younger participants*

Consistent with previous research (Mann & Tolfree, 2003), the hierarchy which existed within the majority of the participants' families made it difficult for the researcher to access younger participants. All opportunities, (including being interviewed by the researcher) were extended to family members according to their age. This was witnessed in that when the researcher asked the families which child would be participating, the parents physically held the younger children back, whilst pushing the older ones forward. This is likely a result of the emphasis African culture places on age-related hierarchies (Mann & Tolfree, 2003).

However, it may also partly stem from the marginalisation of children's voices- especially those of younger children (Christensen & Prout, 2002). Even following the researcher's explanation regarding the importance of accessing participants across the young carers' age bracket (12-18 years of age), the parents nevertheless remained committed to their stance. The researcher thus accessed younger participants from families who had no older children or who placed less emphasis on the aforementioned hierarchy.

#### *Communicating with the participants*

As suggested by Harden et al. (2000), the researcher found that the extent of the participants' formal education had an impact on the interview process. Participants who regularly attended school were better able to express themselves during the interviews.

However, given that the majority of the young carers' parents were in need of constant care and attention themselves, due to the severity of their illness, many children were absent from school (Cluver, 2008). Consistent with McCauley (2002) and Harden et al. (2000), these children were more likely to be developmentally at a disadvantage relative to

their peers, and consequently may have struggled to communicate as confidently and fluently as those children who were in regular attendance. This affected the researcher's ability to get the children to offer their opinion during the interview and to subsequently comprehend its content

### *Topics of a sensitive nature*

During both interview sessions, the participants indicated they were uncomfortable when discussing certain topics. These included the HIV/AIDS status of their parent(s) or guardian(s), sexual activity and death.

The majority of the participants' parents were infected with HIV/AIDS and they were thus coping with the stigma attached to this disease. From the interviews conducted with the participants, it became clear that not only had this stigma sought to silence them, but their parents had further compounded this silence for fear of their status being exposed and consequently being rejected by their community. Thus, as suggested by Cluver and Gardner (2007), it is in the young carer's nature to remain 'quiet' and be hesitant to share with others, especially with those from outside their families. This made it difficult for the researcher to access their opinions on this section of the questionnaire.

In a similar vein, the topic of sexual activity was one which participants attempted to avoid. This is seen in the following comments: "That's not something we talk about" and "No-one talks about that in my house". Comparable with previous research (Eaton, Flisher & Aarø, 2003), due to the personal and private nature of sexual activity, sex is a topic which often remains unspoken in families. Given that children are frequently assumed to be immature, unknowledgeable and inexperienced in this field, their exposure to discussions containing content relating to sexual activity is likely to be limited (Eaton et al., 2003). As suggested by Eaton et al. (2003), this is possibly an indication of the difficulty they experienced when required to express their opinions on the topic. Thus, the researcher's initial attempts to engage the participants on this topic were largely unsuccessful.

As suggested by Robson (2001) death of the parent or guardian was another difficult topic to broach, given the sensitive nature of the matter and the potential for the re-opening of old wounds associated with the loss of one or more parent. Furthermore, in the Xhosa culture it is considered distasteful and inappropriate to speak of death or anything connected to this matter (Mdleleni-Bookholane, Schoeman, & van der Merwe, 2004). The child may not even know the cause of death or be included in the funeral process. Consistent with Mdleleni et al.

(2004), this was evident when attempts made by the researcher to engage the Xhosa participants in a discussion on death were largely avoided.

These above issues initially limited accessing feedback on the sections of the questionnaire pertaining to these three topic areas. Thus the discussion initially remained superficial. As suggested by Olsen (1996), one possible explanation for this was the sensitive nature of the topics; however it may also have stemmed from the participants' skepticism regarding the authenticity of the researcher's promise of confidentiality. Nevertheless, the researcher was able to minimise the effects of the above challenges by a variety of means.

### **Overcoming the challenges**

The above challenges were to an extent overcome through the manner and style in which the interviews were conducted. They sought to acknowledge the nature of the relationship between the researcher and the participant, the importance of developing this relationship and ensuring that the participants were made aware of their contributions to the pilot study.

#### *The nature of the relationship between researcher and participant*

Previous research has indicated the importance of acknowledging the unequal nature of the relationship which exists between the researcher and the participant (Valentine, 1999). It is a commonly accepted theoretical principle, that the researcher holds the major share of the power in the research setting (Babbie & Mouton, 2004). This is especially the case when the participant is a child (Valentine, 1999).

Given their role, young carers have already been exposed to this power play in their relationships with their parent(s) or guardian(s). Their acceptance of such a set-up can be noted in the following quotations: "I just do what I'm told, I know my mother is the boss"; "They're older than me, if I don't help I get into trouble" and "Why tell them what I think? They don't care". These quotations are indicative of the participants' feelings of reduced power in their relationship with their caregivers. Through the researcher's acknowledgement of the unequal power relations, she was able to address the effects of such a relationship on the participants

Consistent with previous research (Valentine, 1999), the researcher found that by developing rapport with the child, ensuring they felt their contribution was important, physically sitting alongside them, using colloquial language and adopting a listening stance, encouraged and increased the level of sharing. The effect was noted in the change which occurred in the participants' demeanour in the second interview as opposed to the first. The

participants' character (positive and open), body language (sitting forward, smiling, making eye contact with the researcher) and their increased level of communication, were indicative of the fact that they were comfortable with the status of their relationship with the researcher.

