

Research Protocol

Coping with Loss: A Family Bereavement Initiative for Adolescent Girls in the Free State, South Africa November 10, 2014

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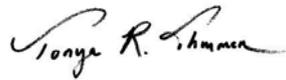
Program Partner

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Declaration of Confidentiality

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Summary

Coping with Loss is a randomized controlled trial to assess the effectiveness of family bereavement interventions targeting female adolescents who have experienced the death of someone important in their lives. Adolescents aged 13-17 will be invited to participate in an 8-session school-based peer support group focused on coping with loss. To complement the support groups, their caregivers will be encouraged to attend a parallel 9-session positive parenting program. The program concludes with a joint adolescent-caregiver session. Interventions will be implemented by Social Workers from Child Welfare Bloemfontein and Childline Free State (CWBFN & CLFS) that have provided support services for orphans and vulnerable children (OVC) at 12 schools in the Free State Province since 2013. The study population will be identified through the CWBFN & CLFS intake process and consist of bereaved female adolescents in grade 9 from 11 participating schools. Eligible adolescents will be randomly assigned to receive the intervention in 2015 or wait-listed for enrollment in early 2016. Survey data will be collected from adolescents and caregivers before and three months following the completion of the interventions. Data will be analyzed to assess for pre- and post-test differences between the intervention and wait-listed group on key psychosocial outcomes, including measures of psychological distress, social support and adolescent-caregiver interactions. Results from the study will be used to develop evidence-based youth bereavement counselling programs to be implemented in additional areas of South Africa. The results will be presented to South African OVC social service organizations as well as submitted to peer-reviewed scientific journals for wider dissemination.

I. Introduction / Background

Significance

The HIV/AIDS epidemic, accidental injuries and violence have gradually increased the mortality rate among prime age adults in South Africa since 1997 (Statistics South Africa, 2006) leading to an increase in the number of children experiencing bereavement. Of the approximately four million orphans in South Africa in 2012, over half (62.5%) are due to parental death from AIDS (UNICEF, 2013). Studies have found that parental loss in childhood and adolescence is associated with a range of immediate and later life outcomes including problems at school, depression, criminality, early sexual activity, and unemployment (Aynsley-Green, 2012). However, support counselling for bereaved children and adolescents is virtually nonexistent in South Africa (Collingwood, 2014) and children are often not encouraged to express grief or even attend memorial services for the deceased. A randomized controlled trial of AIDS orphans in Uganda found that school-based peer support groups reduced the symptoms of anxiety, depression and anger compared to a control group that did not participate in the peer support groups (Kumakech, 2009). The addition of a caregiver component that addresses the caregiver's grief as well as support strategies for the grieving youth is in keeping with PEPFAR best practices for OVC programs as evidenced by multiple studies (Nyberg, 2012). This base of evidence demonstrates both the unmet need and potential impact of family bereavement initiatives that will be offered by CWBFN & CLFS in Free State. This research will contribute to the evidence base for effective programming for bereaved adolescents in South Africa as well as other high HIV prevalence populations.

Study Aim

The aim of this study is to assess the effectiveness of time-limited adolescent grief counseling peer groups coupled with caregiver training and support in improving the psychosocial wellbeing of bereaved female adolescents.

II. Study Interventions

Implementing Partner

Child Welfare Bloemfontein and Childline Free State (CWBFN & CLFS) is a non-governmental organization in South Africa that celebrated 100 years of programming in 2014. They offer an array of child protection services as detailed on their website: <http://www.childwelfarebfn.org.za/index.php>. Supported by PEPFAR funding from USAID Southern Africa, their services include the placement of qualified Social Workers within schools to identify and provide specialized care and support initiatives to orphans and vulnerable children (OVC).

Setting

Free State Province of South Africa is located south of Johannesburg on Lesotho's western border. The capital of Free State Province is Bloemfontein. The prevalence of HIV in the 14-49 age group of Free State is among the highest of all of South Africa's provinces at 19.6% (Human Sciences Research Council, 2013). However, the prevalence of HIV among women attending antenatal clinics is even higher at 32.9% (Department of Health, 2012). Twenty-seven percent of children in Free State are orphans (Meintjies and Hall, 2011).

Abangane Support Group for Adolescents

Abangane ('friends' in Zulu) is the name of the support group program that CWBFN & CLFS offers to bereaved female adolescents in Free State. The program consists of 8 sessions, each with standardized activities and discussion content based on training and resources from the Khululeka Grief Support Program in Cape Town, South Africa. Khululeka Grief Support was started in 2005 by a group of social workers, psychologists and counsellors in response to the large number of children orphaned by AIDS. From these efforts, the group developed the Khu Kit, a guide for training and mentoring grief group facilitators and creating peer support groups for bereaved children and youth. The Khu Kit includes a resource book that provides training and reference materials (including referral agencies) for grief group facilitators. The Khu Kit also includes exercises and creative activities designed to stimulate group discussions that will help children and adolescents to deal with loss and associated grief. More information about Khululeka Grief Support can be found on their website: <http://www.khululeka.org/>

CWBFN & CLFS Social Workers have received training and support from Khululeka to implement the program and have for the last year facilitated groups employing various activities among bereaved adolescents. Based on their implementation experience and with guidance from Khululeka, CWBFN & CLFS established a core standardized 8 session curricula for Abangane that will be implemented across the study sites. Groups will also be gender-specific given the greater enrollment to date of females and concerns about non-conductive behavior in mixed-gender adolescent groups.

Abangane groups will be offered during the first two terms of the 2015 school year to grade 9 female adolescents from 11 schools. The schools are located within three clusters of schools: an urban cluster in Bloemfontein and two rural clusters in Ficksburg/Clocolan and Parys/Vrededorst. The program will operate in eleven schools with two adolescent groups operating in each school per term in ten of the schools and one group in one of the schools (Yakisizwe) for a total of 21 groups. Six different schools in term one and five different schools in term two will receive the intervention per the schedule shown in Table 1. Two groups will be offered per school (except Yakisizwe with only one group) with an average of 10 participants in each group. Thus, 21 groups during the first two terms will serve an expected 210 female adolescents. Groups for boys will be made available in Term 3 where there is sufficient demand.

