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Adapting and disseminating a community-collaborative, evidence-based HIV/AIDS prevention programme: Lessons from the history of CHAMP

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Abstract

In recent years, calls for the scaling-up, or more broad dissemination of evidence-based HIV prevention programmes, have increased. This paper responds to the call for increasing applicable knowledge about programme dissemination by reviewing the history of a major evidence-based human immunodeficiency virus (HIV) prevention and mental health promotion programme that has been adapted successfully and pilot-tested across four settings – including two major cities, as well as in the United States, Trinidad and Tobago and South Africa – to date. This programme, entitled CHAMP (the Collaborative HIV Prevention & Adolescent Mental Health Project), is distinctive primarily for its emphasis on community collaboration and power-sharing, and also its incorporation of individual, family and community-level interventions. The history of programme development, including theoretical foundations and results across sites, is discussed with a particular emphasis on the implications of CHAMP'S dissemination thus far.

Keywords

HIV prevention programme; dissemination; family-focused HIV prevention; community collaboration; CHAMP

Introduction

In response to the fact that the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) pandemic has outpaced expanded efforts to contain it, calls for more broad dissemination of evidence-based HIV prevention programmes have increased over recent years (Fisher, 2007; Joint UN Advocacy Programme on Girls, Young Women and HIV and AIDS, 2006; Steinbrook, 2006; UNAIDS, 2005, 2006, 2007). This paper responds to this call by reviewing the history of a major evidence-based HIV prevention and mental health promotion programme that has been adapted successfully and pilot-tested across four settings.

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This programme, entitled 'CHAMP' (the Collaborative HIV Prevention & Adolescent Mental Health Project), in its American and Caribbean contexts, and the AmaQhawe programme in its South African setting, is relevant to discussions concerned with dissemination for its emphasis on community collaboration and power-sharing, and also for its inclusion of individual, family and community-level factors in its interventions. Following a brief discussion of the theoretical foundations of the CHAMP approach to HIV prevention, the processes of programme translation, adaptation and evaluation in two international contexts are considered.

The historical context of HIV prevention programme development in the early 1990s

The CHAMP family programme was developed in 1994 to meet the specific HIV prevention and mental health needs of increasingly at-risk urban youth of colour. The programme's aims were shaped by (1) shifting demographics of the HIV/AIDS epidemic in the United States; and (2) shifts in the theoretical landscape of developmental psychology. After the mid-1990s, Latinos and African Americans – and women and youth in particular – were facing increasing and disproportionate HIV risk through heterosexual contact. This is explained primarily by the overrepresentation of Latinos and African Americans in low-income urban neighbourhoods, where they face increasingly adverse odds for contracting HIV due to higher overall rates of neighbourhood prevalence coupled with poorer access to preventive health care, early detection and treatment services (Rotheram-Borus, Mahler & Rosario 1995; Zierler, & Krieger, 1997).

Secondly, the salient changes that occurred in the field of adolescent developmental psychology that impacted the theoretical foundation of HIV prevention studies included: (1) increasing recognition that issues related to culture and context could play highly influential roles in defining youth development; (2) a resultant emphasis on contextually specific prevention programmes that could be tested within specific subpopulations in the United States (McLloyd, 1990; Spencer, & Dornbusch, 1990); (3) the emergence of theoretical models that focused the HIV prevention field on risk and protective factors for specific subgroups (Cicchetti & Garmezy, 1993; Garmezy, 1993a,b; Masten, & Curtis, 2000; Masten, & Powell, 2003); (4) the emergence of the field of developmental psychopathology, which introduced the concept that developmental adaptation to context is best explained as a continuum (Sroufe, & Rutter, 1984); and finally (5) the notion that development continued beyond childhood into adolescence in distinct ways (Hill 1987; Steinberg, 1987). In light of such transformed ideas about the nature of youth development, prevention science became an increasingly popular field of study (Tolan, 2001; Tolan, & Gorman-Smith, 2002; Tolan, Gorman-Smith, & Loeber, 2000).

It was against this transformed backdrop of developmental psychology that CHAMP investigators began to think about what kind of programme could best meet the needs of poverty-impacted, urban youth of colour. Available prevention science literature underscored the obstacles that could be posed by insufficient school-based resources, lack of community participation and tensions between community residents and outside researchers, when university-led research teams attempted to study prevention in poverty-impacted urban neighbourhoods (Dalton, 1989; Thomas, & Quinn, 1991). This literature warned that prevention programmes that failed to appreciate local and culturally specific stressors or the target group's core values would most probably fail to achieve their long-term objectives, including HIV prevention (Boyd-Franklin, 1993).

