PSYCHOSOCIAL SUPPORT
FOR
HIV/AIDS CAREGIVERS

for

AIDS RESPONSE

REVIEW

28 March 2008
Overview

1. Working definition of psychosocial support (PSS)
2. The rationale for PSS
3. The elements of PSS
4. Problems encountered in PPS
5. Best practice
6. Summary

Appendix: Resources

1. DEFINITION

The term psychosocial support\(^1\) is used to describe any type of local or outside support that aims to protect or promote psychosocial well-being.\(^2\)

The following table is based on the Regional Psychosocial Support Initiative (REPSSI) model that deconstructs the words in order to define the concept of psychosocial support.\(^3\) The domain or meaning of the words is provided, as well as the description and the possible programmatic application.

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<tr>
<th>Domain</th>
<th>Description</th>
<th>Possible programmatic application</th>
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| Psycho                        | Belonging, faith for the future When an organization or community group provides, organizes, or stimulates some form of counselling and support that creates a platform that makes it possible for a person to process feelings, share experiences, etc. | • Mentoring, supervision, group processes, and group counselling  
• Debriefing in experiential learning  
• Home visits with quality time  
• Drop in centres |

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\(^1\) Agencies outside the health sector tend to speak of supporting psychosocial well-being. People working in the health sector tend to speak of mental health, but historically have also used the terms psychosocial rehabilitation and psychosocial treatment to describe non-biological interventions for people with mental disorders. Exact definitions of these terms vary between and within aid organisations, disciplines and countries.


In terms of HIV/AIDS, PSS looks at the ongoing psychological and social problems of HIV infected individuals, their partners, families and caregivers, and ways in which to promote their psychosocial well-being. As HIV infection affects all dimensions of a person's life - physical, psychological, social and spiritual - PSS can assist people and their carers to cope more effectively with each stage of the infection and enhance their quality of life. Research shows that it is important not only to focus on the effects of HIV/AIDS on clients and their families, but the significant effects on the carer.4

2. RATIONALE

The rationale for PSS comes from international and regional guidelines that have identified the psychosocial effects of HIV/AIDS. In 2004, the International Federation of the Red Cross coordinated what became known as the Code of Good Practice for NGOs Responding to HIV/AIDS. One of its goals is the “provision of economic, material and psychosocial support and development of life skills of children, parents and carers” (See Treatment, care and support in section 4.2).5 According to the World Health Organisation (WHO), “The provision of psychosocial support is an important part of care at both [the] institutional and community level.”6

Experience from organisations shows that carers exposed to HIV/AIDS can themselves enter a state of crisis as a result of their work.7 It was also found that management often does not recognise this fact and thus fails to provide adequate support to carers. The nature of HIV/AIDS work is such that carers are exposed to high levels of personal demands, and they find themselves in challenging situations. This results in personal and often debilitating stress for the carers.

The stress is caused by factors like:

- Repeated exposure to difficult circumstances
- Exposure to suffering and death
- Exposure to difficult emotions and personal stories

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• Long work days
• Continuance of care after work hours
• Lack of adequate resting time and sleep
• Facing moral and ethical dilemmas
• Exposure to helplessness, anger, and lack of gratitude
• Feelings of detachment from the carers support system at home
• Lack of organisational and emotional supervision
• Stigma and discrimination
• Poor working conditions
• Inadequate financial compensation
• Inadequate policies and implementation by management.

Effects of no PSS

Carers are often inadequately trained and prepared for the work that they do. Specifically, they are not adequately prepared for the emotional challenges and reactions that they will encounter. Without proper PSS, this stress will lead to burnout, reassignment to non HIV/AIDS work, illness, resignation, and high staff turnover.8

Not having PSS has significant negative effects on the:

• Carer
• Quality of care provided to clients and patients
• Clients
• Employing organisation
• Management of the epidemic.

3. ELEMENTS

The three examples below highlight different aspects of PSS element, namely: competencies, work plan, and process.

(1) PSS Competencies

Some of the key elements of PSS are:

• Active listening
• Bereavement and grief management
• Stress management
• Trauma processing and management
• Coping and resilience
• Life skills education
• Identity and goal setting
• Self-esteem and confidence development
• Cultural sensitivity
• Community empowerment
• Regular peer supervision
• Regular professional supervision
• Ongoing training and development
• Personal and organisational development

8 Stephen van Houten. 2005. Interviews with Nurses in the Western Cape.
- Spiritual support.

(2) Work Plan: How it is Done

**Developing guidelines and training for psychosocial care**

- Psychosocial support should be specifically included in national guidelines for the management of HIV/AIDS.
- Training on the provision of psychosocial support should be incorporated into the curriculum for all health care providers and carers.
- Guidelines for home care services can be developed and should include the provision of basic psychosocial care by community volunteers, family caregivers, and carers.
- Training courses for community volunteers can be organised and provided by health care workers.
- Strategies for providing psychosocial support can be developed for specific groups of carers (e.g. home-based carers, VCT counsellors, etc.).