<i>Area</i>	<i>Term 1</i>	<i>Term 2</i>
Bloemfontein (Urban)	Kopanong & Commtech	Dr Blok & Kagisho
Ficksburg (Rural)	Clocolan & Tshepang	Tlotlisong & Boitumelo
Parys (Rural)	Boitlamo & Yakisizwe	Boiphihlelo

The groups will be held at the schools after classes have let out and facilitated by two adults, including at least one Social Worker experienced with the program. Both groups will be co-facilitated by a Child and Youth Care Worker (CYCW) who has received accredited training on OVC care and support services. CYCWs are trained as part of the Isibindi program offered from the National Association of Child Care Workers (NACCW), which is

working in partnership with CWBFN & CLFS in these communities. The Social Workers will monitor the CYCWs performance as co-facilitators.

Positive Parenting Program

Primary caregivers of Abangane participants will be recruited to participate in a 9-session caregiver-only group facilitated by the same CWBFN & CLFS Social Workers and CYCWs that conduct the adolescent groups. The intervention will primarily consist of the structured seven session Positive Parenting course designed by Parent Centre of South Africa based in Cape Town, South Africa (<http://www.theparentcentre.org.za/>). The course focuses on key parenting skills for building positive child-caregiver relationships, including: understanding adolescents' behavior and feelings, building adolescent's self-esteem, discipline, communication, assertiveness and cooperation and problem solving. The existing program also explicitly addresses adolescents' grief. Parent Centre staff received training from the Khululeka Grief Support Program in 2013 and subsequently revised their programming to incorporate adolescents' grief issues. The CWBFN & CLFS social workers have been trained by the Parent Centre to implement the seven core Positive Parenting sessions and will receive ongoing mentoring from this team throughout implementation. Furthermore, CWBFN & CLFS in collaboration with Khululeka has developed two additional grief-focused sessions that will form part of the Positive Parenting program. These additional sessions are designed to help caregivers address their personal grief as well as better support adolescents' bereavement. The sessions are based on appropriate information and activities within the Khu Kit as well as CWBFN & CLFS's ongoing implementation of a teacher-focused grief sensitization and training initiative begun in 2013.

One caregiver group will be offered at each participating school with all of the caregivers to the participating adolescents combined to attend the same parenting sessions. Thus, eleven groups with an expected 20 participants in each group are anticipated for a total of 210 caregivers. Given the large group sizes, smaller break-out group discussions will be facilitated by both Social Workers and CYCWs. The Positive Parenting groups will meet at either the same school that their child attends or a community library in the evenings and/or weekends. The specific times and places will be decided according to the needs of most caregivers in the group.

Memory Box

As a conclusion to the above interventions, adolescents and their caregivers will attend a session together where they will jointly participate in making a memory box into which will be put pictures, mementos and other gestures (e.g., a letter to the deceased, magazine cut outs of things the deceased liked). General art supplies and guidance will be provided by CWBFN & CLFS and adolescents and caregivers will also be invited to bring tokens from home to include in the memory box. During this session caregivers and adolescents will further be encouraged to share what they have learned from participating in the intervention and their future goals. This session is designed to promote closure of the grief initiatives while also reinforcing positive adolescent-caregiver relationships. The memory box component will draw in large part on the related experience of CYCWs who are encouraged and trained to conduct this activity.

III. Impact Evaluation & Study Design

Sample

The sample will be identified through CWBFN & CLFS's intake data which they routinely collect to identify OVC for their reporting and service planning purposes. The intake form was completed in October of 2014 by 8th grade students from the six schools slated to receive the program in Term 1 of 2015. This process will be repeated in March 2015 among 9th graders at the remaining five schools where the program will be provided in Term 2.

The intake form includes basic demographic and contact data and questions to help determine the adolescent's eligibility and interest in participation. In particular, adolescents report whether they have experienced the loss of someone close to them, and those with this history are asked about their current level of grief using a five-item subscale from the Core Bereavement Items scale (Burnett et al. 1997), as well as their interest in participating in a related support group.

CWBN & CLFS will provide Tulane with access to intake data collected between October 2014 and March 2015 to derive the sampling frame. All beneficiary data files will be password-protected. Identifying information that the researchers will have access to will include the respondents' name (adolescent and caregiver), household location, gender, age, and date of intake along with information on their guardian. Other data in the intakes includes their history of loss and interest in support groups, as primary program eligibility criteria for the intervention under investigation. Limiting the sampling frame to those who want to join will help to promote maximum participation. CWBFN & CLFS decided to limit participation to female adolescents because girls have demonstrated greater commitment to the support groups previously and because of concerns regarding non-conductive behavior in mixed-gender groups.

Study Design

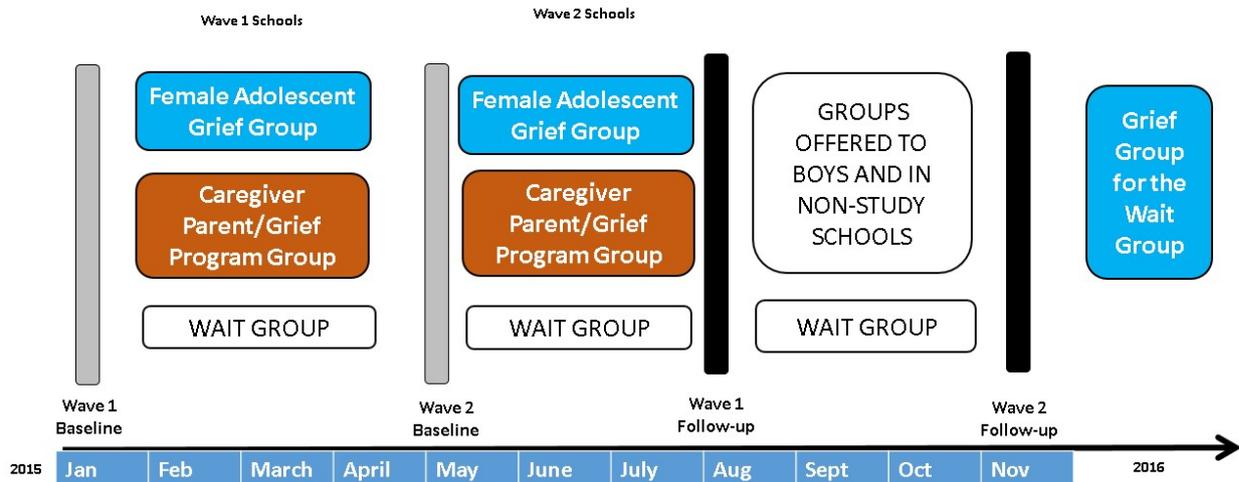
Eligible female adolescents at each school will be randomly selected to receive the intervention in 2015 or wait-listed for enrollment in early 2016. If the number of eligible adolescents exceeds the study's capacity, the intervention and wait-listed groups will be randomly selected first with any that were not selected for study participation free to participate in future groups after the close of the study. The sample will be stratified on school and orphan status to ensure equal numbers of students in the intervention and wait groups as well as equal numbers of orphans in each group. The random samples will be checked for balance on age, grief scores from the intake form and relationship to the deceased. If there are significant differences between the intervention and wait groups with respect to any of those factors, the randomization will be performed again until the groups are balanced.

