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“They give us hope”: HIV-positive caregivers’ perspectives on the role of social support for health

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Abstract

A number of studies indicate that social support is associated with better health outcomes among HIV-positive caregivers of children, suggesting its potential importance for interventions aimed at safeguarding the wellbeing of this population. However, there is very little published literature assessing the support-health relationship or evaluating applied social support interventions with HIV-positive populations in HIV-endemic contexts of the developing world. The global literature on social support and health suggests that, in order to refine theory and improve interventions, greater attention should be paid to specific dimensions of support, such as types and sources, as well as the processes through which support may be affecting health outcomes. This article presents and discusses data from in-depth interviews with twelve HIV-positive primary caregivers of children living in an HIV-endemic, low-resourced, urban South African community. The primary aim of this qualitative work was to provide further insight into survey findings of a positive relationship between social support and self-reported general health and functioning, by exploring caregivers’ personal experiences of being supported within their community, and their perceptions on how this ‘informal’ support may be influencing their health. Our qualitative data highlight the importance of instrumental and emotional support for this population, the relevance of support provider characteristics and some of the processes or pathways that are likely explaining the support-health link. These processes include psychological factors such as mastery and hope, coping strategies and positive health behaviours. We provide recommendations for future research to further this work, and discuss implications for health interventions.

Published empirical work shows that social support is associated with better health outcomes among HIV-positive caregivers of children, and may be an important component of interventions aimed at safeguarding the wellbeing of this population (Casale & Wild, 2012). This is particularly relevant for public health in HIV-endemic communities in the developing world, given cumulative mental and physical health risks of living with HIV (World Health Organisation, 2005, 2008) and caring for multiple - biological and foster - children (Kuo & Operario, 2011; Musil, Warner, Zauszniewski, Wykle, & Standing, 2009). However, a recent literature review identified only fifteen existing studies assessing the relationship between social support and health among HIV-positive caregivers of children, of which only one was conducted outside of North America, and none in Africa (Casale & Wild, 2012). Similarly, studies evaluating applied social support interventions among HIV-positive caregivers are few and fairly recent, and derive mainly from the developed world;

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moreover, they have not shown conclusive results (Davies, Hortona, Williams, Martin, & Stewart, 2009; S. Mason & Vazquez, 2007; Mitrani, McCabe, Robinson, Weiss-Laxer, & Feaster, 2010). It is clear that there is much scope for research aimed at informing support interventions and policy in HIV-endemic contexts of Southern Africa and beyond.

The global literature suggests that in order to refine theory and develop effective support interventions, it is important to achieve a better understanding of the complex links between social support and health, and the specific dimensions and contexts of support (Uchino, 2006). This includes investigating the importance of different types and sources of support, as well as the biological, psychological and behavioural pathways or processes through which social support may be affecting health outcomes (see: House, Umberson, & Landis, 1988; Thoits, 2011; Uchino, Bowen, Carlisle, & Birmingham, 2012; these processes will be described in further detail in the results and discussion section below). Yet these nuances of the support-health relationship remain under-explored in the literature. Or rather, we know that social support ‘works’, but we don’t know enough about the nature of the mechanisms and factors involved in making it work (Sarason & Sarason, 2009). These arguments reinforce the potential contribution of mixed-methods and qualitative studies to this area.

The purpose of this article is to present and critically discuss findings on the perceived effects of social support on health, from in-depth qualitative interviews with twelve HIV-positive primary caregivers of children. Participants were caregivers eighteen years or older living in an HIV-endemic, low-resourced urban South African community, who had previously participated in a broader health survey with 2477 caregivers, of which 1198 were from this particular community. Quantitative survey results, documented elsewhere, highlight a statistically significant positive association between social support and self-reported general health and physical functioning among adult (18 years or older) HIV-positive and HIV-negative caregivers of children 10–17 years (Casale, Wild, Kuo, & Cluver, 2012, July-b)ⁱ. The qualitative work aimed to further explain this finding for HIV-positive caregivers, by exploring their experiences of different types and sources of support, and perceptions of how social support was affecting their health. This paper presents key findings from the qualitative data related to the respective themes of support types, processes and providers, and discusses their relevance for future research and intervention development.

