

**A HEALTH PROMOTING  
MUTUAL-AID GROUP  
FOR CARERS OF  
TERMINALLY-ILL PERSONS**

**BY**

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## DECLARATION

I, Rosemond Mbaliyezwe Dhlomo hereby declare that the work:

“Health promoting mutual aid group for carers of terminally ill persons” is my original work. Sources consulted or cited are acknowledged in the text as well as in the list of references.

SIGNED .....

DATE .....

## **Dedication**

This project is dedicated to all those involved in caring for the terminally ill persons.  
Your compassion has moved me.

“Never be weary of doing good because your labour in the Lord is not in-vain”

May God richly bless you and give you courage to continue caring.

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## ABSTRACT

Caring for an ill person, especially a terminally ill person can be a rewarding yet equally stressful experience. An organisation of carers (mutual-aid group) provides a support system responsive to the special problems of carers, including discussion groups, which are responsive to the inadequacies in the ongoing lives of carers, in promoting mental health. Mutual-aid groups fall within the social action model of community psychology, which aims to promote personal empowerment, defined as the process of gaining influence over events and outcomes of importance to an individual or group. This model is a shift in intervention from prevention to empowerment and from needs to rights. Mutual aid groups are built around such values as co-operation, shared experience, personal responsibility and mutual help in the achievement of a common end.

The present study was in line with the aims of health promotion at a tertiary level, which are to improve solutions for living and increase health, strength, skill and human rights for carers of the terminally ill, in very empowering contexts. The present research followed up on the recommendations by Dhlomo (2000) that more groups catering for the caretakers of people labeled as abnormal should be formed to promote health at a tertiary level. The aims of this thesis were to elicit needs from a group of carers of the terminally-ill, form and evaluate an ongoing mutual-aid group program and especially promote the variables of empowerment and carer effectiveness. It was hypothesised that this mutual-aid group program for carers of the terminally-ill persons would result in improvement of the above-mentioned variables.

Eleven carers committed themselves to be available for the mutual aid group. In line with the social action model, this was a participatory, action research, program-evaluation type of design, where co-researchers (carers) jointly defined the aims of their group, themes to be discussed and the meanings of such variables as empowerment and carer-effectiveness. Psychological techniques used in the present study included a biographical inventory, needs analysis questionnaire, power maps, carer effectiveness rating scale and program evaluation interview guide. The participants pre- and post- tested themselves on the variables of empowerment and carer-effectiveness. The group ran for a contracted period of six weeks and the

members met twice each week. The study realised its aims and research hypotheses. The research encouraged voluntary community participation. It operated on the principle of non-coerciveness, non-hierarchy, decentralisation, spontaneous leadership and it took into account members' psychological issues. From sessions themes which were presented and analysed, it was evident that the study yielded positive results. It led to participants feeling confident and effective in their role of caring. Participants were empowered in that they were involved in the designing of the program, leading sessions and gaining influence over events and outcomes of importance to them.

The mutual-aid group program empowered participants to be able to empower other carers, as most of the participants in the present research committed themselves to starting more groups of the same kind. In that way, they will be cascading the skills and knowledge they gained from the group.

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## 1.1 Introduction

Community psychology is generally considered to have had its origins in the Swampscott Conference in 1965 (Edwards, 1999; Mann, 1978; Duffy and Wong, 2000) and can be briefly defined as psychology of, with, by and for the people, beginning and ending in the community. Its main goals in South Africa are to optimize existing resources, resolve problems of *Apartheid years and facilitate community development through improving relationships within and between communities, especially in poverty-stricken, HIV/Aids infected/affected and violently traumatized regions like Zululand* (Edwards, 1998).

Edwards (1999b) proposed a holistic, integrative, community psychologically orientated model of health promotion based on the work of various researchers. The focus of this model is on building and optimizing identified health (salutogenesis), strengths (fortigenesis), competencies, skills, resources and supplies. Health can be promoted at three levels (primary, secondary and tertiary).

At the primary level, the concern is to promote and improve health (walk/run for life campaigns, life-skills training, etc.). The aim here is to improve solutions for living and increase the incidence of health in all persons in all contexts. At the secondary level the aim is to select interventions that will improve solutions for living and increase the

prevalence of health in empowering contexts. Interventions at this level will improve human rights, empowerment and advocacy for health promotion for all persons and communities, particularly in cases of disempowerment. At the tertiary level, the aim is to improve solutions for living and increase health, strength, skills and human rights for persons of much health potential in very empowering contexts. Interventions at this level include supporting the support persons involved in caring for others. Such interventions would improve meaning, self and social realization and actualization and other higher-level survival needs Maslow, 1971; Edwards, 1999b) among those in helping professions.

Persons needing support at the tertiary level, are carers of terminally-ill persons. Caring for a terminally-ill person can be a rewarding yet stressful experience. It is common for professionals in helping professions and relatives (and caretakers) involved in supporting the ill, to experience many emotions. This could include anticipated grief, anxiety, helplessness, anger etc. They may also suffer burnout, a syndrome of emotional exhaustion, *depersonalization and reduction in personal accomplishment* that can occur among individuals who work with people (Maslach, 1982). According to Maslach (1982), emotional exhaustion refers to feelings of being emotionally extended and depleted of emotional resources. She further defines *depersonalization* as negative, callous or excessively detached responses to people that one is working with. Reduced personal

accomplishment is defined as referring to a decline in feelings of competence and successful achievement in the work situation.

It is important to develop support systems to provide carers with an opportunity to discuss and handle these emotions as that would improve their roles in promoting the health of those they are taking care of. Their effectiveness as caregivers would improve, as well as their own quality of life. Methods for helping carers cope are organized around a theme of enhancing feelings of control and self-efficacy. Control over psychological problems may be maximized by empowering carers, providing education, improving decision making and assertiveness skills and by teaching specific techniques for stress management .

Mutual aid groups are in line with the values, goals and ideology of community psychology. They are sometimes called self-help groups. They have their roots in community rather than in the various professional disciplines. They are a component of the health care system, most likely to be identified with, and accessible to, the community being served by the system. Caplan (1974) pioneered the articulation of the concept of support system and captured many of their essential characteristics. He refers to them as “mutual help groups of ‘people on the same boat’”p.23. Schumaker and Brownell (1984) referred to them as “ready-made social support systems in specific domains of problem”. They are unlike support

systems such as family and friends because members of mutual aid groups relate as peers within the context of their group, each one acting as both provider and recipient of help, focused on their common problem or condition. In a mutual aid group, participants find support and the opportunity to express their fears openly. They discover that they have much value to share and offer. According to Levine and Perkins (1997) there are five broad, overlapping categories of mutual aid groups:

- ◆ persons labeled as abnormal
- ◆ caretakers of people labeled as abnormal
- ◆ persons with socially isolating problems
- ◆ persons affiliated through ethnicity, race or religion
- ◆ quasi-political groups who meet to preserve interests and rights

## **1.2 Motivation**

The present research followed up on the recommendations by Dhlomo (2000) that more groups catering for the caretakers of people labeled as abnormal, should be formed to promote health at a tertiary level. Also, there has been a noted lack of such care provided by the formal health sector.