An overview of the study design is depicted in Figure 1. Intervention and wait-listed participants, including adolescents and their caregivers, will be surveyed prior to the intervention and three months following the intervention. A slight delay between intervention completion and the follow-up survey allows for measurement of outcomes that may emerge and/or persist post-intervention. While there is a "virtual absence of meaningful follow-up data" available in the current literature to guide the timing of longitudinal outcome assessment for bereavement interventions in children (Currier, 2010), evidence from studies among adults with complicated grief suggests that the benefits of cognitive-behavioral therapy persist for 1.5 years post intervention (Wagner, 2007).

Each individual respondent is surveyed only twice, although data collection will occur at four time points to account for the staged enrollment of participants. Per the schedule

presented in Table 1 on page 5, interventions are provided in two waves: in Term 1 (February – April) at five schools and in Term 2 (May – July) at the remaining five schools. CWBFN & CLFS will offer the intervention to non-study participants in Term 3, including adolescent boys at participating schools. The wait listed group will be invited to participate in the intervention beginning the first term of the 2016 school year.

Figure 1. Study Design and Data Collection Timeline



Sample size

The sample size and number of grief groups are determined by the capacity of CWBFN & CLFS to provide services. The program will operate in eleven schools with two adolescent groups operating in each school per term in ten of the schools and one group in one of the schools for a total of 21 groups. Each group has an ideal capacity of ten adolescents. To account for potential loss to follow-up a 20 percent oversample will be taken for a maximum of 252 adolescents recruited into the intervention arm of the study. An additional 252 adolescents will be recruited into the wait-listed group. The study may therefore involve as many as 504 adolescents and their 504 caregivers, but is expected to be 420 adolescents and their 420 caregivers after loss to follow-up.

Detectable Differences

Sandler (2010) was able to detect a significant change in the Intrusive Grief Thoughts Scale, also used in this study, among participants of a group bereavement counselling program immediately following 12 group sessions. Our anticipated sample size, excluding participants lost to follow-up, of 420 adolescents is larger than Sandler’s reported sample size of 244 adolescents.

The primary outcomes for this study will be measures of bereavement among adolescents. Calculations for minimum detectable differences with a fixed sample size of 210 adolescents among 21 clusters (grief groups) are based on Sandler’s reported standard deviation (sd=1.02) for the Intrusive Grief Thoughts Scale among the intervention group. We compared our results to his observed change in the intervention group ($\Delta=0.18$).

We used the method reported by Hemming (2011) for calculating minimum detectable differences for cluster randomized controlled trials with a fixed number of clusters assuming

equal cluster sizes. Power was set at 80% and the significance level was set at 95%. We present the minimum detectable differences (MDD) below for intra-cluster correlation coefficients (ICC) of 0.01, 0.02 and 0.05.

<u>ICC</u>	<u>MDD</u>
0.01	0.088
0.02	0.125
0.05	0.197

Thus, with 21 clusters we would be able to detect a minimum difference similar to that reported by Sandler (2010) with intra-cluster correlation of 0.04 ($MDD_{0.04}=0.18$).

Standard deviations were reported in the literature for two other grief measures that we will be using: the Grief Evaluation Measure (Jordan, 2005), and the Grief Cognitions Questionnaire for Children (Spuij, 2014). The authors of those articles did not report observed changes due to an intervention, but the minimum detectable differences for our study based on their reported standard deviations are both less than one-fifth of one standard deviation from their reported means.

Following the method specified by Hemming (2011), we checked that our sample size and number of clusters would be sufficient to achieve 80% power to detect group differences at 95% significance level. Hemming's rule specifies that the sample size under individual randomization must be larger than the number of clusters (of equal size) multiplied by the intra-cluster correlation coefficient.

$$k > n_i \rho \quad \text{where: } k = \text{available number of clusters}$$

$$n_i = \text{required sample size under individual randomization}$$

$$\rho = \text{intra-cluster correlation coefficient}$$

To achieve the detectable difference reported by Sandler (2010) ($\Delta=0.18$) under individual randomization, we would need 176 study participants per study arm. The number of clusters required under Hemming's method would be:

<u>ICC</u>	<u>$n_i \rho$</u>
0.01	1.8
0.02	3.5
0.05	8.8

Thus, our 21 clusters (grief groups) should be sufficient. However, if intra-cluster correlations are not found at the group level, but rather at the school level (of which there are 11), we should still have a sufficient sample size to detect a statistically significant difference.

Analysis

The analysis plan will include a preliminary analysis of baseline data to assess the prevalence and levels of bereavement among study participants and an impact analysis conducted using both pre- and post-test data to determine the effect of the intervention. Data from the adolescent surveys will be merged with data collected from their caregivers to create an analytical dataset containing a broad array of risk factors and potential confounders. A secondary analysis will be performed to determine the effect of program participation on orphans, although we recognize that we will have more limited statistical power to assess impact in this limited group.

Randomization to intervention and control groups will assure that the groups are comparable at baseline, thus avoiding bias due to self-selection into program participation. Intent to treat analyses will be performed to avoid bias due to non-participation (i.e. intervention participants will be considered as ‘treated’ regardless of their attendance at the intervention). Intra-cluster correlations (e.g. by group, school and time) will be tested for and multilevel methods used to adjust standard errors in the analysis.