It was appropriate that this occurred in the second interview given that this was the session in which feedback was accessed from the participant. The first interview thus provided the researcher the opportunity to establish their role as non-threatening and honestly wanting to learn from the participant. Affirmation of this is seen in the following quotations which developed as a result of participants being asked how they felt about the role of the researcher: "I felt comfortable, like you really wanted to hear my story, no-one wants to hear my story really"; "It was so cool hey, I felt like I could talk to you always" and "You're not like my parents, you listen". These quotations contributed towards affirming the participants' willingness to participate in the process.

#### *Helping others*

Similar to previous research (Valentine, 1999), the researcher found that by informing the young carers of the importance of their feedback, which indirectly would help other young carers in the future, the extent of their contribution in the second interview was significantly increased. The young carers indicated that having this knowledge resulted in them sharing their opinions regarding the questionnaire and interview experience more openly than they would otherwise have done. This can be seen in the following quotations: "Knowing that I am helping other children like me makes me want to talk" and "I don't know if I want to tell you this, but if it is going to help the other children I want to".

#### *Importance of forming a relationship*

Consistent with Robson's findings (2001), it is evident that the value children place on being heard and acknowledged is not to be underestimated. The researcher found that developing a relationship with the participants had invaluable benefits. In this case, this was especially true given the often unstable nature of the relationships they have with their parent or guardian. As suggested by previous research (Robson, 2001), the researcher being able to provide this supportive framework, within the capacity and boundaries of her role, was in turn rewarded by the participants' enthusiasm to contribute. Thus, acknowledgement and development of the above factors resulted in increased participant participation; however, this was not to say that the pilot study was without its limitations.



## **Limitations**

Two of the limitations of this study included the small sample size and that the sample was drawn from a single area. This may have influenced the representativeness of the sample and consequently the ability to generalise the results to the entire population of the parent study (Babbie & Mouton, 2006).

In the parent study, the Young Carers Questionnaire will be administered across three provinces: the Western Cape, KwaZulu-Natal and Mpumalanga. The Western Cape sample will include a commercial farming area, similar to that of Klapmuts. However, the pilot sample is less likely to be representative of the KwaZulu-Natal and Mpumalanga samples, given the differences in language, culture and ethnicity. Thus, the opinions of the 10 isiXhosa- and Afrikaans-speaking young carers from the Cape Winelands area could potentially differ in some respects from those young carers participating in the other provinces. However, the sample size in the pilot study is in line with that of previous studies using similar methodologies in which in-depth data tends to be prioritised over representativeness (Yorkston et al., 2008). Furthermore, the pilot sample is likely to be similar to all the parent study samples in terms of age, socio-economic status, and educational level.

In addition, minor language barriers (such as colloquialisms and slang used by the participants) existed between the researcher and the participants. This may have affected her understanding and interpretation of the participants' comments.

Lastly, the sensitive nature of the topic under study and consequently the family's non-disclosure, made it difficult to recruit participants and to determine whether they met the inclusion criteria for the pilot. However, the hospice worker's knowledge of the participant's family helped to overcome this limitation.

## **Directions for future research**

As has been indicated, there is limited knowledge on young carers in South Africa (Cluver, 2008). This could be remedied through increasing the research conducted in this field by attempting to understand how young carers think, feel and interact. Furthermore it would be beneficial to understand how young carers differ to other groups of children as these differences may infer the need to interact and conduct research in ways which are appropriate to each group (Olsen, 1996). This knowledge would be beneficial in terms of refining techniques appropriate for working with this group of individuals, over and above the basic theoretical knowledge available on interviewing with children. Incorporation of this

knowledge into the interview process may result in the participants feeling an increased level of comfort given that an attempt has been made to understand their position and acknowledge their role (Olsen, 1996).

This interaction between researcher and participant may be further improved by clearly defining the role and purpose of children in the research process (Christensen & Prout, 2002). According to Christensen and Prout (2002), children can be seen in one of four different positions in the research setting: as an object, a subject, a social actor or as a participant. In this case the children were seen as social actors as they were requested to voice their opinions on the questionnaire. As suggested by Mann and Tolfree (2003), this voice was previously likely to be marginalised as a result of their status as a child in cultural hierarchies and systems of seniority within family. By giving young carers this voice, a new set of social relations developed between the researcher and the participant, changing the power balance between the two parties. The extent of the contribution made by the participants (as seen in the changes made to the Young Carers Questionnaire, see Appendix F) was indicative of the importance of this shift in power and position. Thus consistent with Christensen & Prout (2002), involving children in the pilot study process added to the richness of the data retrieved.

Lastly, the cognitive interviewing technique was effective in that it is a method which can be tailored through questions and a sensitive approach to meet the needs of the children. But the question remains: How else can one get children to communicate their thoughts and feelings on a topic, especially those of a more emotionally demanding and sensitive nature? Possibly in addition to one-on-one interviews, a group forum could be established for the second interview in which participants could discuss their feedback with others (Gilligan, 2001). By allowing children the opportunity to engage with those in a similar situation, the stigma attached to their role may lessen in addition to providing them with a sense of belonging, closeness and acceptance, all of which they may lack in their home environment (Cluver, 2008). The power of shared experience is not to be underestimated in terms of the feedback it may generate in the interview (Gilligan, 2001).

## **CONCLUSION**

Assessing the impact of the role of caring on young carers is crucial in determining and designing intervention programmes which will appropriately address their needs. In order to conduct a successful assessment, the Young Carers Questionnaire needs to be valid for the

sample it is measuring and the context in which it will be administered. The findings of the pilot study contributed towards ensuring this property of validity in this questionnaire.