In response to these obstacles and new ideas, CHAMP investigators drew on the Triadic Theory of Influence, which suggested that risk operates on three levels, including the intrapersonal the social normative and the sociocultural (Flay & Petraitis, 1994). CHAMP investigators also

adopted an ecological perspective, which viewed individual skills, family-level processes and community resources as necessary ingredients for successful HIV prevention efforts (Aponte, Zarski, Bixenstene, & Cibik, 1991, Boyd-Franklin, 1993, Fullilove, & Fullilove, 1993). CHAMP therefore aimed to confront risk by including intervention components aimed at multiple levels, including the individual skills of youth and their parents, family processes, and community resources by supporting and enhancing family processes and encouraging protective relationships between youth and their adult caregivers, as well as to impart information to the entire family about puberty, sexuality and HIV prevention. Finally, CHAMP also sought to create an opportunity for peers to come together in a multiple family group structure and, in so doing, to provide culturally acceptable community-level resources for one another. This was all to be overseen, furthermore, by local stakeholders who would form the basis of a Community Collaborative Board, which would participate in, and share power over, the design, delivery and evaluation of the programme (see McKay, Paikoff, Bell, Madison, & Baptiste, 2000; Paikoff, McKay, & Bell, 1994; Paikoff, Traube, & McKay, 2007).

Additionally, an equally important tenet of the CHAMP studies has been to adapt all interventions to local contexts through the use of empirical findings from the target community. To meet this goal, CHAMP began with a series of focus groups that sought to identify pressing community and family needs, and to define acceptable research projects or service innovations.

Methods and results of the CHAMP family programmes I and II in Chicago, Illinois, USA

The first step in a series of studies that led to the development of the CHAMP family programme was a preliminary research study entitled 'CHAMP I: basic research on families, mental health, and HIV risk'. The goal of this study was to define key variables for HIV risk prevention programmes, and in particular HIV risk prevention programmes that aimed to serve children and families facing extremely adverse risk factors. Accordingly, 315 African American families with preadolescent children (in the 4th or 5th grades), were recruited through children's attendance at a school on or near a major public housing project on the South or West side of Chicago. The residents of these areas faced particularly adverse odds, as their neighbourhoods were affected disproportionately by HIV infection, poverty, joblessness, and other major health and social welfare concerns.

Members of the community joined with programme staff to conduct semi-structured interviews with youth and caregivers across three time-points; ages 10–12, 12–14 and 17–19 years (McBride, Paikoff, & Holmbeck, 2003; Paikoff, 1997; McKay, & Paikoff, 2007). Age-appropriate questions were posed to children at each data wave and videotaped interactions of family problem solving were coded for analysis. Data on the following domains were targeted: (1) family demographics (Parfenoff, Williams, McCormick, Greenwood, & Holmbeck, 1997); (2) family interactions (Paikoff et al., 1997); (3) parental control (Paikoff et al., 1997); (4) family support and teenage motherhood (Paikoff, 1997); (5) family communication (Parfenoff, & McCormick, 1997); (6) child friendship relationships (McCormick et al., 2000); and (7) child individual processes (Donahue, Parfenoff, & Holmbeck, 1998; Sagrestano, McCormick, Paikoff, & Holmbeck, 1999).

Analysis of data obtained through this study revealed a number of important findings. Most significantly, a study that considered youth sexual debut and links to individual and family factors found that girls were more likely to delay sexual debut past early adolescence, and that family conflict and less positive affect were associated with earlier sexual debut (McBride et al., 2003). A second study examining adolescent depression and family factors found that increases in conflict and decreases in parental monitoring were associated with increases in child depressive symptomatology; increases in conflict and decreases in positive parenting

were found to be associated with increases in parental depressive symptomatology (Sagrestano, Paikoff, Holmbeck, & Fendrich, 2003; for details on other related studies see DeLucia, Paikoff, & Holmbeck, 2007; Tolou-Shams et al., 2007).

In the second phase of CHAMP-related research, investigators pilot-tested 'CHAMP II: family-based intervention to prevent adolescent HIV risk'. In this longitudinal experimental study, 491 early adolescents and their caregivers were recruited from four elementary schools on the South Side of Chicago. Youth and their families were assigned randomly to either the CHAMP family programme or a longitudinal interview condition during the autumn of the youths' 4th or 5th grade year. The randomized sample received their first intervention when the youth were in the 4th or 5th grades, and again 2 years later (at the 6th or 7th grade level).