## **1.3 Statement of the problem**

Can a mutual aid group for caregivers of the terminally-ill empower and improve their effectiveness in their role of promoting health?

## **1.4 Aims**

The main aim of the present project, in line with the aims of health promotion at a tertiary level, was to improve solutions for living and increasing health, strength, skill and human rights for carers of the terminally-ill (persons of much health potential) in very empowering contexts.

## **1.5 Objectives**

The objectives of this study were to:

- elicit needs from a group of carers
- form and evaluate an ongoing mutual aid group program
- promote empowerment
- improve caregiver effectiveness by improving meaning, self-realization and social realization and self-actualization and other higher level survival needs.

## **1.6 Hypothesis**

A mutual aid group program will result in:

- improvement of caregiver effectiveness
- empowerment for participants.

## **1.7 Résumé**

Caring for an ill person, especially a terminally ill person can be a rewarding yet stressful experience. A mutual aid group program will provide a support system responsive to their unique needs and special problems. The present study is relevant in that it is in line with the aims of health promotion at a tertiary level, which are to improve solutions for living and increase health, strength, skill and human rights for carers of the terminally ill, in very empowering contexts. Before hypotheses are subjected to rigorous empirical research, literature related to community psychology, health promotion, mutual aid groups, caring and empowerment will be reviewed and presented in the next chapter.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter reviews previous literature on the subject of health promotion, using mutual aid groups as well as related literature. It is important to note that not much literature is available on the subject 'caring for the carers', which indicates that this area needs to be explored further.

### **2.2 Carers**

Carers are dedicated people at all levels of society who provide care in the home for older people, people of all ages with disability and those who are chronically or terminally ill (Corr et al., 1997). Informal care is provided for others, it is non-institutional, usually unpaid, it is kinship based and/ or provided for individuals with long-term need for help and support.

Schofield et al., (1998) differentiated five levels of caring.

- ◆ Level 1: includes all kinds of caring
- ◆ Level 2: differentiates between professional (paid) caring and other (unpaid) caring

- ◆ Level 3: divides unpaid caring into volunteer (choice) and family (no choice) caring.
- ◆ Level 4: Family caring may either be reciprocal, involving mutual dependence or may be responsible for imbalance in dependency
- ◆ Level 5 involves parenting (normal expectations) and care-giving which transgresses normal expectations

Van Dyk (2001) sees carers as divided into the following groups and individuals:

- ◆ At family level, there are mostly women and young girls. There is however a noted trend whereby men are either volunteering or forced into being carers at home. However, when one parent dies and the other falls sick, children are also faced with the burden of care.
- ◆ The backbone of community care programs is volunteers. Volunteers can work informally (friends, neighbours and church members) or formally (recruited, trained and supervised).
- ◆ Health care professionals (nurses and welfare workers) offer home-based care and /or recruit and train volunteers.
- ◆ Lastly, there are traditional healers who are not formally recognized yet, so they remain untrained and unsupported by formal health services sectors except in a few places.

### **2.2.1 The broader picture confronted by carers**

The following facts emphasize the need for more carers:

- Ageing population
- Increased rates of chronic illness and disability (these are the concerns regarding the burden on health and welfare system).
- Changes in family structure
- Participation of women in the workforce
- Mobility of families (these are concerns regarding the reduced pool of people to provide informal care).
- Shift from institutional to home-based care concerns changes in attitudes regarding locus of treatment/care and accommodation choices (Schofield et al., 1998).
- The role that women play in caring: Usually women are more affected by the need for care at the end of life. Women provide almost 3/4 of all care for dying patients. At the same time, women who need care receive less assistance from family members than men and are more likely to have to pay for assistance. In part, the inability of women to receive assistance from family and friends is related to the fact that terminally ill women are less likely than men to have a spouse or partner. However, even when they are married, women use more paid help. Women are apparently called on to provide care to dying family members, but when they themselves are dying, they must rely to a significantly greater extent on paid help.
- The need for support for family members: Society should recognize and support the substantial amount of time family members devote to caring for terminally ill patients, whether through tax credits or by other means.
- The decline in marriage rates and the higher divorce rates: Declines in marriage rates and higher divorce rates could portend increasing reliance in the future on paid workers to provide the non-medical care needed by terminally-ill patients, thereby increasing costs (Corr et al., 1997; Van Dyk, 2001; Schofield, 1998).

When faced with the news that a family member has been diagnosed with a terminal illness, many people worry about what they should say and do. They want to help, but fear that they will say or do something that will further upset the loved one. Dying persons have the same physical, emotional, and spiritual needs as everyone else. In addition to the typical needs, persons who are dying are often concerned about being abandoned, losing control over their bodies and lives, and *being in overpowering suffering, pain and distress. What they need most of all is to be cared about, not just cared for during their suffering* (Corr et al., 1997).

Suffering:

- involves a perceived threat to the self which may involve the physical body, the psychic and social self, or both
- is inherently emotional, unpleasant, and psychological more than physical, and
- constitutes an enduring psychological state, not a transient or fleeting experience.

Suffering in terminally ill patients typically results from multiple sources of diverse origins. Pain is likely to be a major factor, but the fear that the pain cannot be relieved or the perception that it is indicative of a deteriorating physical condition may cause far more suffering than the pain perception itself. Biological signals of local distress are likely to cause much more suffering if perceived to indicate a worsening of the terminal illness as opposed to an unrelated cause (Corr et al., 1997).

Parts of a patient's suffering almost always involve general symptoms unrelated to pain, like weakness, excessive fatigue, sleep disturbance, loss of appetite and weight loss. Frequently, it also involves other more specific physical symptoms like nausea, constipation, and shortness of breath. At the same time, suffering frequently results from distress of psychic origin, like guilt, anger, frustration, perceived loss or helplessness, threat to self-image or body image, or simply the awareness of the threat of death. All of these may produce or exacerbate an underlying depression. Finally, suffering frequently results from social problems such as isolation or a sense of abandonment, loss of social status and/or social influence, and the loss of self-esteem which follows the loss of ability to work and earn an adequate income for oneself and one's family. These latter types of psychological distress are frequently referred to as "existential suffering" (Corr et al., 1997).

### **2.2.2 Special needs of care-recipients**

Some of the needs of terminally ill persons are special i.e. they can only be met by individuals with special expertise, for example, prescriptions for pain medication must be written by a physician. However, many of the dying person's needs can be met by anyone. It is important to be familiar with the various ways in which we can help those who are dying. Even when we can not do something specific, all of us can listen to and be with the dying person and his or her family.

According to Corr et al. (1997), there are four main areas of care for those who are coping with dying - physical, psychological, social and spiritual. Each is described here. While the information applies directly to the dying person, it is also relevant to others who are coping with dying - the family members, friends, and associates of the dying person, as well as professional and volunteer caregivers.

