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Development and formative evaluation of a family-centred adolescent HIV prevention programme in South Africa

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ABSTRACT

Preventing HIV among young people is critical to achieving and sustaining global epidemic control. Evidence from Western settings suggests that family-centred prevention interventions may be associated with greater reductions in risk behaviour than standard adolescent-only models. Despite this, family-centred models for adolescent HIV prevention are nearly non-existent in South Africa – home to more people living with HIV than any other country. This paper describes the development and formative evaluation of one such intervention: an evidence-informed, locally relevant, adolescent prevention intervention engaging caregivers as co-participants. The programme, originally consisting of 19 sessions for caregivers and 14 for adolescents, was piloted with 12 groups of caregiver-adolescent dyads by community-based organizations (CBOs) in KwaZulu-Natal and Gauteng provinces. Literature and expert reviews were employed in the development process, and evaluation methods included analysis of attendance records, session-level fidelity checklists and facilitator feedback forms collected during the programme pilot. Facilitator focus group discussions and an implementer programme workshop were also held. Results highlighted the need to enhance training content related to cognitive behavioural theory and group management techniques, as well as increase the cultural relevance of activities in the curriculum. Participant attendance challenges were also identified, leading to a shortened and simplified session set. Findings overall were used to finalize materials and guidance for a revised 14-week group programme consisting of individual and joint sessions for adolescents and their caregivers, which may be implemented by community-based facilitators in other settings.

1. Introduction and background

Globally, young people aged 15 to 24 account for 40% of all new HIV infections each year, making effective prevention programming for adolescents a critical precursor to epidemic control (UNAIDS, 2012). More individuals are living with HIV in South Africa than any other country (UNAIDS, 2014), and for several years declining prevention knowledge has been coupled with increasing behavioural risk (Shisana et al., 2014). The country's latest National HIV Prevalence, Incidence and Behaviour Survey found that prevalence rises sharply in adolescence and peaks in young adulthood, especially for adolescent girls and young women (Shisana et al., 2014). Adolescent orphans and those affected by HIV face even higher risk than their same-age peers (Cluver, Orkin, Boyes, Gardner, & Meinck, 2011; Operario, Underhill, Chuong, & Cluver, 2011).

Overall, little is known about the effectiveness of family-centred interventions for adolescent HIV prevention in sub-Saharan Africa (Harrison, Newell, Imrie, & Hoddinott, 2010; Kuo et al., 2016). Although the label 'family-centered' may refer to a range of designs (Pentecost, Ross, & Macnab, 2018), we use it here to mean the inclusion of at least one primary caregiver in an intervention intended to effect adolescent behaviour change. Family-centred programmes, including those oriented to the caregiver-adolescent dyad, have been found to be more effective at reducing sexual risk behaviour among participating adolescents in the long term (Rotheram-Borus et al., 2003; Stanton et al., 2004). Despite this evidence, review of the literature suggests

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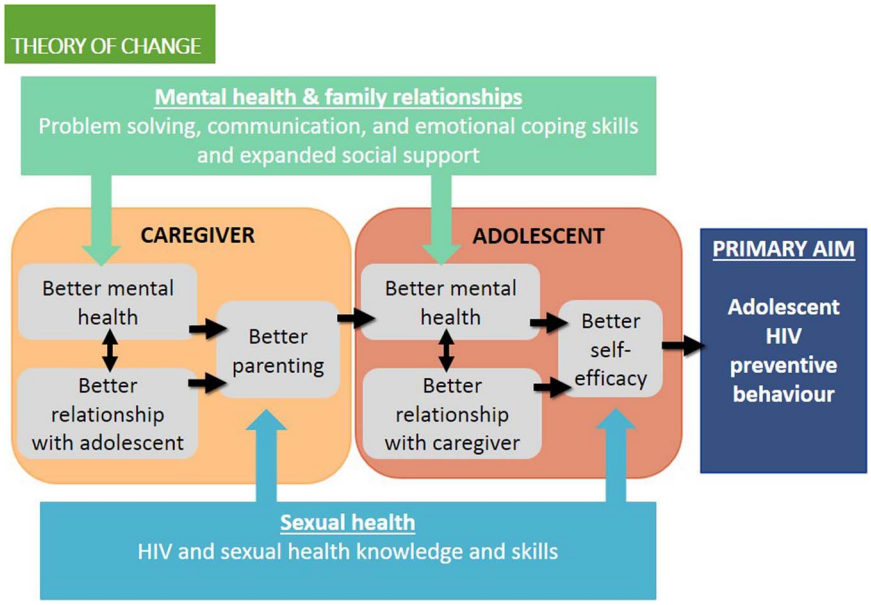

Fig. 1. Let's Talk Theory of Change.

that family-centred programmes focused on adolescent HIV prevention in sub-Saharan Africa are rare, and have targeted specialized sub-groups or limited participation to one member of the dyad. For example, two interventions with encouraging pilot trial findings from South Africa were tailored for either pre-adolescents or those living with HIV (Armistead et al., 2014; Bell et al., 2008; Bhana et al., 2014). Other models in the region engaged caregivers exclusively (Bogart et al., 2013; Poulsen et al., 2010; Vandenhoudt et al., 2010).