To date, proximal and distal outcomes have been, and continue to be examined (see Paikoff et al., 2007, for more details). Data from CHAMP II have formed the basis an examination of the impact of intensive community-collaborative outreach strategies focused on parent involvement in recruitment and participation enhancement (McCormick, 2000; McKay et al., 2004). At the proximal level, the CHAMP family programme has been associated positively with multiple improvements in variables related to family functioning and the precursors to sexual risk-taking in youth, including family decision-making and communication, as well as the time youth spend in situations of sexual possibility (McBride et al., 2007; McKay et al., 2004).

The community-collaborative translation of CHAMP II to families across sites

In addition to the roll-out of CHAMP II in Chicago, CHAMP collaborators received funding to develop a programme to enhance the research capacity of community partners and to develop and test a model for the dissemination of CHAMP's community-based model in New York City, the second epicentre of the HIV virus in the United States at the time. In both sites, programme design, adaptation to local concern, delivery, effect and transfer of ownership have been under constant consideration.

The CHAMP Collaborative Board from Chicago was instrumental in establishing a second community board in the Bronx, New York, with Chicago board members advising on hiring and training decisions, while remaining open and interested in the ways in which a new Board in a new site would need to adapt current procedures. Replicating the Collaborative Board structure across sites provided an opportunity to examine the ways in which the tension between replicating a protocol-driven model and maintaining an emphasis on local needs, preferences and obstacles could be managed. At present, data comparing investigations of local needs in these different regional contexts have revealed significant differences between Chicago and New York in terms of parenting hassles, parental mental health and number of children in the home. These specific issues have been incorporated into the CHAMP–New York programme curricula and planning by members of she Collaborative Board.

CHAMP's collaborative projects in South Africa and Trinidad

With the CHAMP family programme established in the two epicentres of HIV/AIDS in the United States, the CHAMP Boards and investigators were encouraged to translate CHAMP's collaborative methods to the cultural contexts of other underserved areas (Bell, Bhana, McKay, & Petersen, 2007). In 2002, CHAMP investigators and members of both collaborative boards decided to embark on the adaptation of CHAMP to local contexts in South Africa and Trinidad and Tobago.

Processes of dissemination of the core CHAMP model in Trinidad and Tobago and South Africa have been marked by several major similarities and differences that are worth

highlighting in light of the need for increased dissemination. One major difference is that in Trinidad and Tobago, CHAMP investigators from the United States did not partner with a local university, but rather partnered with a direct, service agency, the Family Planning of Trinidad and Tobago (FPATT). First, in Trinidad, FPATT is a widely recognized, nongovernmental organization with a 50-year history of service to the local, community. After federal funding to adapt and pilot-test a CHAMP–Trinidad programme had been procured, FPATT oversaw the creation of a 15-member Community Board comprised of stakeholders, including primarily adults with experience in HIV/AIDS prevention or youth-focused work on the island. Together, the Board, FPATT staff and CHAMP–US investigators pursued three phases of adaptation, including a pre-implementation, implementation and evolution and maintenance phase (based on the work of Kraft, Mezoff, Sogolow, Neumann, & Thomas, 2000). In the first phase, investigators worked with FPATT staff and the Community Board to establish the salience of various components of the CHAMP family programme for island youth.

Secondly, in the implementation phase of programme translation, the Community Board and FPATT staff worked with investigators to tailor the curriculum to local values and needs identified in phase 1. They then delivered a pilot programme to 20 families. In the final phase of this project, preliminary results of the programme were assessed and further refinement and issues concerning future implementation on a larger scale were discussed (Voisin, Baptiste, Martinez, & Henderson, 2006).

Four major obstacles and tensions arose in CHAMP Trinidad and Tobago. These issues centred on anxiety over trust and power-sharing in a postcolonial context and balancing science and service goals. First, people in Trinidad and Tobago, felt generally suspicious of foreigners – particularly Americans – whom many Trinidadians associate with the negative impact of some tourism and media (Jack, 2001; Voisin et. al., 2006). Investigators met this challenge to trustbuilding by (1) welcoming local scrutiny of their motives and ideas, including potential tokenism: and (2) hiring a neutral 'cultural translator' (as suggested by Porkomy, Baptiste, Tolan, Hirsch, & Talbort, 2004), who was familiar with cultural norms present in American and Trinidadian societies, and who mediated aspects of the working alliance. Secondly, through their experiences adapting CHAMP to the Trinidadian context, CHAMP-US investigators learned that although power-sharing is ideal, in a situation where federal funds from a more powerful state are mobilized to test a model of care for which US-based investigators must assume final responsibility for fiscal management and institutional review, power is not shared completely. With this in mind, investigators navigated obstacles related to power-sharing concerns by acknowledging the complexity of these issues through transparent communication, remaining very clear about the institutional guidelines and expectations that they faced, and being more flexible in other areas where they were not constrained by external guidelines.