**Developing services for HIV infected people, family members and carers**

- Assess what mental health and supportive services are available at both the governmental and non-governmental level that could be strengthened or replicated. Assess what additional services are needed.
- At the community level, groups can be started to provide for the needs of individual patients and affected family members. Psychosocial support services that address the specific needs of vulnerable groups can be especially important (e.g. women, children, etc.).
- A comprehensive support system linking and coordinating existing psychosocial services with each other and to health services needs to be established.
- At the hospital or clinic level, groups for health care workers in high HIV prevalence areas will be especially important for the support of nurses, physicians, and carers who may be seeing large numbers of HIV infected patients. Supervision of carers is key in assisting them to cope with issues related to HIV/AIDS.
- Peer groups (whether of carers working under stressful conditions, people living with HIV/AIDS, or family members of people with HIV/AIDS) can be a very effective way of providing psychosocial support.
- A comprehensive support system linking and coordinating existing psychosocial services with each other and to health services thus maximizing all resources needs to be set up.
- Building community capacities to provide counselling and support will ensure sustainability, continuity of interventions and community development.

(3) Process for Establishing PSS

1. Documentation and Dissemination

It is important to make practical information and existing materials on PSS available to HIV/AIDS carers. The goal of this is to improve the quality of care given to persons living with HIV/AIDS through effective PSS. Case studies from the field need to be continuously analysed for lessons learned. Training materials, as well as literature on intervention methods, assessment and evaluation, are to be made available. Material needs to be continually updated from external and internal resources. Updating this material should be included as a specific function in the

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key staff member’s job description. An external review of information and materials needs to be conducted annually.

2. Needs Assessment

Training organisations need to conduct needs assessments of PSS. Also, participating organisations should be required to conduct their own needs assessments – this is important because while there are generic criteria, each organisation operates in a unique context that needs to be taken into account when structuring PSS. Training, development, and supervision are key elements identified through such needs assessments. The mainstreaming of PSS in each organisation is a useful way of going about implementing and improving PSS. The role of management buy-in and ongoing commitment is crucial to the success of such initiatives.

3. Training, Development, and Supervision

Based on the needs assessment, ongoing training, development, and supervision are implemented. Because of the general lack of understanding in management of these interventions, external assistance is often required with the planning, implementation, and evaluation. In the Western Cape, the personal and organisational development of carers is generally poorly structured and implemented. Also, supervision is generally not conducted regularly enough; the supervision groups are too big; carers complain of not receiving enough time for cases and personal issues; and there is not enough importance placed on its value for the carer and the subsequent effect that this has on the clients with whom they work.

4. Evaluation

Regular monitoring and annual evaluation of PSS is crucial to quality management.

4. PROBLEMS ENCOUNTERED IN PSS

Lack of management/organisational buy in

This is a problem on an international and national level. PSS is usually not given adequate importance in business plans and strategic planning, and thus suffers from the lack of financial support and adequate human resources. This has resulted in management paying lip service to PSS and to poorly planned and inconsistent PSS to carers.

Lack of collaboration

There is very little data concerning collaborative initiatives between organisations. Collaboration is one way of pooling resources and cutting the costs of PSS. MSF has highlighted the need for further collaboration with other HIV/AIDS organisations working in the psychosocial domain.

Cost

Little is documented about the cost of providing PSS. Initial costs are basically the cost of training. Ongoing costs are generally not budgeted for, and thus elements like ongoing training and development, and professional supervision are not provided. If provided, for example supervision, it is done inconsistently with no reference to the maximum period between supervision sessions, the size of the supervision groups, and the process of supervision.

Selection
There is no data on basic selection criteria for carers, and no collaborative initiatives to develop such criteria.

**Findings from a Western Cape Study**

1. Caregivers are not receiving sufficient psycho-social support.
2. Demographic variables such as age, sex, health of PLHA, type of caregiver, monthly income, number of HIV-related deaths, and number of PLHA’s cared for did not affect a caregivers coping ability.
3. 41% of caregivers feel they are not currently coping with the stressors of care-giving and 88% are experiencing one or more symptoms of burnout (the most common being insomnia, with 48% of participants experiencing this symptom).
4. Care-giving has affected physical, mental and spiritual health of caregivers and many expressed that there had been significant decrease in their functioning as a result of their care-giving for PLHA’s.

**5. BEST PRACTICE**

The International Federation of the Red Cross and Red Crescent Movement have made important contributions to the issue of PSS. They have acknowledged the impact of HIV/AIDS work on carers, as well as the fact that an increasing number of carers might also be dealing with the increased stress of being HIV+. Finally they have stressed the important role that managers play in creating and maintaining a supportive work environment. Examples from their learning module are included below.

**Learning objectives**

At the end of this module, participants should be able to:

- Describe how reactions to stress may impact on carers
- Give details of warning signs of stress or burnout among carers
- Describe how to provide psychological support to carers

**Warning signs of burnout**

Burnout may occur after a prolonged period of time on a job. It implies that the stress factors have taken over, and that helpers are no longer able to distance themselves from the situation. Helpers can benefit from learning about burnout, so that they may recognize the signs in themselves as well as in others. Among the symptoms discussed, participants may have discovered the following:

- Wounded ideals
- Cynicism
- Feeling unappreciated or betrayed by the organization
- Loss of spirit
- Grandiose beliefs about own importance

**Burnout signs**

- Heroic but reckless behaviour

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Neglecting one’s own safety and physical needs (not needing breaks, sleep, etc.)
Mistrusting colleagues and supervisors
Antisocial behaviour
Excessive tiredness
Inability to concentrate
Symptoms of illness or disease
Sleep difficulties
Inefficiency
Excessive use of alcohol, tobacco or drugs.