Statistical Methodology

Average treatment effect will be estimated using a difference-in-differences, DID, model based on the difference in key outcome indicators from baseline to follow-up for each child and compared between the intervention and wait-listed groups. The DID regression estimator will use the full panel of baseline and follow-up data to estimate the main effects of the intervention. The DID model assumes that the intervention exposure is independent of the outcome under study conditional on a set of observable characteristics. Stratified randomization by school and orphan status will help to ensure that this assumption holds. Differencing the data within individuals (i.e., using measures of change from baseline to follow-up) will also ensure that the independence assumption holds and the model produces consistent estimates of impact. Specifically, we will model the change in an adolescent outcome (ΔY_{it}) as a function of secular change over time (γ), the intervention (ΔP_{it} , causal impact), a set of controls (ΔX_{it}), and an error term: $\Delta Y_{it} = \gamma + \Delta P_{it}\lambda + \Delta X_{it}\beta + \Delta \varepsilon_{it}$.

Multilevel modeling will be used to address potential intra-cluster correlation attributable to the selection of respondents nested within grief groups nested within schools. More specifically, we would like to control for the potential for reduced heterogeneity of respondents from clustering of participants within grief groups (e.g., multiple adolescents aged 13-17) and within schools relative to simple random sampling. Not accounting for such clustering might impact upon inference by inappropriately reducing standard errors. To address this issue – as well as to potentially incorporate the contextual effects of school and community-level influences on adolescent outcomes – the PROC MIXED procedure in SAS will be employed to estimate multilevel models that incorporate the underlying correlations among respondents.

Theoretical Framework

Figure 2 on the following page is an adaptation of Stroebe and Schut’s Dual Process Model of Coping with Bereavement (2010). The Dual Process Model identifies a range of stressors underlying bereavement, namely loss- and restoration-oriented stressors. Loss-orientation reflects aspects of the loss experience itself, such as rumination, emotional response and yearning, as well as the relocation/breaking of bonds with the deceased. Restoration-orientation reflects the secondary sources of stress, that is, adjustments to changes in one’s life as a consequence of the loss. This may include changes to roles and responsibilities, family reorganization, and financial implications. Also central to the dual process model is the idea that bereavement is not a linear progression; rather, it is a dynamic process where the grieving individual oscillates between confronting and avoiding the stressors and tasks of grieving as part of appraisal coping. We revised Stroebe and Schut’s framework to elaborate upon loss- and restoration-oriented stressors, including unique stressors associated with HIV-related loss for children and adolescents.

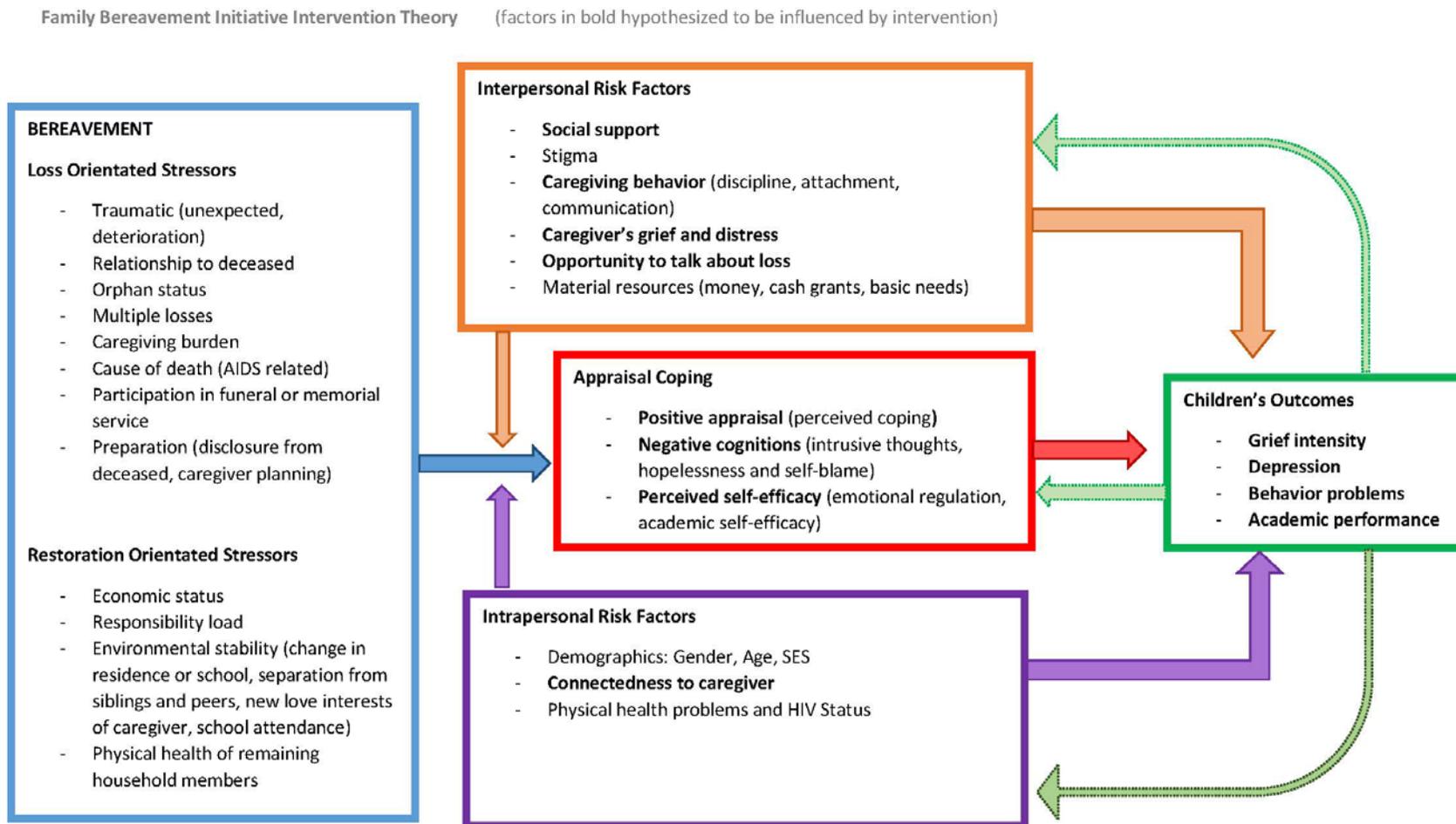
Our framework also integrates interpersonal and intrapersonal factors contributing to parental bereavement as identified by Haine et al.’s descriptive study of evidence-based bereavement interventions (2008) and Sherr and Mueller’s (2008) systematic review of HIV and mental health. These contributing factors interact with the bereavement stressors to influence the manner of appraisal coping, that is, how the bereaved individual assesses and