The value in conducting in-depth and rigorous pilot studies, such as the one conducted in this research project have often been underestimated in the discipline of psychology. This pilot has shown that children can make a useful and important contribution to informing both the research method and the materials used, and that in the future researchers working with children should consider actively involving them in the research process rather than simply making them the objects of the study. The cognitive interviewing technique effectively allowed for the incorporation of the young carers' voices in questionnaire design. The above is clearly indicative of the advantages of such work for improving measuring instruments and managing some of the challenges involved in conducting research with vulnerable children in developing countries. Thus, given the contribution this study has made to the parent study, it could be suggested that pilot studies such as this one should be more widely used in the future.

## REFERENCES

- Achenbach, T. (1992). *Manual for the Child Behaviour Checklist/2-3 and 1992 Profile*. University of Vermont: Burlington.
- Adolescent Pathways Project. (1992). *Social support scale: Psychometric development summary*. New York: New York University.
- Akintola, O. (2008, October). *Towards equal sharing of Aids caring responsibilities: Learning from Africa*. Paper presented at the United Nations Division for the Advancement of Women, Geneva, Switzerland.
- Aldridge, J. (2008). All work and no play? Understanding the needs of children with caring responsibilities. *Children & Society, 22*, 253-264.
- Amaya-Jackson, L. (1995). *Child PTSD Checklist*. North Carolina: Duke Treatment Service.
- Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report, 2*. Retrieved May 7, 2009, from <http://www.nova.edu/ssss/QR/BackIssues/QR2-1/aronson.html>.
- Babbie, E., & Mouton, J. (2006). *The practice of social research*. Cape Town: Oxford University Press.
- Banks, P., Cogan, N., & Riddell, A. (2002). Does the covert nature of caring prohibit the development of effective services for young carers? *British Journal of Guidance & Counselling, 30*, 229-246.
- Beatty, P. C., & Willis, G. B. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly, 71*, 287-311.
- Becker, S. (2009). *Young Carers Tasks and Outcomes Questionnaire*. Retrieved May 7, 2009, from [http://saulbecker.co.uk/v1/downloads/young\\_carers/Young%20Carers%20Outcomes%20Manual%20April%202009.pdf](http://saulbecker.co.uk/v1/downloads/young_carers/Young%20Carers%20Outcomes%20Manual%20April%202009.pdf).
- Boyden, J., & Dercon, S. (2008). *Young lives: An international study of childhood poverty*. Retrieved May 18, 2009, from [www.younglives.org.uk](http://www.younglives.org.uk).
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.
- Burton, P. (2008). *National Primary School Violence Survey 2007*. Cape Town: Centre for Justice and Crime Prevention.
- Christensen, P., & Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood, 9*, 477-497.

- Cluver, L. (2008). *Young carers for AIDS-ill parents: Social, health and educational impacts*. Unpublished manuscript, University of Oxford, UK.
- Cluver, L., & Gardner, F. (2007). Risk and protective factors for psychological well-being of children orphaned by AIDS in Cape Town: A qualitative study of children and caregivers' perspectives. *AIDS Care, 19*, 318-325.
- Cluver, L., Moshabela, M., Gardner, F., Operario, D., Mauchline, K., & Lane, T. (2009). *Draft Young Carers Questionnaire*. University of Oxford, UK.
- Cox, J., & Cox, K. B. (2008). *Your opinion, please! How to build the best questionnaire in the field of education*. Belmont, CA: Corwin Press.
- Davis, J. M. (1998). Understanding the meanings of children: A reflexive process. *Children & Society, 12*, 325-335.
- Department of Health and Medical Research Council. (2007). *Demographic and Health Survey 2003*. Pretoria: Department of Health.
- Earley, L., Cushway, D., & Cassidy, T. (2007). Children's perceptions and experiences of care giving: A focus group study. *Counselling Psychology Quarterly, 20*, 69-80.
- Eaton, L., Flisher, A. J., & Aarø, L. E. (2003). Unsafe sexual behaviour in South African youth. *Social Science & Medicine, 56*, 149-165.
- Elgar, F. J., Waschbusch, D. A., Dadds, M. R., & Sigvaldason, N. (2007). Development and validation of a short form of the Alabama Parenting Questionnaire. *Journal of Child and Family Studies, 16*, 243-259.
- Evans, R., & Becker, S. (2007). *Hidden young carers: The experiences, needs and resilience of children caring for parents and relatives with HIV/AIDS in Tanzania and the UK*. Retrieved April 4, 2009, from <http://209.85.229.132/search?q=cache:YmCjNtXrM4wJ:www.reading.ac.uk/nmsruntime/saveasdialog.asp%3FIIID%3D14617%26sID%3D63941+Hidden+Young+Carers:+The+Experiences,+Needs+and+Resilience+of+Child+ren+Caring+for+Parents+and+Relatives+with+HIV/AIDS+in+Tanzania+and+the+U+K.+Evans+and+Becker&cd=1&hl=en&ct=clnk&gl=za>.
- Gerard, A., & Reynolds, C. (1999). Characteristics and applications of the Revised Children's Manifest Anxiety Scale. In M. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment* (pp. 323-340). Mahwah, NJ: Lawrence.
- Gilligan, R. (2001). *Promoting resilience*. BAAF: London.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry, 38*, 581-586.

