

# Mothers affected by HIV&AIDS: The *Kgolo Mmogo* project

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## Abstract

*In this short report, I discuss the way in which an assumption at the outset of a longitudinal study on HIV-positive mothers has been challenged three years into the study. The assumption concerns the employment status of the participants. The *Kgolo Mmogo* project<sup>1</sup> is investigating the resilience factors in mothers (n=440) and children (n=440) who are dealing with the affect and effects of HIV&AIDS.<sup>2</sup> The study consists of long-term data collection on the psychological resilience factors in both groups. The assessment data are paralleled by intervention research that tracks the effects of a group-based support intervention in terms of which the mothers and children are assigned to groups within a randomised control trial design. In designing the intervention, a basic assumption was that the study would show variance in the group participation rates of the mothers due to anticipated health fluctuations. As a result, the intervention was designed to make provision for home visits should a mother be absent from three consecutive group sessions. However, preliminary data from the study indicate that absenteeism from groups can more often be explained in terms of new employment than in terms of health problems. This preliminary finding may have implications for the design of future interventions in respect of mothers affected by HIV&AIDS.*

**Keywords:** HIV-positive mothers; employment; resilience; support groups; group intervention

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<sup>1</sup> The *Kgolo Mmogo* project is funded by the National Institutes of Health (NIH), NIMH grant R01 MH076442-01; *Kgolo Mmogo* means 'growing together'.

<sup>2</sup> Principal investigators: Brian Forsyth, *Yale University*, and Irma Eloff, *University of Pretoria*. The project team consists of Michelle Finestone, Liesel Ebersöhn, Ronél Ferreira, *University of Pretoria*, Alex Boeving, Wake Forest University, Jenny Makin, Maretha Visser, *University of Pretoria*, Kathy Sikkema, *Duke University*, and Margaret Briggs-Gowan, *Yale University*.

## Introduction

The need to provide effective, sustainable psychological support to mothers and children affected by HIV&AIDS is well documented (Amoateng, Richter, Makiwane *et al.*, 2004; Forehand, Steele, Armistead, *et al.*, 1998; Giese, Meintjes, Croke *et al.*, 2003). However, understanding the complexity of designing support interventions is still problematical, especially as findings from long-term studies are just starting to emerge. The fluctuating health status of mothers, increased stress levels, child-caretaking responsibilities, the time demands of frequent health visits and the pressures of dealing with grief are just some of the issues that need to be catered for in interventions in order to achieve the desired outcomes for participating mothers. A study by Barnard (2004) indicated that young HIV-positive women often experience uncertainty, loneliness, rejection, guilt, fear, anger and depression upon diagnosis. These women also often state that they have limited knowledge of HIV&AIDS and that they have particular concerns about the attitudes of their employers regarding their status because these attitudes may impact on their ability to take care of their families. These findings highlight the complexity of women's coping strategies, which simultaneously include personal coping and also anticipating the ways in which their children will cope with their possible death.

In this report, I discuss the progress of the *Kgolo Mmogo* project with particular reference to the way in which a primary assumption at the outset of the study is being challenged by emerging findings on the employment/unemployment status of the mothers in the study. I begin by providing a brief overview of the *Kgolo Mmogo* study where I describe the research methodology and discuss the study's hypotheses in relation to the initial assumptions. I conclude by considering the assumption that mothers may be absent from group intervention sessions for health reasons, and the actual reasons that have emerged over time in the *Kgolo Mmogo* project.

## Background to the *Kgolo Mmogo* project

The *Kgolo Mmogo* project is a collaborative, five-year randomised controlled trial study funded by the National Institutes of Health (NIH). It focuses on psychological resilience in South African mothers and children who are affected by HIV&AIDS and is conducted by a multidisciplinary team of researchers from Yale University (USA), the University of Pretoria (South Africa) and Duke University (USA). The study rests on two parallel tracks of data collection. The first track is the collection of longitudinal data on resilience factors in mothers and children using composite psychological assessment scales (i.e. CES-D, Brief COPE, Positive Religious Coping, Vineland, CCNES, CBCL and the PSI with the mothers and the BarOn EQ-I: YV, RCMAS, CDI, KIDCOPE, CSCS and the SDQ with the child participants). Parallel to the psychological data collection is a theory-based support intervention conducted with the mother and child participants to assess the efficacy of a group-based intervention while mothers are dealing with the effects of the disease on themselves and their families.