cope with the stress of bereavement. Appraisal coping may be positive, resulting in personal growth, or negative, such as intrusive thoughts and self-blame. In turn, appraisal coping influences the bereaved child's outcomes of grief intensity, depression, behavioral problems and academic performance. Implicit in the framework is that if a child experiences intrusive thoughts and self-blame, he/she is more likely to suffer from depression and behavioral disturbances; likewise, if he/she is able to find meaning and personal growth from the loss, the child is less likely to be depressed and may experience a lower intensity of grief. The relationship between outcomes and coping appraisal is bi-directional because the degree of grief intensity, depression, and behavioral problems can affect the individual's appraisal of self-coping. Likewise, an individual dealing with depression and grief is less likely to sustain a sense of self-efficacy and more likely to have negative cognitions towards the loss.

As the framework indicates, interpersonal and intrapersonal factors may also directly influence child outcomes. For example, high levels of social support and ample opportunity to talk about loss may serve as protective factors against grief, depression, and behavioral problems. Stigma surrounding a parental death due to AIDS, lack of familial and social support, and poverty may exacerbate levels of depression and grief. As with appraisal coping, interpersonal and intrapersonal factors have a bi-directional relationship with child outcomes, meaning that child outcomes can influence mutable factors such as social support and caregiver's grief and distress.

In interpreting the framework, it should be noted that factors in bold are items hypothesized to be influenced by the intervention under study.

Figure 2. Theoretical framework linking survey content to expected program outcomes.



Survey Instrument

Two surveys have been developed for this study: one for adolescents and one for their caregivers. The adolescent instrument is designed to gather two types of information: 1) grief intensity and depression hypothesized to be affected by the interventions and 2) demographics and background information that may serve as important explanatory and control variables. The caregiver instrument will collect information relevant to the household and caregiver (e.g., poverty, chronic illness, caregiver mental health), as these factors may mediate outcomes for the adolescent. Both the caregiver and the adolescent surveys will include scales to measure caregiver/child communication as an indicator of joint effect of both the adolescent and caregiver programs. At follow-up, the adolescent and caregiver instrument will also include a module to obtain information on their perceptions of the interventions of interest. Many of these domains will be captured applying standardized indicators and scales that have been previously validated with populations in sub-Saharan Africa. Instruments will be delivered in the preferred language of the participant, Sesotho. A summary of the content of each survey instrument follows.

Adolescent survey: The adolescent survey identifies the youth's relationship to the deceased and circumstances surrounding the death, but is comprised mainly of psychological/behavioral scales to measure levels of distress and associated behaviors being experienced at the time of the survey. We will also collect data on a series of secondary outcomes in order to better elucidate the pathways by which the interventions may be working.

Abangane is designed to reduce distress related to bereavement, thus grief intensity and depression are key psychological outcomes. Grief intensity of the adolescent will be measured primarily using items from three standardized instruments: Core Bereavement Items (CBI), Grief Cognitions Questionnaire for Children (GCQ-C), and Intrusive Grief Thoughts Scale (IGTS). Core Bereavement Items (CBI) is a 17-item scale that is widely used to assess levels of normative grief (Burnett, 1997). The CBI is perhaps the most commonly applied instrument for measuring grief in studies that appear in the published literature. The Grief Cognitions Questionnaire (GCQ) was developed in 2003 by researchers in the Netherlands, "to facilitate the assessment of potentially problematic cognitions after bereavement." A version designed for use with children (GCQ-C) was developed and validated separately in 2014 (Boelen 2014). Questions from the 20-item GCQ-C capture negative thinking, understanding of grief and anxiety about death (Spuji, 2014). The nine-item Intrusive Grief Thoughts Scale (IGTS) was developed in 1999 for the Family Bereavement Program run by the Program for Prevention Research at Arizona State University.¹ It measures the extent to which bereaved individuals experience intrusive, undesired thoughts about a death. In a 2009 study of 109 parentally bereaved youth ages 8 to 16 years, "Confirmatory factor analysis affirmed the validity of the factor structure and reliability of the Intrusive Grief Thoughts Scale in the current sample," and the scale exhibited cross-gender validity (Little et al, 2009). This tool's prior use in evaluating the effectiveness of a family-focused bereavement intervention, including for youth who had lost a parent to illness, makes it a good candidate for inclusion in the present study.

¹ Program for Prevention Research. Family bereavement program manual. 1999. (Available from Program for Prevention, Arizona State University, P.O. Box 876005, Tempe, AZ 85287-6005.)

Depression will be measured by the 20-item Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D has been used previously with high reliability among both adults and youth in South Africa (Smit et al., 2006; Thurman et al., 2011; Pretorius, 2001), and we will utilize the version designed specifically for children and adolescents (Weissman 1980, Faulstich 1986). Further, to reduce distress and its clinical manifestations, *Abangane* builds coping skills and access to social support. Thus, secondary outcomes will include key indicators of coping, self-efficacy and social support. The adolescent survey will also capture demographics that will serve as explanatory and/or control variables (e.g., race, stressful life events, and stigma).

Caregiver survey: The caregiver survey collects household demographic and economic data that adolescents may not know and/or would make the adolescent survey too lengthy, including household assets, receipt of core social grants, and adequacy of living conditions. It also covers problematic behavior of the adolescent, a key outcome that the intervention is hypothesized to affect. The adolescent's behavior is captured using the Brief Problem Monitor-Parent Form (BPM-P) (Achenbach 2011). BPM-P is a 19-item subset of the Child Behavior Checklist (CBCL) that captures problem behavior in children.

Caregiver-specific questions include psychological scales to measure their grief levels and depression, which may affect the coping ability of the adolescent and may also be affected by the caregiver group sessions. Specifically, the caregiver's grief level is measured using Core Bereavement Items (CBI) described above and the the Grief Evaluation Measure (GEM). GEM was developed by Jordan et al. (2005) to assess the risk of developing complicated grief. This is a 10-item subscale of the original instrument. It is completed by both the adolescent and the caregiver. Caregiver depression levels will be measured by an adapted 10-item version of the Center for Epidemiologic Studies Depression Scale (CES-D) by Zhang et al (2012).