#### **2.2.2.1 Physical care**

One of the biggest concerns of dying persons is the control of acute and chronic physical pain. Other symptoms that may be as distressing or even more so than the physical pain include constipation, diarrhea, nausea, vomiting, weakness, loss of appetite, shortness of breath and dehydration. Those who place a high value on self-image may be concerned about hair loss, dark circles around their eyes and changes in their skin color. Effective care must address all of the dying person's physical symptoms. Physicians can help with pain management, while family members and other caregivers can be trained to provide physical care that will help to lessen the affliction.

#### **2.2.2.2 Psychological care**

It is important to take seriously what dying persons are feeling. They are likely to express negative feelings including anger, sadness, anxiety and fear. Their

emotions are real and they need to be identified, acknowledged and expressed. When faced with these, many would-be helpers are uncomfortable - they wonder what they should say and do. Unfortunately, there is no universal right thing to say or do; however, several things seem to be helpful. Some include being present, speaking the truth and listening actively. A gentle touch is often psychologically healing. Many dying persons are comforted when caregivers gently touch their wrist or arm, hold their hand or hug them.

Hope also provides positive effects in dealing with sickness and terminal illness. There is a link between a patient's strong confidence and beneficial physiological effects. Patients should be encouraged to mobilize all their spiritual, emotional, intellectual and physical resources to fight back. Hope is a secret weapon. Patients should be shown that positive expectations can pull them in that direction physically.

#### **2.2.2.3 Social care**

Dying persons want to maintain relationships with the special people in their lives. They may be concerned about their roles within the family, in the work force and in the community. Many worry about who will care for and support their survivors, who will continue their special project at work and what will happen to their possessions. Carers can help by allowing the individual to talk about his or her concerns, to think about options and ways to fulfill needs and

then by being an advocate for them. It is important to note that it is disempowering when carers take over the work of the dying person. It is sufficient to be present and to serve as a sounding board so that the individual can recognize options and think about ways to fulfill needs. Social workers, family therapists, counselors and lawyers may also be of help with social concerns.

#### **2.2.2.4 Spiritual care**

Has my life made a difference? What is the meaning of life - to me, to those closest to me and in the large order of things? Have I accomplished my goals? What will happen to me after death? Dying persons often bring up issues that are spiritual in nature. When they ask these questions out loud, they usually are not interested in our response, but rather, are articulating issues that are on their own minds. They verbalize the issues as a way of developing their own thinking. It is important for dying persons to work out their own answers to their questions. Again, it is usually helpful for someone to be present, to be empathic and to listen. It is beneficial to affirm that the dying one's life has been and continues to be meaningful to others. Providing creative opportunities in music, literature, drama, visual arts, dance and other arts can be an important way of helping individuals with spiritual tasks.

### 2.2.3 Caring for the carers

Although care must be primarily directed at the patient's suffering, the psychological distress, fatigue and needs of carers need to be addressed along with those of the patient. Carers are faced with existential issues such as vulnerability of youth, continuous physical and psychological deterioration, their own mortality, the fear of contagion and death. They therefore must learn how to take care of themselves, preventing stress and burn-out or at least managing it (Van Dyk, 2001).

To this end, carer care for family and appreciation of the emotional drain on health providers needs to be considered by the management team as part of the division of responsibilities. This means physicians and families must work together to set the goals of therapy appropriate for each stage in the terminal process. From the beginning the support team must plan ahead for the time when aggressive therapy aimed at cure is replaced with one aimed at prolonging meaningful life, realizing that this, too, will subsequently be replaced by a third goal of maximizing comfort, care and relieving terminal suffering. Failure to accept this anticipated progression or ambivalence in goal setting by the patient, family, or physician will invariably lead to needless suffering. On the contrary, by discussing beforehand the eventual need to make these goal transfers, the team will be well positioned to decide on the details of future plans as the need arises over the course of the disease (Corr et al., 1997).

Schofield, (1998) suggests that doctors (who are likely to see the carers for treatment) do the following to care for the carers:

- Find out if their patients are carers.
- Be aware of local services and have available up-to-date information.
- Provide verbal and written information about medical issues and services.
- Recognize that the stress of caring can have significant impact on the health and well being of carers.
- Provide encouragement, convey a positive regard for carers and value their role.
- Encourage carers to use available supports, not to wait for a crisis.
- Emphasize the importance of taking a break.
- Develop a trusted relationship with both carer and the care recipient to help deal with conflicts or concerns (or refer them for psychological help)  
(Schofield, 1998).

The aim of caring for carers is to promote health, well-being and quality of life of family carers and those for whom they care; providing recognition of their work, information, training, respite care and advocacy to promote social inclusion.

#### **2.2.3.1 Carers caring for themselves**

It is common in the caring profession that people who care about what they are doing, end up getting over-involved with their client's problems.

At first, the client is a victim, perceiving persecution by a situation or someone. It could end up with the carer being a victim if s/he gets over-involved. The carer can only help, they can't make changes for the client.

Van Dyk (2001) gives the following guidelines to avoiding being a victim:

- A carer is a guide, not the solution
- A carer and client must agree on what they are going to do together.
- A carer must make it clear that the client must help him/herself and work towards his/her own solution.
- A carer must make it clear what they can do and how long it can take
- A carer must know his/her professional boundaries and refer when it is no longer possible to help.
- A carer must know his/her knowledge and skill area and must not work beyond that but use the referral system.
- A carer must debrief regularly with other carers.
- A carer should seek professional support or help from supervisors when they are unable to cope.

### **2.3 Health and health promotion.**

*Good health requires good habits (Halonon & Santrock, 1996).*

Psychological states and lifestyles are powerful in promoting health.

Therefore the ultimate responsibility for influencing health rests with the individuals themselves. This does not negate the importance of our genetic pre-dispositions and the power of viruses and bacteria, but it is believed that our daily behavioural choices and our general attitude about life plays an important role in the quality of our health.

Health - care professionals generally operate from various models in pursuing their work. These models determine the scope and nature of what is investigated, and the ways in which results are interpreted. All psychotherapeutic systems have a view of human nature, a concept of disease etiology, and a vision of psychological health. This vision of psychological health is the end-point of 'successful' therapy as defined by each particular orientation. According to Wardrop (1993), the World Health Organization's (WHO, 1946) proposed definition of health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, is the 'ought' or 'should' toward which every counsellor, therapist, and healer should seek.

Jahoda (1958) pointed out that most definitions of positive health call attention to one or more of the following six aspects:

- the attitude shown by a person to self
- the style and degree of self actualisation
- the degree of personal integration achieved by the individual

- the degree of autonomy achieved by the person
- the degree of the person's conception of reality
- the degree of environmental mastery achieved by the person.