- Hammell, K. W., & Carpenter, C. (2004). *Qualitative research in evidence-based rehabilitation*. Retrieved April 4, 2009, from [http://books.google.co.za/books?id=qyjNrAvjVQUC&dq=Qualitative+research+in+evidence-based+rehabilitation,+Hammell+and+Carpenter&printsec=frontcover&source=bl&ots=WT\\_1gfMjuW&sig=IISIDwyQQ0\\_I\\_zHknw7jUY0mCFE](http://books.google.co.za/books?id=qyjNrAvjVQUC&dq=Qualitative+research+in+evidence-based+rehabilitation,+Hammell+and+Carpenter&printsec=frontcover&source=bl&ots=WT_1gfMjuW&sig=IISIDwyQQ0_I_zHknw7jUY0mCFE).
- Harden, J., Scott, S., Backett-Milburn, K., & Jackson, S. (2000). Can't talk, won't talk? Methodological issues in researching children. *Sociological Research Online*, 5. Retrieved May 9, 2009, from <http://ideas.repec.org/a/sro/srosro/2000-32-2.html>.
- Health Systems Trust. (2007). *South African health review 2007*. Retrieved May 16, 2009, from <http://www.hst.org.za/publications/711>.
- Israel, B. A., Eng, E., Schulz, A. J., & Edith, A. (2005). *Methods in community-based participatory research for health*. Retrieved May 16, 2009, from [http://books.google.co.za/books?id=fN6I3\\_IJW-wC&dq=Household+map%2Bresearch+studies&source=gbs\\_summary\\_s&cad=0](http://books.google.co.za/books?id=fN6I3_IJW-wC&dq=Household+map%2Bresearch+studies&source=gbs_summary_s&cad=0).
- Jobe, J. B., & Mingay, D. J. (1989). Cognitive research improves questionnaires. *American Journal of Public Health*, 79, 1053-1055.
- Kovacs, M. (1992). *Children's Depression Inventory*. Niagra Falls: Multi-health Systems.
- Labadarios, D., Steyn, N. P., Maunder, E., MacIntryre, U., Gericke, G., Swart, R., Huskisson, J., Dannhauser, A., Vorster, H. H., Nesmvuni, A. E., & Nel, J. H. (2003). National food consumption survey in children aged 1-9 years: South Africa 1999. *Forum Nutrition*, 56, 106-9.
- Lancaster, G. A., Dodd, S., & Williamson, P. R. (2004). Design and analysis of pilot studies: Recommendations for good practice. *Journal of Evaluation in Clinical Practice*, 10, 301-312.
- Lazarus, S. R., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lopman, B. A., Barnabas, R. V., Boerma, J. T., Chawira, G., Gaitskell, K., Harrop, T., Mason, P., Donnelly, C. A., Garnett, G. P., Nyamukapa, C., & Gregson, S. (2006). Creating and validating an algorithm to measure AIDS mortality in the adult population using verbal autopsy. *Public Library of Science Medicine*, 3, 1273-1281.
- Mann, G., & Tolfree, D. (2003). *Children's participation in research: Reflections from the care and protection of separated children in emergencies projects*. Stockholm: Save the Children.

- Mason, S., Berger, B., Ferrans, C. E., Sultzman, V., & Fendrich, M. (2008, October). *Developing a measure of stigma-by-association with African-American adolescents whose mothers have HIV*. Poster session presented at the NIMH Annual International Research Conference on the Role of Families in Preventing and Adapting to HIV/AIDS, Providence, Rhode Island.
- McCauley, U. (2002). *Now things are zig-zag': Perceptions of the impact of armed conflict on young people in Liberia*. Stockholm: Save the Children.
- Mdleleni-Bookholane, T. N., Schoeman, W. J., & van der Merwe, I. (2004). The development in the understanding of the concept of death among black South African learners from the Eastern Cape, South Africa. *Health SA Gesondheid, 9*, 3-12.
- Mynard, H., & Joseph, S. (2000). Development of the Multidimensional Peer-Victimization Scale. *Aggressive Behavior, 26*, 169-178.
- Olsen, R. (1996). Young carers: challenging the facts and politics of research into children and caring. *Disability & Society, 11*, 41-54.
- Padfield, M., & Procter, I. (1996). The effect of interviewer's gender on the interviewing process: A comparative enquiry. *Sociology, 30*, 355-366.
- Parker, I. (2005). *Qualitative Psychology: Introducing radical research*. New York: Open University Press.
- Pillay, Y., Nyathikazi, D., Bismilla, R., & Bromfield, I. (2008). *Researching Equity in Access to Health Care*. REACH Project.
- Rebok, G., Riley, A., Forrest, C., Starfield, B., Green, B., Robertson, J., & Tambor, E. (2001). Elementary school-aged children's reports of their health: A cognitive interviewing study. *Quality of Life Research, 10*, 59-70.
- Reproductive Health Research Unit & Lovelife. (2005). *The National Survey of HIV and sexual behaviour among young South Africans*. Retrieved May 16, 2009, from <http://www.healthlink.org.za/healthstats/203/data>.
- Roberts, D., Bernard, M., Miska, G., & Head, E. (2008). *Experiences of children and young people caring for a parent with a mental health problem*. Retrieved April 4, 2009, from <http://www.scie.org.uk/publications/briefings/briefing24/index.asp>.
- Robson, E. (2001). Interviews worth the tears? Exploring dilemmas of research with young carers in Zimbabwe. *Ethics, Place & Environment, 4*, 135-142.
- Rosenthal, R., & Rosnow, R. (2009). *Essentials of behavioral research*. New York: McGraw-Hill.

- Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., Janvas, J., Weiller, E., Keskiner, A., Schinka, J., Knapp, E., Sheehan, M. F., & Dunbar, G. C. (1997). The validity of the Mini International Neuropsychiatric Interview (MINI) according to the SCID-P and its reliability. *European Psychiatry, 12*, 232-241.
- Simon, S. (2008). *Pilot study*. Retrieved April 7, 2009, from <http://www.childrensmc.org/stats/plan/pilot.asp>.
- Snider, L., & Dawes, A. (2006). *Psychosocial vulnerability and resilience measures for national-level monitoring of orphans and other vulnerable children: Recommendations for revision of the UNICEF psychological indicator*. Cape Town: UNICEF.
- Statistics South Africa. (2001). *Census 2001: Household Questionnaire*. Pretoria: Statistics SA.
- Tourangeau, R., Rips, L. J., & Rasinski, K. (2000). *The psychology of survey response*. New York: Cambridge University Press.
- Trochim, W. (2006). *Nonprobability sampling*. Retrieved October 26, 2009, from <http://www.socialresearchmethods.net/kb/samprnon.php>.
- Valentine, G. (1999). Being seen and heard? The ethical complexities of working with children and young people at home and at school. *Ethics, Place and Environment, 2*, 141-155.
- Van der Merwe, A., & Dawes, A. (2000). Prosocial and antisocial tendencies in children exposed to community violence. *Journal of Child and Adolescent Mental Health, 12*, 19-37.
- Vivier, G. (2006). *Recording administration of pilot questionnaires: An efficient method to improve quality of data*. Retrieved April 8, 2009, from [www.statistics.gov.uk/events/q2006/downloads/W04\\_Vivier.ppt](http://www.statistics.gov.uk/events/q2006/downloads/W04_Vivier.ppt).
- Weiten, W. (2004). *Themes and variations*. Belmont, CA: Wadsworth.
- World Health Organisation. (2003). *ICF CHECKLIST Version 2.1a, Clinician Form for International Classification of Functioning, Disability and Health*.
- Yorkston, K. M., Baylor, C. R., Dietz, J., Dudgeon, B. J., Eadie, T., Miller, R. M., & Amtmann, D. (2008). Developing a scale of communicative participation: A cognitive interviewing study. *Disability and Rehabilitation, 30*, 425-433.



**APPENDIX A**

**Young Carers Questionnaire (first version)**

## APPENDIX B

### The Young Carers Study: Measures and Constructs

**Table B1.**

#### Measures and Constructs: Child Outcomes

<b>Mental health outcomes</b>	
	<p><b>Depressive symptoms:</b>            The <u>Child Depression Inventory (short form)</u>[1] (10 items). This was used in our previous studies of AIDS-orphanhood, and showed an acceptable <math>\alpha=.67</math> (2006) and <math>\alpha=.69</math> (2009). The CDI has strong psychometric properties, and has been used in multiple South African populations [2], including an adapted version [3], which was validated against the Beck Depression Inventory (<math>r=0.81</math>). Internal consistency ranges from .71 to .94. [1, 4].</p>
	<p><b>Anxiety symptoms:</b>  <u>Children’s Manifest Anxiety Scale – Revised</u>. [5] reduced items (14 items). In the previous orphan study, the full scale showed an <math>\alpha.80</math> (2005), and the reduced scale showed <math>\alpha .75</math> (2006) and <math>.80</math> (2009). The RCMAS has been standardized in US populations, shows good internal consistency and test-retest reliability (.68 after 9 months) [5, 6]</p>
	<p><b>Post-traumatic stress symptoms:</b>  <u>Child PTSD Checklist</u> (28 items) [7], accompanied by cartoons from the <u>Levonn scale</u> [8], which has been used in the local population [9]. This was used in our previous study of AIDS-orphanhood, and showed <math>\alpha.94</math>. The Child PTSD Checklist has been used more than any other PTSD scale with Black African youth in South Africa [10, 11]. [12]. On US populations, the scale shows <math>\alpha .82-.95</math>. Test-retest reliability at one week was <math>r=.91</math> [13]. The scale corresponds to DSM-IV diagnostic criteria.</p>
	<p><b>Suicidality/self-harm:</b>  <u>Mini International Psychiatric Interview for Children and Adolescents Suicidality and self-harm subscale</u> [14] (5 items). The MINI-Kid has been extensively validated in developed world populations, and shows strong internal consistency and test-retest reliability [15, 16].</p>
	<p><b>Behaviour problems:</b>  <u>Child Behaviour Checklist</u> [17] delinquency subscale (12 items) <math>\alpha=.62</math>. The CBCL-YSR has been normed on a mixed-ethnicity US population, and was used in the Family Health Project study of orphan well-being in the USA [18] and in South Africa [19]. Alphas range from .71 to .95 [20, 21], and test-retest values from .47 to .79. The CBCL-YSR is commonly used as a ‘gold standard’ in testing convergent validity of other instruments.  <u>Strengths and Difficulties Questionnaire</u> [22] conduct problems subscale (5 items). The SDQ is well-validated, and has been translated into 51 languages, including isiXhosa and isiZulu [23]. In a norming study with 10,438 children (Goodman 2001), the SDQ showed mean <math>\alpha=.73</math> and <math>.62</math> retest stability at 6 months.            Two devised items on carrying of weapons were added – these were adapted from the <u>National Primary Schools Violence Survey</u>, to include carrying of</p>