In light of these limitations, we sought to develop a curriculum-based, family-centred adolescent HIV prevention programme for use in South Africa with vulnerable adolescents and their caregivers. Extensive multi-stage formative evaluation work was embedded in the process. Following background research and expert reviews during the initial development phase, the formative study aimed to capture implementers' and beneficiaries' first experiences with the programme through qualitative interviews and a focused analysis of programme monitoring data reflecting training feedback, participant attendance, and implementation fidelity at the session and activity level. Formative evaluations are increasingly utilized as standalone research efforts or to complement outcome evaluations, and are particularly useful when piloting or adapting interventions for new settings as was done in this case (Lau, 2006). Investment in formative research also allows for greater understanding of how complex programmes function, and provides results that may be used to improve interventions (Oakley, Strange, Bonell, Allen, & Stephenson, 2006). This paper describes the results of this integrated development and assessment effort as well as subsequent revisions to the intervention, called Let's Talk[1] (referred to locally as *Masikhulume* in isiZulu and *Hare Buwe* in Sesotho).

2. Programme planning and development

A literature search was first undertaken to explore the relative significance of multi-level factors influencing risk behaviour among adolescents in low-resource, HIV-affected communities. Notable considerations included higher rates of family dysfunction and mental health problems reported among orphans and other children affected by HIV (Cluver, Gardner, & Operario, 2007; Sherr, Croome, Parra Castaneda, & Bradshaw, 2014; Thurman, Kidman, Nice, & Ikamari, 2015). Ample research supports the existence of a relationship between adolescents' sexual and reproductive health outcomes and the quality of their relationships with primary caregivers (Cluver, Orkin, Boyes, & Sherr, 2014; Markham et al., 2010). The mental health of caregivers affects this relationship (Allen et al., 2013; Lachman, Cluver, Boyes, Kuo, & Casale, 2013) and has also been linked to adolescent sexual risk behaviour (Meinck et al., 2017; Mellins et al., 2009). Associations between poor mental health and high risk sexual behaviour among youth have also been reported (Nduna, Jewkes, Dunkle, Shai, & Colman, 2010). These findings highlight the promise of programming that goes beyond offering standard HIV prevention education and behavioural skills promotion to address participants' mental health and family relationships.

Programme development was based on three theoretical frameworks. Eco-developmental theory recognizes family dynamics as pivotal to adolescent outcomes (Szapocznik & Coatsworth, 1999) and is increasingly used to guide adolescent HIV prevention and care (Ortega, Huang, & Prado, 2012; Perrino, Gonzalez-Soldevilla, Pantin, & Szapocznik, 2000; Prado et al., 2010). Cognitive behavioural theory (CBT) posits that thoughts, emotions and behaviours are linked and that modifying one can affect the others in predictable ways. The evidence base for CBT is robust, and several recent reviews support its efficacy for treating psychological problems, including depression and anxiety, in adults and children generally as well as HIV-affected subgroups (Butler, Chapman, Forman, & Beck, 2006; Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012; Sherr, Clucas, Harding, Sibley, & Catalan, 2011). Lastly, Bandura's social learning theory upholds that learning occurs in a social context – such as a support group setting – through direct experience, observation, modelling and imitation (Bandura, 1977).

A multi-level theory of change for the programme was established (Fig. 1), suggesting that better mental health among both caregivers and adolescents would improve their relationship, contributing to more positive parenting and adolescent self-efficacy. Thus, the programme was intended to help participants build emotional coping, communication, and problem solving skills with a focus on resolving issues that commonly arise in family life. The group also provides a forum for participants to develop social and emotional support and expand their peer network. The development of key competencies to prevent HIV and promote sexual health is fundamental to the programme. To build

[1] The authors wish to acknowledge another programme in South Africa called *Let's Talk!* which similarly focuses on improving parenting practices to prevent children from acquiring HIV. That programme focuses exclusively on parents and there is no affiliation with the current programme under study. Further details on that programme are available elsewhere (Bogart et al., 2013).