According to the Jakarta declaration on health promotion (in Dennil, King, Lock and Swanepoel, 1995) health is a basic human right and is essential for social and economic development. Pre- requisites of health are peace, shelter, education, social security, social relations, food, income, empowerment of women, a stable eco-system, sustainable resource use, social justice, respect for human rights and equity. Health promotion strategies and programmes should be adapted to local needs and possibilities of individual countries and regions and take into account differing social, cultural and economic systems (WHO, 1981; Ottawa Charter in Dennil et al., 1995).

### **2.3.1 What health promotion entails**

Health promotion means building healthy public policy, creating supportive environments, strengthening community action, developing personal skills and re-orienting health services (WHO, 1986; Dennil et al, 1995).

Health promotion puts health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept responsibility for health. Health promotion policy combines diverse but complementary approaches including legislation, fiscal measures, taxation and organizational change. It is coordinated action that leads to health, income and social policies that foster equity. Joint action contributes to ensuring safer and healthier public service, and cleaner and more enjoyable environments. Policy requires the identification of obstacles to the adoption of healthy policies in non-health sectors, and ways of removing them. The aim must be to make healthier choice for policy makers as well (WHO, 1986; Dennil et al, 1995).

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environments constitute the basis for a socio-ecological approach to health. The overall guiding principle for the world, nations, regions and communities alike is the need to encourage reciprocal maintenance (to take care of each other, our communities and our natural environment). The conservation of natural resources throughout the world should be emphasized as a global responsibility. It should be recognised that changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organizes work should help create a healthy society. Health

promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable (Dennil et al, 1995; WHO, 1986).

For health promotion to be successful, communities must be empowered and have control over their own initiatives and activities. They must draw on their own human and material resources in the community to enhance self-help and social support. Health professionals must learn to work with communities (Dennil et al, 1995; WHO, 1986).

Personal and social development must be enhanced by providing health information and health education to help people develop the skills they need to make healthy choices. This should enable people to prepare themselves for the different stages of life as well as for chronic illness or injury, should they occur. This preparation should take place in schools, at home, at work and in community settings.

Reorientation of health services to be shared by individuals (health professionals, community groups, health service institutions and government departments) will ensure shared responsibility for health promotion. This requires that the health sector move beyond the provision of clinical and curative services, to a health promotion approach sensitive to cultural differences (Dennil et al., 1995).

### 2.3.2 Aims of health promotion

Health promotion action has many aims among which are the following:

- making political, economic, social, cultural, environmental, behavioural and biological conditions favourable through advocacy for health.
- reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of these things which determine their health. This must apply to both men and women.
- mediation between differing interests in society for the pursuit of health. This is a major responsibility of professional and social groups and health personnel. The pre-requisites and prospects for health cannot be ensured by the health sector alone, but it demands co-ordinated action by all concerned i.e the government, health and other economic sectors, non-governmental organizations, local authorities, industry and the media. People from all walks of life should be involved as individuals, families and communities (WHO, 1986).

One example of health promotion in South Africa is the celebration of the World Mental Health Day (10 October). One of the organizations that celebrate it is the South African Federation for Mental Health. Besides health for all, this organization also has a special focus on women (since 1992):

- to enable women to fully understand and acknowledge the value and importance of health as an essential ingredient in self-actualisation, role performance and total well-being.
- to promote skills development for women, which will impact positively on their health. These would include the development of positive self-esteem, problem solving skills, the ability to resolve conflict, assertiveness skills and stress management.
- to enable women to enhance the health of their daughters.
- to promote health-focussed organizations and work places, which would enhance the health of women.
- to create an awareness within the work place about the contribution healthy women make towards productivity and thus wealth creation.

This organisation believes that networking is essential in order to achieve the objectives. Their target groups include settings where the largest number of women could be accessed like the following:

- *National Women's Organisations.*
- *Tertiary Institutions.*

- Corporate Business.
- National and Provincial Government Departments.
- National Welfare Organizations (WHO, 1986).

### **2.3.3 Threats to health**

Poverty is one of the greatest threats to health. So are the demographic trends such as urbanisation, the prevalence of chronic diseases, increased sedentary behaviour, resistance to antibiotics and other commonly available drugs, increased drug abuse and civil and domestic violence. These threaten the health and well-being of hundreds of millions of people.

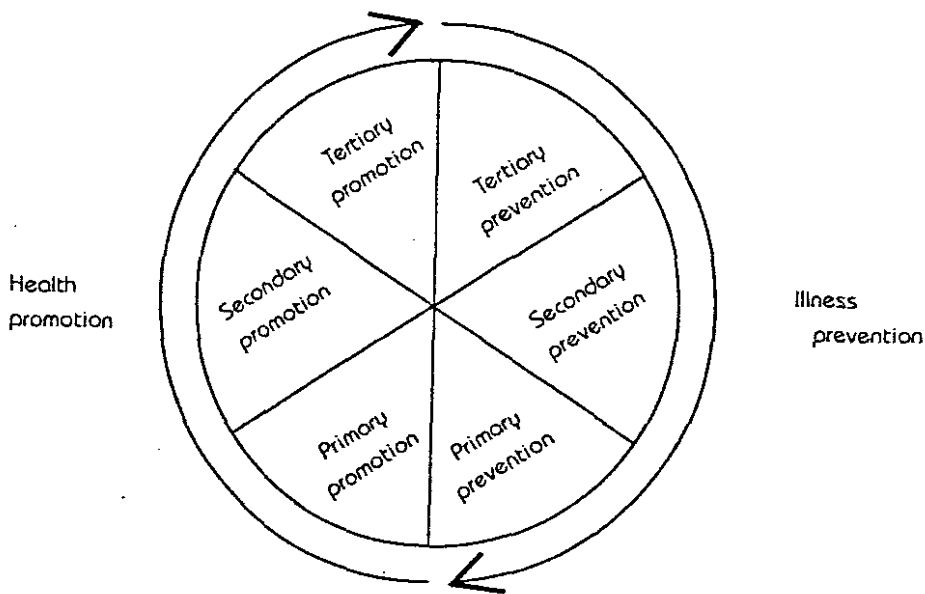
New and re-emerging infectious diseases (eg. HIV and AIDS) and greater recognition of health problems require urgent responses. One cannot ignore trans-national factors such as integration of the global economy, financial markets and trade, access to media and communication technology as well as environmental degradation due to the irresponsible use of resources. These changes shape values, lifestyles throughout the life-span and living conditions across the world. Some have great potential for health, (such as development of communications technology) and others, such as international trade in tobacco, have a major negative

impact. It is vital that health promotion strategies evolve to meet changes in the determinants of health (WHO, 1986).

#### **2.3.4 Illness prevention and health promotion**

There has been a noted keen commitment and emerging progress by health professionals in mounting an array of health promotion and prevention programs (Winnet et al, 1989). For over a quarter of a century, most significant reports about the incidence and prevalence of mental health disorders have noted that needs far outstrip resources and services.