	weapons both inside and outside school (2 items)
	<p><b>Alcohol and substance use:</b>  <u>National survey of HIV and risk behaviour amongst young South Africans</u> [24] (4 items)  One item from <u>Child Behaviour Checklist</u> [25] delinquency subscale addresses drug and alcohol use.</p>
	<p><b>Pro-social behaviour:</b>  <u>Strengths and Difficulties Questionnaire</u> [22] pro-social subscale (5 items)</p>
	<p><b>Peer relationship problems:</b>  <u>Strengths and Difficulties Questionnaire</u> [22] peer problems subscale (5 items)  In our prior orphan study, this showed <math>\alpha.47</math>.</p>
<b>Sexual health outcomes</b>	
	<p>Items from the <u>National survey of HIV and risk behaviour amongst young South Africans</u> [24] will be used to measure sexual activity (screening item), HIV knowledge, self-perceived risk of HIV-infection, self-efficacy/agency in relation to condom use, age of sexual debut, concurrent sexual partners, frequency of condom use, transactional sex, sexual activity under the influence of alcohol and under the influence of drugs, and self-perceived risk of HIV. Items from this survey will also be used to measure forced sex (by verbal and physical force) and pregnancy (14 items).  Items from the <u>South African Demographic and Health Survey</u> (2003) [26] will be used to measure sex with older partners and use of contraception. (2 items)</p>
<b>Physical health outcomes</b>	
	<p>Items from the <u>South African Demographic and Health Survey</u> (2003) [26] the World Health Organisation Stop Tuberculosis Team, and the KwaZulu-Natal Department of Health TB symptom guidelines, were used to provide symptoms of pulmonary TB. Access to and adherence to TB testing and medication were measured in 4 items, based on items from the <u>REACH</u> (Researching Equitable Access to Healthcare) 4-province study.  The Health Systems Trust South African Health Review 2006 [27] was used to identify common diseases of childhood, and items from the DHS will be used to identify other illnesses. (16 items total). <i>Chronic illnesses</i> is measured by prevalence of asthma, epilepsy and diabetes; <i>minor ailments</i> include cold/flu and worms, <i>acute conditions</i> include pneumonia, diarrhoea and burns, and <i>physical disability</i> includes visual disability and others, but not learning disabilities, as these may be unreliable in a self-report.</p>
<b>Education outcomes</b>	
	<p>Items from the ‘Young Lives’ study [28] will be used to determine education outcomes: age of enrolment, grade for age, repetition of grades and reasons, school dropout and reasons, school fees, and daily allocation of time for school and homework (10 items). Items will also examine missing school due to responsibilities (10 items).</p>

Table B2.

**Measures and Constructs: Risk and Protective Factors**

<b>Child caring tasks</b>	
	The Becker ' <u>Young Carers Tasks and Outcomes Questionnaire</u> ' [29] was adapted for relevance to sub-Saharan Africa. It was also added to with tasks identified in the qualitative stage of the Young Carers study, and will be used to measure tasks undertaken and time spent on tasks for young carers (23 items). Particularly important to TB-infection are items measuring <i>use of protective measures</i> : protective gloves and handwashing (items given by DoH).
<b>Parental and caregiver morbidity</b>	
	Parental morbidity will be measured at two separate stages. Firstly, in the ' <u>Road of Life</u> ' (an adaptation of a social work-tool, 'the river of life'[30]). Children will identify where parental sickness caused a change in living environment, a household move, or was a significant milestone in their lives. Secondly, children will identify on the <u>Household map</u> whether there are any sick or disabled people in the home. Where there is a sick person, the children will identify who they helped look after most, and completed a 'confidential sickness report sheet'. This sheet will be placed in a separate, sealed envelope (a technique used for sensitive information in the Cape Area Panel Survey and recommended by our Child Advisory Team). The sickness report sheet will identify chronicity of illness, extent of illness and frequency of illness, using items from the <u>World Health Organisation International Classification of Functioning, Disability and Health</u> [31]. (4 items) Subscales from the 'Activity limitation and participation restriction' section (mobility and self-care domains) will be used to assess extent of disability (7 items). Cause of sickness will be identified using a <u>verbal autopsy questionnaire</u> [32], developed for use in areas with over 20% HIV-prevalence, and showing sensitivity of 83% and specificity of 75% in a Zimbabwean cohort. This questionnaire is designed primarily to identify symptoms of AIDS, and in order to a) reduce the potentially stigmatizing nature of this, and b) identify other types of illness affecting caregivers, added items include the most common causes of adult illness in South Africa, as identified in the <u>Demographic and Health Survey</u> (2003) and the <u>Health Systems Trust Annual Review</u> (2006) (18 items).
<b>Parental/Caregiver mortality</b>	
	Parental mortality will be measured at three separate stages. Firstly, in the 'Road of life' tool, and secondly, in a picture activity to determine presence of multiple bereavement, dates of bereavement and cause of parental death. The qualitative picture activity was designed for use in a previous study of AIDS-orphanhood [33-38] and included discussion of bereavement with interviewers, and the drawing or writing of messages (children often drew flowers, or crosses, or hearts for deceased family members). Where children identify parental death, they will complete a 'confidential report sheet' (which will be kept in a sealed envelope with the sickness sheet). This follows the <u>Verbal Autopsy questionnaire</u> [32], with added items for common alternative causes of mortality, and including non-illness causes, such as road traffic accidents and homicide (18 items). The verbal autopsy questionnaire used