Limitations

Quality and dose of exposure: Findings may be biased towards the null if the interventions are implemented poorly, including if program roll-out, quality or intensiveness is not delivered as intended. CWBFN & CWFS will work to ensure quality implementation. CWBFN & CWFS have experience implementing the grief groups in schools in the Free State and will use those experiences to guide effective implementation in the new schools. Social workers from CWBFN & CWFS have received expert training from Khululeka Grief Support in the Eastern Cape. Social workers with prior experience implementing the grief groups will work with their supervisors to monitor program quality and support consistent implementation. Attendance by participating adolescents will be encouraged through multiple avenues, including meeting with their caregivers during the Positive Parenting sessions, establishing attendance rules at the onset, and having the school-based social workers meet with non-adhering adolescents during the school day. While CWBFN & CWFS will make every effort to encourage participation, not all adolescents will attend with the same frequency; variations in exposure dose will be measured at follow-up and through attendance records (collected by each CWBFN & CWFS group facilitator and consolidated at headquarters) and explicitly accounted for in advanced models. We will also compare effect estimates from our intention-to-treat analyses with those from "per-protocol" analyses (i.e., limited to participants who were truly exposed to the full interventions as they should have been implemented).

Sample size and loss to follow-up: As with any study, our detectable difference calculations are sensitive to a number of assumptions, and additional procedures may be necessary to meet these assumptions. As in any longitudinal study, loss to follow-up could be problematic, particularly if loss represents those most bereaved or from the most unstable home environments. We will minimize loss by collecting contact information through a Household Tracking Form at baseline and validating this information with data collected during the home visit to interview the caregivers. The facilitators will also track grief group attendance and follow-up immediately with those adolescents who stop attending (in the event that a child has moved, the facilitator will provide updated information for use in our tracking database). It should be noted that the time from baseline to follow-up is relatively short, only six months, which reduces the likelihood of an adolescent relocating out of the area relative to longer periods. School-based social workers from CWBFN & CWFS can follow-up with any adolescents who fail to complete the follow-up survey and make arrangements for them to do so.

Cross-over contamination: Students from the same school will be randomized into intervention and wait groups which could result in cross-over due to adolescents in the intervention arm discussing the content of the grief groups with students in the wait-group arm of the study.

Generalizability: There are multiple methods for measuring the key psychosocial outcomes with no universally accepted outcome measure so that the results of the study may be influenced by the indicator used and may not be replicable if other measures are employed. The results of the study may not be applicable to adolescents not attending school.

IV. Field Procedures

Intervention Recruitment

Password protected lists of students from each school randomly selected into the intervention and wait-listed arms of the study will be shared only with CWBFN & CLFS personnel working in those schools and they will presume responsibility for recruiting them to participate in the interventions. The Social Workers will visit both the students and their caregivers at home to explain the study and whether they are being invited to participate in the programs now or wait-listed for later enrollment. Further, they will encourage the caregivers to consent to their adolescent's involvement in the intervention as well as their own participation in the parenting group as appropriate. All selected adolescents and caregivers will also be provided with a study information letter that explains that they may be invited to participate in a survey and that their decision to do so is voluntary and will not affect their eligibility to receive services from CWBFN & CLFS nor will the program staff be privy to any of their responses. Consent/assent for study participation will be conducted separately by trained research personnel not affiliated with CWBFN & CLFS as described in subsequent sections.

Study Recruitment

The specific inclusion criteria for the schools, adolescents and caregivers are detailed below.

School Inclusion Criteria

Only schools meeting all of the following criteria will be included in the study:

- CWBFN & CLFS Social Workers operating at the school
- At least 20 bereaved female adolescents who express potential willingness to participate in the support group
- Private space to offer the intervention

Adolescent Inclusion Criteria

- Sesotho speaker
- Caregiver provides consent for study participation
- Adolescent provides assent for study participation

Caregiver Inclusion Criteria

- Sesotho speaker
- Adolescent under his/her care is selected to participate in the study
- Willing and able to consent to their own participation

Notably, the study population will also only consist of adolescents with the characteristics below which are the program's eligibility criteria for intervention enrollment at participating schools during the study period:

- Female gender
- 13-17 years old as of January 1, 2015
- Enrollment in one of the 11 implementing schools
- Enrollment in the 9th grade in 2015
- Experienced the loss of someone close to them
- Expressed interest in participating in the support group
- Has not previously participated in the support group (which was offered to some 8th graders in participating schools)

Survey Preparation

The survey was developed in English and sent to CWBFN & CLFS field supervisors for initial insights into the appropriateness of the content and terms used. The questions were translated from English into Sesotho by a professional translation company not affiliated with the research team or CWBFN & CLFS. Two different translators fluent in both English and Sesotho independently translated each instrument. A third party then compared translations and resolved any discrepancies. During training, the field team will also extensively review all translations to ensure proper translation of the meaning and understanding of the contents.

The translated survey will be pilot tested among 9th grade students who have experienced the loss of a loved one in a school that will not participate in the study, but will receive the grief groups from CWBFN & CLFS in the future. Results from the pilot testing will be used to further refine the survey questions and to adjust the length of the survey so that it does not take more

than one hour to administer. CWBFN & CLFS will assist Tulane research staff to identify appropriate students from the pilot schools.

Cognitive Interviewing

Tulane is qualitatively validating the primary grief assessment instruments for the *Coping with Loss* study. The qualitative assessment has been reviewed and approved by both the University of the Free State Ethics Committee (REC reference #: 230408-011, IRB #: 00006240) and the Tulane University Human Research Protection Program (Board Ref #: 14-661391).

For adolescent psychosocial support programs operating outside of Western contexts, evidence suggesting the best ways to measure outcomes such as grief and self-efficacy is lacking. Tulane is responding to this gap by conducting cognitive interviews with former adolescent bereavement support group participants. In cognitive interviewing, the interviewee will be presented with a series of survey questions constituting established scales and related measures, and verbally prompted to discuss aspects of his/her thought process while formulating a response. Participants in the cognitive interviews are also invited to offer their own ideas for other questions that would function as good measures of the idea or experience being represented. Results will be used to develop accurate, linguistically and culturally competent survey design for quantitative studies addressing adolescent psychological wellbeing, especially among Sesotho speakers. The cognitive interviews occurred in November 2014. The development of the cognitive interviewing protocol, research tools and ethical application submissions in the USA and RSA were completed in October.