A holistic community psychological health model based on principles of harmony and balance was proposed by Edwards (1999b). This model is an intervention model. In that healing implies a transformation from illness to health, two distinct phases of the healing cycle or spiral may be identified, i.e. prevention of illness and promotion of health (Edwards, 1999b). Based on the earlier work of Freud, Adler and Frankl and more recently Caplan (1964), Rappaport (1977), Antonovsky (1984), Strumpher (1990), Orford (1992), Mrazek and Haggerty (1994), Levine and Perkins (1997) and Edwards (1999), health care interventions may be extended as follows:



This figure is a contextual map (spiral) for intervention in the world of an individual, couple, family, group, community, society or any organization. The midpoint may be regarded as a pivot or as a mathematical zero for joint decisions taken with regard to types of intervention.

This model is based on a continuum view of prevention and promotion from primary prevention to primary, secondary and tertiary promotion. It emphasises intervention to promote and improve community health behaviour in general and mental health in particular, as well as prevention and reduction of illness behaviour (Edwards, 1999b). The segments of the model are divided as follows:

- Tertiary prevention is indicated prevention to reduce illness, disability and handicap typically in individuals at high risk as in persons with genetically loaded bipolar affective disorder receiving lithium

carbonate. Basically it is more concerned with rehabilitation (Edwards 1999b).

- Secondary prevention is more concerned with prevention of relapse. It is selective prevention to reduce the prevalence and /or duration of illness in persons at risk as in interventions to reduce harmful drugs during pregnancy, or school-based educational programmes to assist teachers in the early identification and referral of abused children.
- Primary prevention is the prevention of incidence of a problem, i.e. before it even starts. It is basically directed at those individuals at potential risk as in intervention for safe sex.
- Primary promotion is universal intervention to promote and improve health e.g. run/walk for life campaigns, life skills training as enrichment for all children as part of the school curriculum. This intervention constitutes the greatest challenge to researchers and policy makers to actively improve community life.
- Secondary promotion refers to interventions aimed at improving human rights, empowerment and health promotion advocacy for all persons but particularly in cases of disempowerment.
- At the tertiary level, the aim is to improve solutions for living and increase health, strength, skill and human rights for persons of much health potential in very empowering contexts. Interventions at this level would include supporting the support persons involved in caring for others. Such interventions would improve meaning, self and social

realization and actualization and other higher level survival needs (Maslow, 1971; Edwards, 2002) among those in helping professions. Its focus is on helping the helpers (Edwards, 1999).

Edwards further outlined the implicated emphasis areas of this model:

- The holistic spectrum of illness and health.
- Prevention and promotion as community concepts
- Salutogenesis with its special reference to environmental variables.
- Building of strengths and competence through resolution of crises.
- Physical, psycho-social and socio-cultural supplies
- Contextual variables (both distal and proximal).
- Educational health promotion interventions including ongoing government advocacy for such interventions
- Local community education with regard to fitness, well-being, empowerment, human rights, stress and coping, social skills training, mutual aid groups, etc.
- Local community education with regard to crisis theory and intervention as opportunities for decisions for decisions to cope better and improve resources.
- Specific community mental health and well-being education with regard to the above and other traditional mental health criteria.

- Recognition that this model is just one community psychological oriented model, related to all other health models which need to work concertedly to optimise health globally.

### **2.3.5 Priorities for health promotion in the new millennium**

The Jakarta declaration (1997) put forth the following priorities for health promotion in the year 2000 and beyond.

- *Promotion of social responsibility for health by avoiding harming the health of other individuals, protecting the environment, restricting the production and trade in inherently harmful substances like tobacco, safeguarding both citizen in the marketplace and the individual in the workplace and including equity-focussed health impact assessments as an integral part of policy development.*
- *Increasing investments for health development.* In many countries, current investment in health is inadequate and often ineffective. Increasing investment for health development requires a truly multi-sectoral approach, including additional resources to such sectors as education and housing.
- *Consolidating and expanding partnerships for health.* Health promotion requires partnerships for health and social development

between the different sectors at different levels of governance and society. Partnerships offer mutual benefit for health through the sharing of expertise, skills and resources. Each participant must be transparent, accountable, guided by ethical principles, mutual understanding and respect, and adhere to WHO guidelines.

- *Increasing community capacity to empower the individual.* Health promotion should be carried out by and with people, not on or to people. It improves both the ability of individuals to take action, and the capacity of groups, organisations and communities to influence the determinants of health. This requires practical education, leadership training and access to resources.
- *Securing an infrastructure for health promotion.* To achieve this, new mechanisms to fund it locally, nationally and globally must be found. Incentives should be developed to influence the actions of governments, non-governmental organisations, educational institutions and the private sector to make sure that resource mobilisation for health promotion is maximised.

Health promotion is therefore a multifaceted approach, which includes prevention of ill health. This approach includes strategies such as education, community development, mass communication, self-

help/mutual aid, public policy development and even organisational change. Health promotion therefore advocates social as well as individual responsibility for health and is a vital part of primary health care. All countries should develop the appropriate political, legal, educational, social and economic environments required to support health promotion (Dennil et al, 1995; Wardrop, 1993).

### **2.3.6 Challenges for community psychologists**

According to Revenson and Schiaffino (2000) it is time to develop new approaches to take preventive and health promoting services to populations at highest risk (away from clinical settings). Community psychologists should lead these efforts, to assist under-served and disenfranchised populations. This can be made possible by using what Revenson and Schiaffino (2000) call community-based health interventions.

#### **2.3.6.1 Features of Community-Based Health Interventions (CBHIs)**

- They are distinguished from medical interventions in terms of their philosophy, values and assumptions.
- They emphasise the use of education to empower people

- They provide individuals with information and skills to initiate behaviour change through naturally occurring structures and channels of influence
- They develop and sustain a supportive social environment that reinforces and sanctions the changes
- They target populations and communities as the locus of intervention and not just individuals.
- The desired outcome (locus of effects) is change at a community level (community wide social change) which is more difficult and has longer-lasting impact (Winnett et al, 1989; Revenson and Schiaffino, 2000)
- They draw on individual and community strengths, emphasising adoption of healthy lifestyles and reduction of risk factors.
- They emphasise the socio-cultural context in understanding change processes. They are tailor-made to the populations that will receive them
- Their developers must be willing to “give them away” i.e. ownership must be transferred to the members of the community to ensure sustained change, even once the researcher’s involvement has been discontinued (Miller, 1969). Usually the transfer is to community leaders (Winnett et al, 1989) preferably during the initial stages of program development.

### 2.3.6.2 Community as a setting for CBHIs

Mediating structures such as families, churches, schools, supermarkets, restaurants and work sites are linked as agents in a community-wide effort to promote health. This serves a dual purpose.

*Firstly, the presentation of health information happens simultaneously with the development of social norms, which sanction healthy behaviours and make unhealthy behaviours unacceptable.*

Secondly, nesting programs within existing community organisations or developing new community structures guarantees that structures will be left in place once researchers withdraw their participation.