	showed sensitivity of 83% and specificity of 75% in areas of >5% HIV prevalence.
<b>Health care utilization and access</b>	
	8 Items from the <u>REACH study</u> – a 4-province study of health care utilization amongst HIV+ people, will be used to measure health care utilization. Additional open items allow report of reasons for non-access to healthcare (this should allow estimation of accessibility, affordability and acceptability – including affordability of transport. We do not know how many children will not be accessing healthcare due to spending time caring, but the open-ended questions aim to determine this). Time spent in travelling to local clinic and mode of transport are also measured (items suggested by DoH).
<b>Demographic information</b>	
	Child age, gender and basic demographic information will be asked using items from the <u>South African Census (2001)</u> [39]. Household structure will be measured using a <u>Household map</u> , devised for complex extended family structures and used in our previous studies with AIDS-orphaned children and young carers [33-38]. This uses a picture-based tool to determine household members, relationship to children, age, gender, and living arrangements (i.e. who sleeps in which rooms). It also determines whether households have access to kitchen, bathroom and toilet facilities.
<b>Child migration and caregiver changes</b>	
	Child migration and number of changes of primary caregiver will be assessed using the ' <u>Road of Life</u> ' tool, which also measures ages of moves and changes.
<b>Caregiver</b>	
	Existence of primary caregiver, and relationship of child to primary caregiver, will be identified using items from the <u>National survey of HIV and risk behaviour amongst young South Africans</u> [24] (items 8.13-8.14) Primary caregiver will be identified as the person who 'stays with you and takes care of you at home'. Relationships of caregiver to children will be categorized as the following: biological parent, grandparent, other extended family member (aunts, uncles, cousins, adult siblings etc), non-family member (social worker/careworker, foster carer), living in a child-headed or youth-headed households.
<b>Household poverty</b>	
	Poverty will be measured using a range of tools. Items from the <u>South African Census</u> [39] will determine whether children live in formal, informal (i.e. shacks) or traditional structures. Food insecurity will be measured using 2 items from the <u>South African National Food Consumption Survey (1999)</u> [40]. Poverty will also be measured by measuring access to the top 8 socially-perceived necessities for children, as identified by the Centre for South African Social Policy in the ' <u>Indicators of poverty and social exclusion project</u> ' [41], and endorsed by over 80% of the South African population in a nationally-representative survey (the <u>South African Social Attitudes Survey 2006</u> ) [42]. These include items such as 'enough clothes to keep you warm and dry' and '3 meals a day'. Household employment will be measured in the <u>Household map</u> , where employment of any adult or child in the household will be identified, and will distinguish regular, part-time and seasonal/irregular work.
<b>Social Support</b>	
	Social Support will be assessed using the standardised <u>Social Support Scale</u> [43], measuring social support for urban adolescents in each micro-system of

	family, peers and school. Psychometric properties were acceptable: $\alpha=.63$ in a US study. This scale has been used in Cape Town [44] and in our prior study of AIDS-orphaned children. The scale was adapted to replace ‘mother’ and ‘father’ with ‘caregiver’. (24 items) and showed an $\alpha.76$ in our prior study.
<b>Support from state and NGOs</b>	
	Receipt within the household of the major forms of <i>social security transfers</i> (Child Support Grant, Foster Care Grant, Pension, Disability Grant and Care Dependency Grant) will be measured, and reasons for <i>non-receipt of grants</i> assessed using the most-identified causes of non-receipt in a study of welfare access in South Africa [45] (5 items). Assistance in the forms of <i>food parcels</i> and <i>soup kitchens</i> will be assessed using items devised by the National Action Committee for Children Affected by AIDS (NACCA), and followed by items to assess reliability of these services (6 items). Respondents will identify whether their <i>school</i> is a no-fees school, or whether they have a fees exemption (3 items). They will also identify whether they have a state-provided school uniform, school transport or school-feeding scheme (items identified by the Department of Social Development) (3 items). Further items will measure access to <i>social worker</i> and frequency of visits. <i>Home-Based Care</i> services will be measured using items to determine frequency of visits and services provided to the child. A linked study (qualitative and quantitative, PI Dr M. Moshabla) in two of the four study sites will examine in more detail the access, utilization and dynamics of home-based care for these families. Children will also report access to an ID book, birth certificate, and death certificate of parents in case of grant requirements (items suggested by DSD) (3 items).
<b>Traditional practices and forms of support</b>	
	Items in the healthcare utilization section will determine utilization of traditional healers and any reasons for non-use. Social support and family contact with traditional leaders (such as chiefs) is measured with three devised items. It has been determined that the subtlety and complexity of the support given to young carers in AIDS-affected families by traditional practices will be difficult to capture in a quantitative study, and so a linked qualitative study (PI, Ms T. Mahlobo) will be undertaken to examine this in more detail.
<b>Stigma</b>	
	Two scales will be used to assess exposure to AIDS-related stigma. Four items were developed from the previous study of AIDS-orphanhood by stigma researchers in South Africa and from qualitative data, and showed $\alpha = .90$ . In addition, a recently-developed ‘ <u>stigma-by-association scale</u> ’ has been validated to measure perceived stigma amongst US adolescents with HIV+ mothers [46]. This scale was adapted and reduced, with the collaboration of the authors, for relevance to the South African context. The 7 items used show an alpha of .77 on the US sample.
<b>Bullying</b>	
	Bullying will be measured with the 9-item, standardised ‘ <u>Social and Health Assessment Peer Victimization Scale</u> ’ [47], used in research with vulnerable children in Cape Town [48] and in our previous study of AIDS-orphanhood. This scale is adapted from the Multidimensional Peer Victimization Scale, and showed $\alpha=.82$ in a US validation study [49] and $\alpha=.85$ in our AIDS-orphanhood study . Items include: being called names, being hit or threatened and having possessions broken or stolen. This measure generates a total global