Survey Modality

Surveys will be administered face-to-face using computer-assisted personal interviewing (CAPI) technology. Questions and responses are displayed on the screen of a netbook held by the interviewer. The interviewer reads the questions and responses as he or she would in a paper survey and records the respondent's answer by using the touch screen. The data are automatically stored in the database and encrypted, thereby eliminating the need for double capture of surveys and other time-consuming data entry error control processes. System checks and automatic skip patterns are built into the system to avoid interviewer error in question ordering.

Tracking Form

Procedures to reduce loss to follow-up will also be in place. After completion of the baseline survey, primary caregivers will be asked to complete a Household Tracking Sheet which solicits information such as caregiver surnames, contact numbers, GPS coordinates of the household location, and other identifying information. This information is collected to facilitate follow-up surveys. Caregivers will consent to this portion separately and be reassured that contact information will not be stored with their questionnaires and will be password protected. Further details regarding the protection of identifying information are described below.

Data Collection/Field Team

The data collection phase of the study will be led by Tulane researchers and implemented by a qualified research partner selected through a competitive bid process. Required qualifications for the research partner and field team include: extensive evaluation experience in South Africa and undertaking similar evaluations; experience conducting quantitative interviews in English

and Sesotho; and research experience working with vulnerable populations, including adolescents.

In conjunction with Tulane research staff, the research firm will develop interviewer and supervisor training guides and will facilitate an extensive training session. All fieldworkers will be briefed on the purpose of the research and trained on how to apply the research tools and methodologies. Study protocols will be described, studied and tested in detail. Fieldworkers will be specifically trained in ethical procedures for social science research including: maintaining respondent privacy, ensuring voluntary participation and confidentiality, carrying out participant referrals, and dealing with sensitive topics. The training will be followed by pilot test implementation and review. The option to extend the training for two additional days will be maintained depending upon interviewer performance during the pilot.

An interviewer from the research team will visit the caregivers in their home to conduct face-to-face interviews in their local language using the structured survey instrument described above. Caregivers will have already been advised about the study through provision of the Study Information letter. Interviewers will use location information from the intake forms completed by the youth in order to find the households. In the event a household is very difficult to locate, the field team supervisor will meet with agency workers to discuss the location and pinpoint it on a map. Interviews and consent will be completed in private and without the presence of the program affiliates. Consent will be obtained at the outset for interviews with the caregiver as well as the youth, as further described below. The caregiver participant will be asked to select a private room, area in the yard, or other space where s/he is comfortable, free of observers, and cannot be overheard. Observation will be allowed only among children age two years and younger; if privacy is not feasible at the time of the visit, the interviewer will reschedule for an alternative time.

Interviews with youth will also be completed at the adolescent's home outside of normal school hours. Again, interviews and assent will be completed in private and without the presence of the program affiliates. Assent and interview procedures will be conducted in private; no observers will be allowed. If privacy is not feasible at the time of the visit, the interviewer will reschedule for an alternative time.

Informed Consent and Assent

Informed consent and assent will be obtained from every respondent prior to beginning interviews. Caregiver respondents will be asked to provide consent to participate in the survey when they are visited at their home residence and they will also be asked to provide consent for the youth in their care to participate. Adolescents age 18 and over will consent to their own participation.

Parents/caregivers may choose to forgo participation of their minor children in any aspect of the study with no consequences to either themselves or their adolescents. All adolescents who participate in the study will provide informed assent using culturally and age appropriate information.

As part of the consent and assent procedures, the interviewer will explain very clearly before the questioning begins that the respondent's participation is purely voluntary; that the respondent has the right to refuse to answer any question or any part of any question that he or she does not wish to respond to; and the respondent has the right to terminate the interview at any time. All potential respondents will also be made aware at the outset that their participation is voluntary and does not affect their eligibility to receive services from the programs now or in the future.

Respondents will be informed of provisions to ensure confidentiality. The participant will be informed that all answers provided will be held in strict confidence and that their survey answers will not be stored in the same place as their contact information.

Interviewers will inform potential participants of the purpose and nature of the study and outline any possible advantages and/or disadvantages that may affect the respondent should they participate in the study. The consent form will state explicitly that the participants will be randomized to either attend the group sessions or be put on a wait list. The caregivers will be informed that if their child has been assigned to the wait list then they will not be eligible to participate in the caregiver group sessions and will receive referrals to other social services.

To ensure that the participant is aware that the survey includes questions on highly personal and sensitive topics, the interviewer will forewarn the participant that some of the topics are difficult to talk about. They will be made aware of the expected length of time the survey will take. All potential respondents will be asked if he/she has any questions before they are asked whether he/she would be willing to consent or assent to participate in the survey. The interviewees will be provided a blank copy of the consent or assent form, which explains the study purpose and procedures and also provides contact information in the event that they have questions at a later date. Where respondents are literate, consent and assent forms will be signed and dated by respondents. In cases where the respondents cannot read, the consent or assent process will be conducted in the presence of a witness, usually a family member, friend or neighbor. This witness will be an independent observer, not part of the research team or the program being evaluated, and will remain present throughout the consent/assent process. If verbal consent/assent is obtained, the respondent will be asked to sign the consent form indicating written consent/assent. Those who are unable to sign will be asked to make a mark in lieu of signature. The witness (typically a family member, friend and/or neighbor) will likewise be asked to sign the consent or assent form and will leave thereafter in order to preserve confidentiality during the interview.

Signed consent/assent forms will be stored for three years should verification processes be required. In addition to the actual consent or assent form, the interviewer will record on the electronic questionnaire that the consent or assent procedure has been administered, and whether permission to conduct the interview has been granted.

Several procedures are in place to promote certainty that the potential respondents understand the information being presented and are therefore able to provide true informed consent or assent. One key way this will be achieved is to ensure the accurate and professional translation so that information is presented accurately and simply within their native language. All consent forms and the survey questionnaires will have been translated by two separate independent professional translators into the appropriate study language, Sesotho, and then rectified by a third party into English, thereby helping to ensure proper translation of the meaning. Further, all information within the consent and assent forms will be presented in an easy to understand manner. Fieldworkers will carefully and slowly read the consent or assent form explaining the study procedures and participants' rights. The fieldworkers will have been trained on strict ethical procedures and the importance of informed consent and voluntary participation and encouraged to use judgment if they feel that further explanation should be provided prior to obtaining consent or if they determine the respondent is perhaps unable to provide informed consent due to any cognitive impairment.