In preparing for their tasks, helpers must gain a realistic expectation of what they can achieve through their work. They must understand that they cannot help being affected by the work and might need somebody afterwards reviewing what they have been through and assisting them in processing reactions. The helpers, the manager and the organization must all be aware of and respect limitations, both personal and practical. To avoid burning out valuable helpers, it is the responsibility of all concerned to treat each other with compassion and respect.

Caring for the psychological needs of helpers

The needs of helpers are quite similar to those directly affected. A supportive environment is one of the many crucial factors in minimizing stress. This can be achieved in the following ways:

- Guidance and support from managers and peers should be accessible on a daily basis or soon after the event
- An organizational culture of openly talking and sharing problems without fearing the consequences
- Regular and frequent meetings which bring all staff together and foster a feeling of belonging to a team
- Respect for the principle of confidentiality means that people can feel safe in admitting stress and seeking help
- The creation of a culture where getting together after a critical event is the norm, e.g. a peer support system.

Sharing experiences from work has a team building effect and helps to prevent psychological problems. Reactions that are not addressed and processed might lead to a crisis, whereas sharing these difficulties with others will reduce misunderstandings, distortions and incorrect interpretations. A supportive environment where it is not only allowed but also encouraged to talk about emotional reactions and limitations will both ensure the quality and effectiveness of activities and the well-being of helpers.

Supportive supervision

The traditional role of supervisors is to see that helpers perform with consistent and sufficient effort and to maintain the quality of that work within management standards. However, more recent models of supervision also place supervisors in the role of supporting the emotional and developmental needs of helpers. In other words, supervisors are now expected to nurture helpers as a human resource with limitations on how far those resources should be pushed or stretched. This is particularly important in the instance of psychological support programme helpers who may well need some psychological support themselves. Supervisors play an important role in this regard by providing helpers with someone they can call on for additional guidance or information to solve the problems of others, or more personally with problems they may be facing. In the Red Cross - Red Crescent context it is recognized that this model will mostly be applied in an informal fashion. One promising alternative, as detailed below, is the teaming of peers into supportive groups that pool their knowledge, perspectives, and experiences for the benefit of each other.

Peer group support

A group of peers can function not only as an informal support group of people who socialize both during and after work, but also in a formal framework by gathering periodically to discuss the work and problem solve together. In this way, the more common form of social support, provided by spending leisure time together or interacting cooperatively on the job, is supplemented with a formal tool for improving the skills and effectiveness of all concerned.

Suggested guidelines for formal peer support

- Meetings lasting about one hour should be held as frequently as possible (usually every week)
- All members should attend meetings whenever possible
- Each week a different member takes the role of peer facilitator
- The meeting should begin with the facilitator presenting the agenda, based on items previously requested by members
- Each item on the agenda is presented by the person who is requesting input
- Finally, the person who received the input gives each peer feedback on the effect or influence of their input
- In extreme circumstances, such meetings might be held daily.
- Attending this meeting should be as important as doing good work.
- All members should gain insight from being in this role.
• Members may add something to the agenda later if time allows.
• Each peer gives their input based on their own experiences.
• In this way peers are made aware of the person’s reaction to their input and communication flow is maintained in all directions. At times peers will want to discuss or debate each other’s input, which is only natural. This should not be done, however, until each peer has been given the chance to give their input without interruption and has received their feedback. Otherwise, the process will get side-tracked and never be completed.

6. SUMMARY

The following issues stem from this review of psychosocial support for HIV/AIDS carers:

• HIV/AIDS carers are exposed to emotional and other stress that impacts significantly on their well-being and the quality of their work.
• PSS programs for HIV/AIDS carers are essential
• Carers need support in the form of education, information, psychosocial support and counselling.
• Managers need to commit themselves and their organisation to proper selection, training, development and support of carers.
• PSS programs for HIV/AIDS carers are situated in the following wider context: human rights and equity, participation in decisions that affect their lives, not causing unintentional harm to clients, openness to evaluation, building on available resources and capacities, integrated support systems, and multilayered supports.
APPENDIX: RESOURCES

- International Federation of Red Cross and Red Crescent Societies. 2001. *Psychological support: Best practices from Red Cross and Red Crescent programmes*, IFRC.
- International Federation of Red Cross and Red Crescent Societies. 2001. *Guidelines for the implementation of a psychological support programme in emergencies*, IFR, International Federation of Red Cross and Red Crescent Societies.
- Regional Psychosocial Support Initiative (REPSSI). For Children Affected by HIV/AIDS. Noreen M Huni is the Executive Director of REPSSI and is based in Zimbabwe. See: [www.repssi.org](http://www.repssi.org), noreen@repssi.org