Methodology

In-depth semi-structured interviews were conducted in November and December 2011, with 12 HIV-positive and 12 HIV-negative primary caregivers of children living in an HIV-endemic urban township, about 15 kilometres from the city of Durban in South Africa. Sampling for this study was purposive (J. Mason, 2002; Patton, 2002). Participants were selected based on socio-demographic and health information derived from the database of a previous (2009/2010) health survey with 1198 caregivers in this urban site. Written informed consent was obtained from all caregiver participants, after consent forms were read aloud in the participants’ mother tongue (isiZulu), and participants were given the opportunity to ask any clarification questions on the study or related ethics issues. This paper analyses only data collected from interviews with the twelve HIV-positive caregivers, given its specific interest in the role of social support for the health of this group of caregivers. HIV status was determined using an algorithm applied to the quantitative data set, taking into account self-report of HIV status and reported HIV-related symptoms

ⁱPositive significant associations were found between higher perceived functional social support (as measured using the Medical Outcomes Study Social Support Survey) and better self-reported general health and functioning (as measured by the average score for the 12-item Short Form Health Survey/ SF-12 subscales) for both HIV-positive and HIV-negative adult caregivers of children.

(Lopman et al., 2006)ⁱⁱ. Moreover, since women represent the large majority of caregivers in this community (89% of community survey participants were female (Casale, Wild, Kuo, & Cluver, 2012, July-a), they were also more strongly represented in our qualitative sample (8 participants were female and 4 male).

A topic guide was used to guide the interviews. Interviews were between one and two hours in duration and were carried out in the local language (isiZulu), transcribed, translated into English, and cross-checked for quality and consistency by a second bilingual translator. Thematic analysis of the data was conducted incorporating aspects of framework and inductive approaches (Corbin & Strauss, 1990; Miles & Huberman, 1984; Neuman, 2006; Ritchie & Spencer, 1994). Topic guide questions and an initial analytical framework were developed based on the research questions of interest described above - that is: which types, sources and pathways may be explaining the observed support-health relationship for these caregivers - and the key theoretical and empirical literature in this area (see for example: House, Umberson, et al., 1988; Lakey & Orehek, 2011; Thoits, 2011; Uchino, et al., 2012). The analytical framework was iteratively refined taking into account relevant and recurrent issues emerging from the text (Attride-Stirling, 2001). Dominant and less dominant themes, as well as areas of agreement and disagreement, were identified. Nvivo software was used to support the coding and management of the data. Ethics approval to conduct this research was received from both the University of Kwazulu-Natal and the University of Cape Town.

Results and discussion

a) Types of support important for the health of caregivers living with HIV

The main types of social support documented in the literature are emotional support (e.g. love, care and comfort), instrumental support (e.g. material items or other forms of practical assistance), informational support (e.g. advice) and appraisal support (e.g. constructive feedback) (Heaney & Israel, 1997). Consistent with survey findings, all respondents agreed that social support positively affected their mental and physical health; none of the respondents had experienced negative effects of support. Both male and female caregivers agreed that both instrumental help and emotional support were crucial in helping HIV-positive caregivers feel less anxious or depressed regarding their condition. Providing home-based care for a person with HIV-related illness was considered particularly important, especially during the advanced stage of the disease. However, respondents argued that the combination of these types of support was critical. For example, there was overall consensus that tangible help, even in the form of food or money, would have limited effects on the mental and physical health of HIV-positive individuals in the absence of emotional and appraisal support such as love, care, empathy and encouragement. As explained by a female caregiver:

If you give them [HIV-positive individuals] hope, you have done everything, hope for them means 'I will survive'. It is very important because I can give you money, you can do whatever but if you tell yourself that 'I will survive', you will survive ... because when you are taking that pill, you are taking it because 'I want to get well.'

ⁱⁱThe algorithm used to determine HIV-positive status in the quantitative survey was based on caregiver reports of an HIV-positive status and/or adherence to ARV treatment, as well as the presence of three or more HIV-related signs and symptoms deriving from a Verbal Autopsy questionnaire (VA). The VA was developed for use in areas with over 20% HIV-prevalence, and shown to have a sensitivity of 83% and specificity of 75% (Lopman, et al., 2006). This questionnaire was designed primarily to identify symptoms of HIV-related illness, in settings where data on cause of death or illness is unavailable or unreliable (Hosegood, Vannestea, & Timæus, 2004; Lopman, et al., 2006).

b) Ways in which social support is influencing the health of caregivers living with HIV

Theory and empirical evidence suggest that social support may impact health outcomes through various, potentially co-existing, pathways and processes. These processes may be biological, psychological and behavioural processes that include promoting self-esteem, encouraging positive health behaviours, and increasing access to resources that help cope with stress (Heaney & Israel, 1997; House, Landis, & Umberson, 1988; Lakey & Cohen, 2000; Thoits, 1982). Findings from our data, summarised below, suggest that certain psychological variables and coping processes were key to explaining positive effects of social support on mental health for male and female HIV-positive caregivers. In turn, better mental health, as well as positive effects of support on health access and behaviours, were perceived to positively affect physical health.