Thirdly, investigators found that the competing missions of a direct service agency, community members and researchers was a serious challenge, Local stakeholders had difficulty understanding the value of allocating funds for methodical 'study', when more funds allocated to service provision could help more people. Investigators explained how funding mechanisms work in the United States and the long-term benefits of evidence-based programming, yet explanation was no immediate salve. In this regard, a crucial lesson learned from the implementation of CHAMP–Trinidad includes the need to allow for extra time for local deliberation, particularly with regard to issues of research, human subject protection and local ethical review (Voisin et al., 2006).

Finally, although preliminary results of the pilot study are limited by the CHAMP–Trinidad and Tobago study's design and sample size (n = 20), results suggest that parents and youth reported significantly increased: (1) HIV/AIDS knowledge; (2) parent/child discussions of sensitive topics, and (3) increased readiness to procure condoms and to properly use a condom

among the predominantly female sample. A more sophisticated research study is now under way (n = 250).

The South African translation of CHAMP proceeded in a slightly different way. In South Africa, CHAMP–US investigators partnered with colleagues who were based in local university contexts, as opposed to direct service settings. In this context, investigators faced the need to develop a theoretical context for the adaptation of CHAMP, but faced fewer organizational constraints related to research. Instead, based on the theories underpinning the Theory of Triadic Influence – a theory that was easily recognizable and endorsable by transnational funders in the United States – the investigators focused on three universal theoretical principles to guide preliminary investigations of a future CHAMP–South Africa, including: (1) the importance of social capital in facilitating health and health-enhancing behaviour change; (2) the need to build health-enhancing peer social networks among child and youth participants in HIV prevention programmes; and (3) the need to strengthen families as protective factors by strengthening parental supervision and monitoring skills.

These theoretical principles were then translated into guiding principles of a pilot programme called AmaQhawe (CHAMP–South Africa). The first guiding principle emphasized in CHAMP–South Africa is 'rebuilding the village', or building social capital within communities. The second is 'improving bonding, attachment and connectedness dynamics', which includes a focus on health-enhancing negotiation of sexual behaviour and networks. The third is 're-establishing the adult protective shield', or strengthening families by strengthening caregivers and familial relationships in the face of hardship, (see Bell et al., 2007, for further details).

With inspiring results from a National Institutes of Mental Health (NIMH)-fiinded R-01 preliminary investigation in South Africa, the transnational team of investigators layered these guiding principles described above atop the community-collaborative programme development and implementation model that had already been developed in substantially two US contexts. A Community Collaborative Board of influential community leaders, community health workers, teachers and caregivers has been established in Kwa-Zulu Natal to found the 'AmaQhawe Project', or 'CHAMP–South Africa' (CHAMP–SA).

Currently, two versions of a CHAMP–South Africa manual have been developed and are being tested. At the suggestion of the AmaQhawe Family Project Board, an innovative project manual has been developed and pilot-tested twice, using an open-ended cartoon narrative, in order to facilitate critical and dialogic participatory group learning (Campbell, & MacPhail, 2002; see Petersen, Mason, Bhana, Bell, & McKay, 2006, for further details). Results from, the pilot-test of the most recent manual are still under consideration. Pending results, the next item on the agenda of the AmaQhawe Family Project Boards is dissemination (see Bell etal., 2007).

Conclusion

With extremely encouraging results or preliminary results from across four sites, the history of CHAMP'S origin and evolution proves that: collaboration between university-based researchers and severely underserved community members is not merely possible, but that such collaboration works extremely well and can be disseminated across contexts, when careful attention is paid to power-sharing and contextual programme design and implementation, The transnational adaptation, implementation and testing of CHAMP in two postcolonial regions that have been severely impacted by HIV attests to the importance of CHAMP's record of power-sharing in the United States, as issues of trust-building, power-sharing and relying on local knowledge to adapt potentially controversial programmes to meet local needs and abide by local values is of paramount importance in transnational contexts. Secondly, the experience

of the AmaQhawe Family Project and CHAMP'S adaptation, in Trinidad and Tobago underscore the specific importance of investing in careful, collaborative research about the cultural context of disease, development and family functioning, as well as the cautious development of an intervention's message and materials to suit local needs and values, such as varying degrees of literacy, collective decision-making and different roles within extended families. This collective history emphasizes the degree to which collaboration across neighbourhood, national and cultural borders is our best collective defence against an epidemic that does not discriminate and whose cure, today, remains prevention.

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