## Primary aims of the study

The study has multiple aims (Forsyth, 2005). It seeks to

demonstrate the extent of the psychosocial effects of parental HIV disease on young children living in urban communities affected by poverty in South Africa by comparing them with other children whose parents are not HIV-infected but living in the same communities;

assess the effectiveness of the theory-based support intervention for HIV-infected mothers and their children that is designed to improve maternal functioning and help

mothers promote resilience in children at two different ages and stages of development, very young children (aged three years) and school-aged children (aged six to ten years);

identify maternal psychological and medical factors (including initiation of antiretroviral (ARV) treatment), as well as child-related mediating variables, that contribute to changes in the adaptive functioning of children of HIV-infected parents over a 24-month interval.

## Synoptic research methodology

Four hundred and forty HIV-infected women and their children are in the process of being enrolled in a randomised controlled trial. At the time of writing, a total of 287 participants had been enrolled. The study uses various referral sources:

- a. Women who were enrolled in a previous study, the Serithi project, in which they were followed since pregnancy. This study focused on stigma and mother-to-child-transmission factors, but, in it, the women did not participate in a group-based support intervention. In the current study, the children are enrolled in the study when they reach the age of three years, and older siblings between the ages of 6 and 10 years are enrolled in the older children's cohort.
- b. Mothers with advanced HIV disease who have been referred to the Kalafong Hospital Immunology Clinic (Gauteng Province) for ARV therapy and who have children aged between 6 and 10 years.
- c. HIV-positive mothers, with children in the age groups for the study, who have been referred from other health clinics in the vicinity of the Kalafong Hospital.

We are also enrolling, for purposes of comparison, 110 age and gender-matched children (55 children aged 3 years and 55 children aged 6-10 years) of non-HIV-infected women. These women were identified from HIV testing sites in the same community. We are comparing, at the time of enrolment, the age and gender-matched children with the children of mothers infected with HIV. This comparison group will serve the purpose of controlling for variance in resilience factors measured in the child participants of the study.

As mentioned earlier, we are conducting a randomised controlled trial of a six-month, structured support intervention for the HIV-positive women and their children. Mother participants are recruited in waves of 34 participants, and, per wave, 17 mothers are randomly placed in groups. The intervention is activity infused while providing for psychological and developmental variance in the group participants. The intervention is designed primarily to promote child and maternal resilience and is strongly embedded in theories of resilience (Arend, Gove & Stroufe, 1979; Baldwin & Baldwin, 1990; Barnard, 1994; Bolig & Weddle, 1988; Garmezy, 1984a, 1984b, 1991; Mallmann, 2003; Rutter, 1979, 1987, 1990, 1993; Werner & Smith, 1982, 1992). It includes site-specific support groups in two accessible sites in Tshwane, home visiting for those who are ill and parenting education. The groups are conducted separately for the mothers and their children for the first 15 sessions. The final 10 sessions are conducted with the mothers and children present in the same group and are based on communal mother-child activities. The sessions are conducted by trained care workers under the supervision of qualified social workers. A manual provides guidance on planning, materials per session, debriefing and goals for each session.

We are collecting longitudinal data on the HIV-affected groups over 24 months including changes in group members' biographical background, social circumstances, progression of HIV disease (including possible initiation of ARV therapy and, in some instances, death) and measures of parental psychological adjustment, parenting and child developmental functioning.

Finally, we are doing analyses to (i) determine differences between children of HIV-infected parents and children of non-HIV-infected parents at baseline; (ii) assess the effectiveness of the intervention; and (iii) identify factors that either contribute to or mediate child outcomes in terms of resilience.

## Changing an initial assumption

In designing the intervention and compiling the assessment battery, we formulated hypotheses that guided the research design process (Forsyth, 2005):

Hypothesis 1: Children of HIV-infected women have significantly decreased adaptive functioning compared to children of mothers who are not HIV-infected.

Hypothesis 2: A structured support intervention for HIV-infected mothers that includes support groups, home visiting for those who are ill and parenting education that focuses on promotion

Hypothesis 3: Strengths of HIV-infected women, such as increased self-esteem and positive coping, promote more positive adaptive functioning among their children, and this positive effect is most evident among pre-school-aged children. Furthermore, as a woman's medical condition improves following the initiation of antiretroviral therapy, the adaptive functioning of her child also improves.