	score of exposure to bullying.
<b>Negative family processes and child trauma</b>	
	Exposure to family conflict and domestic violence will be measured using items from the <u>UNICEF Measures for National-level monitoring of orphans and other vulnerable children</u> [50] (2 items). This will also be used to identify experience of and frequency of physical and emotional abuse (5 items). Exposure to sexual abuse will be asked using two items devised by social workers in South Africa, and used in our previous study of AIDS-orphanhood (2 items). Sense of safety in the home will be measured using items from the <u>National Primary Schools Violence Survey 2007</u> [51] (4 items). A further item assesses intra-household discrimination (i.e. differential allocation of food between fostered and biological children) and was developed in qualitative pilot work (1 item). Community-level trauma will be measured using items from the <u>Child Exposure to Community Violence (CECV) Checklist</u> [52], adapted to reflect commonest community traumas in South Africa, as identified by national police statistics [53].
<b>Positive family processes</b>	
	Positive parenting, consistency of discipline and caregiver supervision will be measured, using the <u>Alabama Parenting Questionnaire – Short form</u> [54] (9 items). Internal consistency of scales was moderate ( $\alpha=.57 - .62$ ) but correlation with child behavioural symptoms high. In our follow-up orphan study, it gave an $\alpha=.75$ . Succession planning was identified by the South African Government as an important factor, and will be measured using 2 items devised and piloted by our Child Advisory Team.

**APPENDIX C****Consent form for parent(s) or guardian(s)**

Dear Parents/Guardians

We would like to invite your child to take part in research that is being run by a number of universities and by the South African government. The research will be asking about the well-being of children in South Africa. We will be talking to 6 000 children in four different provinces and the research will take what children and their carers say to the South African Government and to other organisations that are working with children. The government will use this research to help their planning for children.

This research will be asking young people for their opinions on the questionnaire; what they like and dislike about the questionnaire and whether they would prefer it to look and read differently. If you give permission, your child will fill in a questionnaire, with the help of an interviewer. The interviewer will ask your child questions throughout the time in which they are completing the questionnaire. This will take about two hours. Young people can choose whether they want to take part or not, and they can stop the interview at any time. Everything we are told will be treated as entirely confidential, unless children are at risk of serious harm, in which case we will try to help them.

If you have any questions or worries about the research, please tell me, Jenny Back, or my supervisor, Lauren Wild and we will be very happy to discuss or explain these issues further to you. Please fill in the slip below and let us know whether you give your permission.

Thank you,

Jenny Back (Student Researcher, University of Cape Town)

If you have any questions or complaints about this study, please contact:

Jenny Back (0828706006, [bckjen001@uct.ac.za](mailto:bckjen001@uct.ac.za)) or

Lauren Wild (021 6504607, [lauren.wild@uct.ac.za](mailto:lauren.wild@uct.ac.za)) (supervisor)

Name of Participant ..... Child's grade .....

Can the child I care for take part in this study? YES NO

Name of parent/guardian..... Date .....



## APPENDIX D

### Information sheet and consent form for participants

Dear Young Carer

Please take time to read this sheet carefully and decide whether you do or don't want to take part. Ask the researcher if there is anything that is not clear or if you have questions. Thank you for reading this.

**What is this study about?** This study is about young people and their feelings about their lives. The government wants to know more about them so they can plan how to help young people and families better. This study is the first step to understanding more about your lives and that is why we want to know what you think of the Teen Talk Questionnaire that will be used in the main project.

**Do I have to take part?** Not at all. It is up to you to decide whether or not to take part. If you do not want to, this will not affect any help you may be getting from anyone. You will not get into any trouble if you do not want to take part.

If you decide to take part, you are still free to stop at any time. You don't have to give a reason. Again, this will not affect any help or support you are getting from anyone.

**What would I have to do?** If you decide to take part, you will first sign a consent form, and then spend about three hours talking together and doing activities with a researcher.

**What if the questions upset me?** You can stop at any point, and you do not have to give a reason. You can also contact me, Jenny Back or my supervisor, Lauren Wild at any point after the group, and say that you want your answers about certain questions to be destroyed, which we will do straight away. If you want to talk to someone about anything that has come up from this, you can tell me, Jenny Back (0828706006) or contact my supervisor Lauren Wild (021 6504607).

**Why should I take part in this study?** By telling us what you think of the questionnaire we will be able to make it better. This may help us to know more about what can help young people in South Africa.

**What if I have a complaint?** If there is anything to do with this research about which you are unhappy, you can complain to me, Jenny Back (0828706006) or contact my supervisor, Lauren Wild (021 6504607).

**Will what I say be kept confidential?** Anything you tell us will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that you cannot be recognised from it. But during this study, it may become clear that you are suffering from serious difficulties. If so, the interviewer will explain to you some possibilities for further help. If there is a safety issue, we may contact a welfare organisation for you. All this will be talked over with you first.

**What will happen to the results of the research study?** The results of this study will be used to make the Teen Talk Questionnaire better. Your opinions and feedback on the



**APPENDIX E**

**Young Carers Certificate**

**APPENDIX F**

**Young Carers Questionnaire (second version)**

**PLAGIARISM DECLARATION**

1. I know that plagiarism is wrong. Plagiarism is using another's work and to pretend that it is one's own.
2. I have used the American Psychological Association (APA) as the convention for citation and referencing. Each significant contribution to, and quotation in, this research report, from the work, or works of other people has been attributed and has cited and referenced.
3. This research report is my own work.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.
5. I acknowledge that copying someone else's assignment or essay, or part of it, is wrong, and declare that this is my own work

SIGNATURE: \_\_\_\_\_

DATE: \_\_\_\_\_