Influence of support on mental health through psychosocial variables

Social support was reported to increase the psychosocial wellbeing of HIV-positive caregivers. The most dominant theme was ‘hope’. Respondents argued that it was crucial to instil among HIV-positive caregivers the hope of survival, of living a relatively normal life and of belief in a ‘better future’. As one female caregiver explained:

To give advice to someone who is HIV [positive], that being HIV [positive] is not the end of the world, things like that. That has a good impact on the infected person... They feel less anxious and have hope when they get the support.

Another female caregiver told of how an HIV support group she was attending helped her feel less anxious, by providing her and the other group members with hope and advice on how to deal with HIV-related stigma:

They give us hope, love and there is a lot that they provide us with ... they advise us to tell our family members that because we are HIV positive it doesn't mean that we are going to infect them with the virus... The support group is the platform where you let out all that makes you sad.

It was suggested this support could change the way the caregiver saw his/herself, thus positively affecting self-esteem and creating a sense of belonging to the community. Or as articulated by one male caregiver, it could serve “to be able to see yourself exactly like other people who are HIV negative”. A further theme raised was that of support leading to respondents feeling more courageous or in control when confronting illness or other stressors. For example, one female caregiver explained that speaking about her problems helped her feel braver and less anxious:

It [support received] does have an effect [on anxiety] as it gives me courage because it is when I have shared what has been worrying me.

Influence of support on mental health through coping processes—The data also suggest that social support could influence caregivers’ coping responses to stressors, in two ways: 1) by encouraging more active problem-solving coping, as a result of greater hope, self-esteem and self-efficacy and 2) by reducing the likelihood of ‘rumination’ as a form of negative avoidance coping, that is helping HIV-positive individuals avoid repetitively thinking about causes and consequences of their illness and imminent death (Smith & Alloy, 2009). This second theme (rumination) was taken up only by female caregivers. These coping responses are illustrated by the following two excerpts:

It [support] makes me feel good about myself and to have more confidence you know, not to run away from the problems but to solve them and continue with life.
(female caregiver)

By attending support groups, one gets to feel relieved even mentally avoiding thoughts of imminent death... By attending these support groups you learn that you are not alone facing this epidemic. (female caregiver)

Influence of social support on physical health—Both male and female caregivers perceived social support to positively influence physical health, through both better mental health, and better health behaviours and access to health resources. First, mental and physical health were clearly considered to be closely related. Various caregivers spoke about feeling ‘emotionally free’ - suggesting an absence of emotional burden - in relation to better physical wellbeing. This interconnection was further highlighted by using terms usually associated with mental health to describe physical health or vice versa, e.g. feeling ‘physically relieved’. A better emotional or psychological state was also associated with the absence or attenuation of conditions such as loss of appetite, high blood pressure, fatigue, headaches and a lower pain tolerance. This is illustrated by these two caregivers’ responses, when asked how they feel after receiving support:

I feel better because I don’t eat when I’m depressed. But my appetite comes back when they encourage and advise me. So my life gets affected, and I get better. (male caregiver)

I feel better, I don’t feel the pain. Sometimes I really feel sick but I feel better after speaking with them [church members] I feel better and tell myself that I’m going to get help. (female caregiver)

Second, the majority of respondents also spoke of how support led them to adopt healthier behaviours. This support mainly took the form of advice or encouragement of people close to them, but in some cases included tangible assistance, such as buying or cooking healthy foods, providing transport to a health facility or fetching medication. Excerpts below provide examples:

... sometime when I would be alone at home smoking and say maybe after two hours my wife arrives, and she will tell me that I was smoking and then I realized that what I was doing was wrong. (male caregiver)

When it is my due date to fetch my medication she [my daughter] ... will wake up early in the morning to go pick up my medication. (female caregiver).

c)The role of support providers for health

It has been argued that relationships with specific support providers may be key to explaining the role of social support as a general resource for health, since people regulate their affect, thought and action through regular ordinary conversations and shared activities with specific providers in both stressful and non-stressful situations (Lakey & Orehek, 2011). Sources of support reported by respondents in this study included significant others and family members, such as sisters and children, but also friends and neighbours, church members and support groups. The significance of specific support provider characteristics was a theme that emerged inductively during interviews with both male and female caregivers. There were various references to the importance of providers who were close to or trusted by the support recipient; for example one female caregiver spoke of her very special connection with a neighbour who provided her with both instrumental help and companionship, and helped her deal with depression. Respondents believed that social support could be especially beneficial for health if provided by individuals with particular experiences or characteristics of relevance to the stressors faced by the recipient. For example, advice and encouragement could be especially effective in preventing depression or anxiety among HIV-positive individuals, if received from an individual (home-based

carer or other) who had experienced the illness themselves and succeeded in regaining health, and/or someone who was empathetic and supportive towards people with the disease:

When someone advises you with something that she/he experienced, and you see that she/he is doing well... you will also have hope that you will also get past that situation that you are facing right now... (female caregiver).