The formal hypotheses of the study are based on assumptions made during the design phase of the study. For instance, in the case of the assessment data collection, assumptions included i) allowing for 'grey', but composite, measurement of resilience as a psychological construct (e.g. multiple psychometric instruments), ii) designing for individual specificity regarding resilience factors (e.g. individual profiles of resilience), iii) acknowledging the interactivity between context and resilience (Eloff, Boeving, Briggs-Gowan, *et al.*, 2007). For the intervention design, assumptions included i) allowing for intermittent group attendance of mother participants due to health reasons (e.g. incorporating home visits in planning), ii) combining functional and psychological support for the purpose of effectiveness (e.g. including practical survival skills as well as psychological coping skills), iii) adhering to child developmental levels in terms of planned activities (e.g. using puppets, drawings, songs and traditional African games).

Embedded in the second hypotheses is the first assumption regarding the intervention, which I will now elaborate upon for the purpose of this report. The second hypothesis states:

A structured support intervention for HIV-infected mothers that includes support groups, *home visiting for those who are ill* and parenting education that focuses on promoting resilience results in improved adaptive functioning among children in both age groups.

The phrase '*home visiting for those who are ill*' in this hypothesis comes from the assumption that additional support would be needed since mothers may be absent from the group sessions for health reasons. Additional support was conceptualised in terms of home visits with the necessary precautions being taken regarding disclosure/non-disclosure to family members. At the start of the project, concerns were, in fact, raised that this prevention (i.e. home visits) had the potential to become overwhelming in the course of the project. However, three years into the project, the preliminary figures indicate trends that challenge the initial assumption regarding group participation and the need for home visits. The number of mother participants at the time of writing (June 2008) was 287 and the number of home visits needed for health reasons, five.

Even though the home visits needed are far fewer than initially anticipated, the groups are still influenced by absenteeism to some extent. However, it seems that absenteeism is not due mainly to mothers being unable to attend the group sessions *for health reasons*. Anecdotal

evidence from other group members and observation data from the social worker conducting the groups indicate, rather, that a major reason for non-attendance is the obtaining of employment by the absent mothers. Table 1 shows some of the observation data that illustrate this phenomenon. Participants are identified by a code KM + [numeric], for example KM 123.

**Table 1: Extracts from observation data**

Wave	Observation data from social worker
Wave 1	KM 147: <i>She was working shifts and at times she would make an agreement with her employer to come to the group.</i>
Wave 2	KM 174: <i>She attended the group until session 20 when she started to work.</i> KM 191: <i>She started the group until the 9<sup>th</sup> session, and she could not attend because she started to work full time.</i> KM 202: <i>She attended till the 18<sup>th</sup> session until she started to work.</i> KM 134: <i>She came back and joined wave 2 but only until session 16 then she started to work again.</i>
Wave 3	KM 260: <i>She attended until the 10<sup>th</sup> session and then started to work.</i> KM 263: <i>She got a job as a domestic worker but made an agreement with her employer to leave early on Thursdays so that she can come to the group.</i>
Wave 4	KM 260: <i>She attended until the 10<sup>th</sup> session and then started to work.</i> KM 263: <i>She got a job as a domestic worker but made an agreement with her employer to leave early on Thursdays so that she can come to the group.</i>
Wave 5	KM 326: <i>She was always attending the group sessions until she got a job (session 16).</i> KM 368: <i>She only attended once. She was called back by her previous job; she was very happy because her family suffered financially.</i>
Wave 6	KM 500: <i>Attended 3 sessions and then started to work.</i>
Wave 7	KM 484: <i>She is working part time and mentioned that from next month she will be working full time.</i>

While it is difficult to ascertain, at this stage in the study, the reasons for mothers regaining employment, it is clear that this trend challenges the assumption that health reasons would be the primary reason for HIV-positive women's intermittent group participation (as is stated in the second hypothesis). The trend is encouraging because it could mean that the health status of the mothers has improved to such an extent that they can re-enter the job market thus creating positive effect for themselves, their children and their families. It could, however, also reflect the economic pressures on the mothers to take care of their families through securing an income because of the lack of other options for financial support. The success of ARV treatment could also be a factor in the mothers seeking employment as they participate in the *Kgolo Mmogo* project soon after diagnosis, which coincides with the introduction of the ARV treatment. When some of the mothers leave the group for employment reasons, their health may have *improved* to the point where they can contribute again in the job market.

There may therefore be multiple causal links for this phenomenon. Final conclusions and correlations will be drawn only at the end of the study when the longitudinal database is completed. For now, however, this trend may mean that the intervention design for mothers affected by HIV&AIDS should take into account the fact that mothers are re-entering employment and are then unable to participate in prolonged group support.

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