Confidentiality

A number of mechanisms are in place to protect the privacy interest of participants. The data collection process will be implemented in a manner that will ensure the confidentiality of respondents is scrupulously maintained. These procedures will be followed by all field staff and will be monitored by on-site field supervisors. Tulane researchers will adhere to strict confidentiality guidelines in handling the survey data.

Field procedures to safeguard confidentiality include:

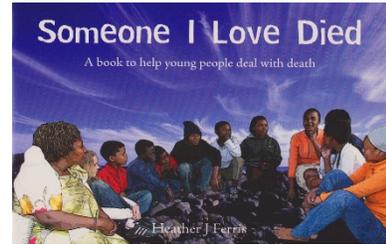
- The program partner will *not* be made aware of individual survey results of any child or caregiver.
- No interviewer will conduct an interview in his/her own home community.
- All researchers and fieldworkers will sign confidentiality forms that will ensure the privacy of participants is scrupulously maintained, both those prepared by and required from the research agency. The program partner will also receive strict instructions about the importance of maintaining confidentiality. Interviewers will also be instructed that they are not to discuss any information provided to them in an interview except with their field supervisor.
- As part of the consent and assent procedures, participants will be informed that the data collected will be held in strict confidence and made aware of provisions to ensure confidentiality, such as the use of unique codes rather than full names on the questionnaire, aggregation of data, and the fact that the information will be viewed only by the research team and kept within password protected files.
- All interviews will be conducted in a safe place where outsiders or other members of the household or school are unable to hear. Only children less than two years of age will be allowed to sit with the caregiver respondent while the interview is occurring. In the event that another individual enters the room/area, interviewers will change the topic so that the content of the interview is not disclosed.

Data procedures to ensure confidentiality include:

- To safeguard the confidentiality of collected data, caregivers and adolescent questionnaires will be assigned unique and interlinking identification numbers, and actual identification information (i.e., names and addresses) will be kept separately from the questionnaires. That is, only unique identifiers, first names and location site will be provided on each of the actual questionnaires (first names and location site are provided to facilitate linking of the multiple questionnaires in the event of a coding error).
- Files that provide the information linking individuals to their unique identifiers will be kept in a separate password protected data file and accessed only by the Tulane University senior researchers. Similarly, the data for tracking sheets which includes contact and identifying information will be captured on a different database than the actual survey data. This data will also be password protected with access limited to lead research team members.
- Particular care will be taken during the presentation of the research findings in that the information presented is sufficiently aggregated to ensure that no one community or individual can be identified. No individual level data that could potentially jeopardize the confidentiality of study participants will be disseminated in any fashion to anyone outside of the study team.

Incentives

Participants in the study will not be provided with any remuneration and will be made aware that their decision to participate will not affect any possible service delivery from CWBFN & CLFS. All adolescents selected for the study will also be provided with a copy of the book endorsed by Khululeka, *Someone I Love Died*, which is a collection of stories from Africa about children's experiences with death (<http://www.khululeka.org/resources>). Given the sampling frame and related survey questions are focused on children and adolescents who have experienced loss, the research team believes that the provision of this book may be a beneficial reimbursement for their time. All eligible adolescents invited to participate in the study will receive a copy of the book at the time of survey implementation even if they decline to participate.



Referrals

The research team recognizes the sensitive nature of discussions of loss and grief with participants, especially adolescents. Questions concerning loss will be approached in a standardized and careful and sensitive manner by trained interviewers. Further, as a precautionary and support measure, a counseling referral mechanism will be organized in collaboration with local program partners. Tulane research staff will arrange with the CWBFN & CLFS, in advance of fieldwork, for qualified community-based counselors to be available during the interview period should a respondent become upset during the interview, thus requiring a counseling referral. Interviewers will be trained to recognize this need and to handle the situation in a sensitive, non-judgmental manner. The fieldworkers will contact their Supervisor who will ensure the referral is completed within 24 hours and that respondents receive the appropriate services. In addition, participants will be provided with a social service sheet detailing local resources available to him or her. The social service sheet will contain contact details for counseling resources as well as other useful services should the respondent become distressed at a later time. Participants may also communicate with their school social workers as needed at any time without referral.

Wait group service delivery

The research team is cognizant of the potential concerns associated with randomized trials and the delay of services for wait group participants. There are currently no grief counselling or grief support groups available to children or adolescents outside of the Abangane support program at these schools and so the wait group will not be deprived of standard services or treatment. Further, the study is occurring within the context of CWBFN & CLFS expected service delivery target numbers, and there is thus no intentional denial of services – rather a method to allow for equal opportunity for immediate enrollment. Lastly, all adolescents will receive useful resources and opportunities that they may not have received otherwise, including the book and social service sheets as well as an eventual opportunity to participate in the intervention. The decision to prioritize service delivery to the wait group adolescents was encouraged by the study team and approved by CWBFN & CLFS, and is a provision that may not have otherwise been available outside of the study context given resource constraints.

V. Study Approval / Ethics Committee

This study is subject to the approval of the Institutional Review Board at Tulane University, to which the investigator is affiliated. Data collection will only commence following review and approval of the study protocol and related materials from both the Faculty of Health Sciences Ethics Committee at the University of Free State and the Tulane University Human Research Protection Program in the USA.

VI. Dissemination of Study Findings

This study is designed to produce knowledge that will improve existing practices and guide future investment in programming for bereaved adolescents in South Africa. Findings will be made available to partners (CWBFN & CLFS and Khululeka Grief Support) as soon as they are available. Dissemination will occur through workshops and presentations, including at the National Action Committee for Children Affected by HIV/AIDS (NACCA) in which the Principal Investigator is a member.

To encourage the scale-up of proven interventions and improvement of existing programming for orphans in Sub-Saharan Africa, findings will also be submitted to peer-reviewed journals for publication. Such publications enhance the credibility of research findings and expand their influence. Upon publication, the articles will be made available through open-access on the Tulane HVC Research project's website (www.hvc-tulane.org).

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