Involvement of community groups in the design and implementation of interventions increases the likelihood that programs will reach their populations as originally designed, that both individual and societal change may occur, and that transfer of ownership of the interventions to community groups is smooth.

Community based health interventions provide settings in which community psychologists can do community psychology: clinics, hospitals, schools work-sites, etc. The research questions pose a fresh

challenge to community psychologists, an opportunity to collaborate with interdisciplinary researchers and health care providers, and a potent opportunity to work on social problems of immediate and long-term relevance.

#### **2.4 Social action model of mental health**

The social action model is especially relevant, for example, in terms of empowerment and advocacy through self-help and groups. The changes in the country as a whole have been a general triumph for the community psychology movement in its struggle against all forms of injustice, oppression and violence and a special success for the social action model (Edwards, 1998). The Zululand and South African context has been one of accelerating social action and transformation. Mass democratic movements within the country, coupled with international sanctions and pressure from political exiles have led to the overthrow of the unjust apartheid system (Edwards, 1998).

The social action model is revolutionary in its political action against oppressive structures such as Apartheid in order to liberate oppressed and disempowered people. In the struggle against oppression, poverty, injustice and other socio-political problems, the social action model constitutes a shift in intervention from prevention to empowerment,

from needs to rights (Seedat et al, 1988; Edwards, 1999). This model exposes and acts against socio-political causes for human behavioural problems, fosters community participation, increases morale, provides resources, skills, local leadership and liberates oppressed communities. Redress and equity issues as well as sharing of specialist psychological resources amongst non-professionals and other community members are special concerns of this model.

The social action model has special value in terms of liberation from all forms of oppression (Bulhan,1990; Fanon, 1986; Seedat, 1999 and Edwards 1998). This model requires great commitment, responsibility, activity and social support for groups by community workers (like nurses, social workers, community psychologists, etc.) in their on-going reflective - generative activities. Sarason (1978), Rappaport (1995), Levine & Perkins (1997) and Edwards (1999) have pointed out that social problems are often dialectical, without permanent solutions and today's solution may sow the seeds for tomorrow's problem. This implies focus on solutions that are flexible, diverse and focussed on the empowerment of people at local grass-roots level.

The Zululand Community Psychology Project constitutes a social action intervention in its provision of psychological interventions to persons previously disadvantaged in terms of Apartheid, redressing

past sequelae of this unjust system through improvement of relationships across divided communities (e.g. divided in terms of political, historical, racial, gender and other boundaries) and providing on-going interventions in a poverty-stricken and crime-filled region (Edwards, 1999). Some examples follow:

- Empowerment of non-professional helpers (a project which assists traditional healers with transport, facilities and registration procedures).
- Establishment of self-help/mutual aid groups (doctoral students working at the Labour Department facilitating empowerment of unemployed people).
- Organization of Zululand Community stakeholders' meetings to promote community psychology programmes, provide instruction and optimise local psychological resources.

## **2.5 Empowerment**

The health professions have long been committed to empowerment, and that is really the ultimate goal of any grassroots organizing effort. Social and economic problems confronting people today are debilitating. They sap energy and destroy morale. Problems can be solved if people learn to act collectively. People joined together to tear

down the Berlin Wall and to overthrow repressive government in Eastern Europe. However, to become empowered to bring about positive and lasting change, people need to be organised. Empowerment is easily defined by first looking at the concept of power per se and its absence i.e. powerlessness.

### **2.5.1 The concept of power**

An essentially *materialistic* understanding of the working of power is central to an adequate account of psychological distress. Hagan and Smail (1997) have made a detailed attempt to develop the theoretical foundations of such understanding. In explaining individual distress, the abstract concept of power may be treated as a concrete factor. It is as fundamental a key to mental health problems as it is to the working of society as a whole. The view that emotional distress is brought both by the operation on the individual of damaging social forces and by the individual's lack of appropriate powers and resources to affect his /her predicament has political implications which may make some health workers uncomfortable (Hagan and Smail, 1997). However, it is widely acknowledged that less powerful members of society are more susceptible than others to mental health problems. Examples of such are children, members of disadvantaged socio-economic groups, ethnic minorities and women. In varying proportions, all are likely to be

subjected to oppressive social forces creating individual distress. The impress of power upon the less powerful is not amenable to psychological operations directed at the level of experience, which has been abstracted from the network of power in which it must necessarily be embedded (Thornicroft, 1991; Hagan and Smail, 1997).

Empowerment is therefore not a matter of instilling a sense of power, but of obtaining power. The four main sources of power are regarded as home and family, social, personal and material resources. The emphasis in the home and family situation is on the degree to which relations with members of the family, past and /or present provide a source of solidarity and support. If, therefore, a family is supportive this is seen as empowering to the individual. However, the family can be a disempowering liability if they are not supportive. In the social sphere, power is defined as the ability to involve and influence others to obtain solidarity with them in the achievement of desired goals. Personal resources (those which come with the individual as biological acquisitions could not be viewed as assets or liabilities per se, but will always be related to social evaluation. Material resources make powers and resources available to the people which makes it possible for them to operate on their proximal environment (Hagan and Smail, 1997).

### **2.5.2 Powerlessness**

Empowerment is easily defined in its absence: powerlessness, real or imagined, or learned helplessness, alienation and loss of a sense of control over one's own life. It is more difficult to define positively only because it takes on a different form in different people or contexts (Rappaport, 1984). Powerlessness is equivalent to poverty. Poverty is not just being without money. It is being cut off, cut out, cut down. It is being without power, without the protection that people with power have. It is being without the protection from the powerful, without choice and suffering the indignity of depending on being chosen. It means having no voice, and no one who has to listen, when you do speak. It is being shoved aside when you are not being used up. Not only those who have no money suffer from poverty but also those whose way of life denies them the power to control what happens to them. The poor are those who have not yet taken back what has been taken from them, who have not found their own power (Kahn, 1991).

The sense of powerlessness is a counterpoint from which the concept of empowerment evolves. It is the sense held by an individual that his or her own behaviour cannot determine the occurrence of the outcomes. It is a sense of being, incorporating past experience, ongoing behaviour and continuing cognition, viewed as an experience embedded in and reinforced by the fabric of social institutions

(Kieffer, 1984). The individual becomes powerless in assuming the role of 'object' acted upon by the environment, rather than 'subject' acting in and on the world. Therefore the individual alienates him/herself from participation in the construction of social reality. According to Freire (1973), this results from passive acceptance of oppressive cultural 'givens' or surrender to a 'culture of silence'.

### **2.5.3 The meaning of empowerment**

Fawcett et al. (1994:47) define empowerment as the process of gaining influence over events and outcomes of importance to an individual or group. This implies that empowerment can mean different things to different people in different times and contexts (Edwards, 1997; Rappaport, 1984). The roots of the ideology of empowerment go deep into the political and philosophical foundations of this country. The concept of democracy is based on the principle of empowering citizens to participate in decisions affecting their welfare. Rappaport (1981) outlined two requirements of an empowerment ideology.