Conclusion

The qualitative data discussed in this paper reinforce, and provide further insights on, evidence of a positive relationship between social support and health among HIV-positive individuals and, more specifically, caregivers of children in an HIV-endemic South African community. It highlights the importance of both instrumental and emotional support for this population, the relevance of support provider characteristics and some of the processes or pathways that are likely explaining the support-health link. We believe this exploratory work makes a valuable contribution to the field of social relations and health. However, its main limitation, as for most in-depth qualitative research with small samples is that the sample population cannot be considered representative of caregivers in this or other similar communities, and findings therefore have limited generalizability. Our findings do, however, point to areas of research which should be the focus of further larger-scale investigation. Below we discuss the implications of each of our three key findings for both research and policy.

First, with regard to types of support, findings suggest that health interventions working with HIV-positive caregivers should seek to combine both emotional and tangible support, for example: home-based care initiatives that provide advice, encouragement and comfort as well as practical assistance with health care, transport to health facilities and caregiving tasks (Davies, et al., 2009). The relative importance of types of support provided should also be taken into consideration when assessing effects of social support networks and interventions on the health of HIV-positive caregivers.

Second, our data on processes explaining support-health links is, to a large extent, consistent with findings of previous (mainly North American) quantitative studies with HIV-positive individuals, showing mediating variables such as: active coping and less avoidance coping (Schmitz & Crystal, 2000); psychological factors such as self-esteem, mastery and hope (Simoni, Montoya, Huang, & Goodry, 2005; Yadav, 2010); mental-physical health links (Jia et al., 2004); and positive effects of health behaviours, such as antiretroviral treatment adherence (Burgoyne, 2005), on physical health. However, our findings add further depth to this work for this specific population of HIV-positive caregivers. For example, they highlight the effects of support on preventing ruminative thinking as a type of avoidance coping, specifically for female caregivers. They also reinforce the existence of multiple 'levels' of mediating variables, such as support effects on psychosocial variables that may influence coping and in turn health outcomes. These biopsychosocial processes, described in the literature (House, Umberson, et al., 1988; also see the diagramme on page 303 of the same article) and emerging from this analysis, would be best investigated through focused social support survey tools, and quantitative pathway analysis. Our data and these previous study findings also suggest that, besides encouraging practical health behaviour and facilitating access to health resources, it would be useful for health interventions working with HIV-positive caregivers to focus on strengthening resourcefulness factors, such as hope, self-esteem and self-efficacy, and more beneficial coping responses. Specifically, caregivers should be protected from social isolation to avoid potential adverse mental health effects of ruminative thinking around their illness and imminent death.

Third, our findings suggest that support interventions should pay particular attention to the qualities of support providers and caregivers' relationship to these providers. Home-based carers or other support providers recruited by health programmes should be individuals with characteristics that allow them to relate to the caregivers' situations and provide empathy without stigmatising. Interventions aiming to strengthen existing 'informal' networks, and/or improve caregivers' interaction with family and friends, may be useful, but are resource-intensive (Mitrani, et al., 2010) and probably not a feasible or appropriate option in many low-resourced settings. Broader access to support groups, e.g. through clinics, may also result in positive health effects, as these groups were highlighted as important sources of instrumental, informational and emotional support, by both our study participants and HIV-positive parents participating in pilot intervention studies in the U.S. (Davies, et al., 2009; S. Mason & Vazquez, 2007). These intervention studies also highlight the benefits of psycho-educational support groups that combine self-care and caregiving information/education with longer-term informal interaction between individuals with similar stressors. In line with our data, they show the importance of confidentiality, trust and, more generally, a safe space where participants are understood and not stigmatised (Davies, et al., 2009; S. Mason & Vazquez, 2007). Our findings highlight the importance of research affording greater attention to the role of specific social support providers in explaining effects of support on health among caregiver and HIV-positive populations, (Lakey & Orehek, 2011), and the influence of provider characteristics on the effectiveness of support interventions.

It should be noted that, while support types, providers and processes are three distinct dimensions of support, it is important to achieve a better understanding of their linkages in relation to health among specific populations; for example, to determine whether the types of support most important for health derive from specific providers and influence health through specific pathways.

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