“On one hand it demands that we look to many diverse local settings where people are already handling their own problems in living, in order to learn about how they do it... On the other hand it demands that we find ways to take what we learn from these diverse settings and

solutions and make it more public. That will help foster social policies and programs and make it more than less likely that others know how to handle their own problems in living or shut out from current solutions and gain control over their lives”(p. 15).

The idea of “empowerment” is uniquely powerful as a model for policy in the field of social and community intervention. Empowerment is viewed as a process: the mechanism by which people, organisations and communities gain mastery over their lives. However, the content of the process is of infinite variety and as the process plays itself out among different people and settings the end products will be available and even inconsistent with one another. The inconsistency is in the ends rather than in the process, yet the form of process will also vary (Rappaport, 1984).

Empowerment could be viewed as an attainment of an abiding set of commitments and capabilities which can be referred to as participatory competence (Kieffer, 1984), incorporating three major intersecting aspects:

- development of more positive self-concept, or sense of self competence.
- construction of more critical or analytical understanding of the surrounding social and political environment.

- cultivation of individual and collective resources for social and political action.

These are interconnected elements of a unitary notion of socio-political competence (Kieffer, 1984). Interventions or self-initiated efforts which promote development of any of the above competencies can be seen as 'empowering' at least in a limited way.

Empowerment may be the result of programs designed by professionals, but more likely will be found in those circumstances where there is either true collaboration among professionals and the supposed beneficiaries, or in settings and under conditions where professionals are not the key actors. Professionals therefore have to intervene in a form and with a style that is consistent with the idea of empowerment rather than the idea of controlling others (Rappaport, 1984).

One needs to understand that empowerment can be the active ingredient in a wide variety of human interactions, and that the end result can take on a variety of forms. For some people the mechanism of empowerment may lead to a sense of control, for others it may lead to actual control, the practical power to effect their own lives. Empowerment can be either understood as an internalised attitude, or as an observable behaviour. It means realising that the

forms, the strategies and the contents achieved will be quite variable from setting to setting. It means diversity of form. It means fostering solutions by a policy, which strengthens rather than weakens the mediating structures between individuals and the larger society. New competencies are learned in a context of living life, rather than being told what to do by experts (Rappaport, 1984).

#### **2.5.4 How individuals manage to move beyond powerlessness**

Kieffer (1984) adopts a view that empowerment is a long term and continuing process of adult development. The transition from powerlessness is seen as progressing through the following phases:

- The “Era of Entry”

During this period, participation is exploratory, unknowing and unsure. Individuals are first discovering their political muscles and potential for external impact. They begin to develop their sense of themselves as political beings.

- The “Era of Advancement”

According to Kieffer (1984), this phase parallels the development of later childhood. The three major aspects of empowering evolution in this phase are centrality of a mentoring relationship, the enabling impact of supportive peer relationships within a collective organizational structure,

and the cultivation of a more critical understanding of social and political relations.

- The “Era of Incorporation”

In this period, self-concept, strategic ability and critical comprehension substantially mature. Through continuing struggle, participants confront and learn to contend with the permanence and painfulness of structural or institutional barriers to self-determination.

- The “Era of Commitment”

Participants continue to struggle with integrating new personal knowledge and skills into the reality and structure of their everyday lives. Participatory competence, then attains its adulthood.

There are two pervasive themes that underlie these phases. First is the function of the continuing internal constructive conflict or the maintenance of the creative force of internal contradiction without which an individual cannot live. In addition to this is the essential contribution of dynamic ‘praxis’. Praxis here refers to the circular relationship of experience and the reflection through which actions evoke new understandings which then provoke new and more effective actions (Kieffer, 1984).

Some people perceive power as something taken and others perceive it as something to be given. However, because of its dynamic nature, power is

both taken and given (Hess, 1984). The powerful do not easily give power away. It is usually taken violently from them when the powerless exert pressure on them which eventuates in the powerful giving some of it away. Usually this is achieved through the help of an interventionist who acts as an advocate for the powerless. The question that arises then is how does the interventionist enter the system? Should s/he be invited or should they enter without invitation? Obviously, how the interventionist enters the system affects the process and outcome because of his/her values.

#### **2.5.5 Relationship between empowerment and prevention.**

Rappaport (1981) has developed the concept of empowerment by providing empowerment with a positive formulation and an alternative set of symbols. The connotation and denotations of prevention and empowerment do overlap but are still clearly distinct. Prevention is primarily concerned with the goal whereas empowerment is concerned with the process and insists on the primacy of the target population's participation in any intervention affecting its welfare (Rappaport, 1984). Whereas prevention addresses health and mental health goals, (the processes may be left to the expediency of the intervener), empowerment requires the acquiescence and participation of those affected by the intervention. One can therefore assume that interventions that do not subscribe to this process will fail.

## 2.6 Mutual-aid groups

The growth of mutual-aid groups is a powerful trend in a society. In 1987, approximately 2 percent of the Canadian population (420 000 individuals) belonged to mutual-aid groups (Gottlieb and Peters, 1991). It is estimated that approximately 25 million Americans have belonged to such groups at some point in their lives (Kessler et al., 1997; King, Steward, King and Law, 2000).

For the purpose of this review, the researcher's interest lies in mutual-aid groups led by participants rather than those led by service providers. These are also called self-help or mutual-support groups. Mutual-aid groups could be defined as voluntary groups that consist of individuals who share a common predicament or concern and where mutual help is provided for and by members (Humphreys & Rappaport, 1994). They are self-governing and self-regulating. They emphasize self-reliance and they offer face - to - face fellowship networking. They are also self-supporting rather than dependent. Such groups have a long history (Lieberman, Borman and associates, 1979).

A number of societal trends have contributed to the growing self-help/mutual aid group phenomenon such as:

- social upheaval,

- medical breakthroughs that have extended people's life expectancy,
- the shift away from institutional care to home and community care,
- financial constraints that have reduced available health services and
- a growing interest in providing services that are family centred (Humm, 1997; Kessler et al., 1997).

### **2.6.1 Typology of mutual-aid groups**

According to Katz and Bender (1976), groups can be broken down according to what is perceived as the *primary focus*.

- Groups primarily focused on self-fulfilment or personal growth. These are referred to as therapeutic groups.
- Groups primarily focused on social advocacy or social action. These include agitating and education directed at existing institutions, professionals, the public; confrontation and social crusading.
- Groups primarily focused on creating alternative patterns for living - group solidarity providing a foundation for society's changing social institutions and attitudes. Here, individual growth and self-fulfilment is obtained, although not the primary goal.
- "Outcast haven" groups provide a refuge for the desperate, attempting to secure personal protection from the pressures of life and society.

## 2.6.2 Why people join groups

Literature suggests that mutual-aid groups meet three basic needs i.e. social support, practical information and a sense of shared purpose or advocacy (King et al., 2000; Bennet, de Luca and Allen, 1996; Madara, 1997). Participation allows carers of ill persons to interact with those who share the same experiences and stresses (Rawlins and Horner, 1988). Empowerment achieved through mutual-aid groups encourages participants' involvement in activities such as lobbying government agencies for funding or changing environmental barriers.

The participants in the group are helped by helping one another, by moving out of a morbid self-absorption and pre-occupation with their psychological problems, great stress and diminished expression of enjoyment. In a group situation, participants find that they have much of value to share and to teach. Participants find support and the opportunity to express their needs and fears openly. Some of the most important therapeutic factors in these groups tend to be universality, cohesion and the imparting of information (Yalom, 1987).

Participants are empowered at personal, interpersonal and political levels and this is cited as the overriding benefit of meeting others in similar life situations (Bennet et al., 1996 and Jacobs & Goodman, 1989). Therefore

there appears to be universal benefits in terms of social support, practical information and a sense of shared purpose, regardless of the nature of the predicament that is the rallying point of the mutual-aid group.

Empirical studies on the effectiveness of mutual-aid groups are rare. However, those that are available indicate fairly consistently that members are satisfied with the support they receive and feel the groups are effective (King et al., 2000; Humphreys and Rappaport, 1994; Arosi, 1992; Biegel and Yamatani, 1987; Humphreys, 1997; Dhlomo, 2000). Some of these studies indicate that members find mutual-aid groups beneficial as a source of information, a support or emotional outlet, and a means of developing ideas and actions.

### **2.6.3 The evolution of mutual-aid groups**

According to King et al., (2000) task-oriented, time-limited groups have been described as going through four stages:

- clarifying a basic purpose,
- generating the skills and resources necessary to meet group goals,
- establishing group cohesion, and
- achieving goals.

Mutual-aid groups are more complex in that they deal with multiple goals, including emotional support and advocacy and do so over a long period of time than do task-oriented groups. Professionally-led support groups go through the following four phases:

- exchanging information,
- developing intimacy,
- solidifying relationships, and
- terminating.

It is not clearly known whether the mutual-aid groups of carers would go through the same evolutionary phases. In a study by King et al., (2000) a sample of nine parent groups was selected. Data were collected through individual, semi-structured interviews with parents and field-notes from the observation of group meetings. The aim was to extract themes related to structural and process characteristics of groups and the issues they faced over time.

The activities of the groups changed over time to meet changes in the needs of participants and to reflect shifts in the philosophy or purpose of the group. Several groups shifted their meeting style from information/education to more emphasis on sharing and discussing issues and concerns.

In all groups, the issue of attracting new members was an ongoing challenge. Members recognized that parent self-help groups were not for everyone, but they also believed that many families would benefit from belonging to such groups. Most groups tried different strategies to attract new families and many had connections with agencies that would refer parents to them.

Cohesion and empowerment were initial excitement for the participants. When most groups were founded, there was a flurry of activity when they realised they could do it on their own. There was a growing sense of belonging, accompanied by a sense of empowerment. As group cohesion grew, members' interests and activities shifted from a focus on their own dilemmas to helping others (King et al. 2000).

## **2.7 Résumé**

The literature reviewed gives more insight into the argument of this thesis. Clearly in terms of the tertiary level of health promotion, carers of terminally ill persons need support system such as mutual aid groups. These groups are in line with values of the social action model of community psychology.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Introduction**

The objectives of this study were to elicit needs from a group of carers, form and evaluate an ongoing mutual aid group program, promote empowerment and improve carer effectiveness by improving meaning, self and social realization and actualization and other higher level survival needs. This chapter is a layout of all the procedures followed to accomplish these objectives.

### **3.2 Sampling**

A mutual aid group was facilitated for the Masibambane project staff of YMCA (Esikhawini). This project has 11 members, including the project co-ordinator, 2 HIV/Aids counsellors, 5 peer educators, 2 youth workers and 1 drama co-ordinator.

The counsellors are mainly responsible for pre- and post-test counselling, involvement in support groups for people living with HIV (PWAs), which is run once every week, and they are also involved in outreach projects/events. They get their clients from clinics and through referrals from youth workers and peer educators as well as other community members who know them.

Peer educators are mainly responsible for forming groups however and wherever they are involved in the community, be it sports, music, drama, church, etc. Their target is the same age group. They give psycho-education on matters pertaining to reproductive health, including sexuality education, how to build up one's self-esteem, assertiveness, etc.

Youth workers are mainly responsible for organizing outreach projects, awareness campaigns and community events. They make posters and invite the wider public to those events. They also do home visits if necessary. If they see a need for counselling, they refer to counsellors.

Drama is one of the media used by the Masibambane project to conscientise the public about HIV/Aids matters. The drama co-ordinator therefore is responsible for production and direction of the drama group and the plays they stage. Their plays are staged in outreach events and awareness campaigns on selected days in the year, e.g. youth day on June 16.

The sample (n=11) was determined by the staff of the project. An ex- staff member had approached the researcher seeking help from the researcher because of the problems he had experienced while he was working for the project. The project co-ordinator was approached with an offer to run the

mutual aid group, and he in turn motivated his staff to join it. According to Yalom, (1985) the group met the requirements for an interactional group.

### **3.3 Psychological techniques for data collection**

The following tools were used to collect data

#### **3.3.1 Biographical inventory**

A biographical inventory was constructed. The following information was obtained from each participant:

- identifying details
- occupational and educational status
- formal training in caring
- length of service in the caring role
- role in the project
- number of terminally-ill clients one has been in contact with
- number of clients that have died (see Appendix A)

#### **3.3.2 Needs analysis questionnaire**

The needs-analysis questionnaire was designed to elicit information concerning the meaning, the joys, the frustrations, special needs,

expectations from the mutual aid group program and the possible future contributions of the carers to the program. It was also designed to ensure that the program addressed the genuine needs of the present group specifically (see Appendix B).

### 3.3.3 Power maps

It is argued in Hagan and Smail (1999) that 'power' may be treated as a concrete factor in the development of individual distress. Power is a fundamental factor in mental health problems. Emotional distress is brought about both by the operation on the individual of damaging social forces and by the individual's lack of appropriate powers and resources to effect his/her predicament.

Power mapping is based on the notion that less powerful members of society are more susceptible than others to mental health problems. Mapping proximal powers bearing down upon people and resources available to them focuses our attention on those aspects of their material situations, which lie at the root of their difficulties and may offer people some possibility of modifying their circumstances. The preoccupation therefore is not with the individual's will, responsibility, linguistic competence, motivation or readiness to change attitudes, but on those

features of the individual's social environments which are relevant to his/her predicament.

The researcher used the power-mapping wheel model to assess the power available to individuals in the following areas of life:

- home and family life
- social life
- personal resources, and
- material resources (Hagan and Smail, 1997)

Each of these areas is located in quadrants, which are divided into segments. There are concentric rings, which convert segments into a five-point scale of 0 – 4 (see Appendix C).

#### 3.3.4 Carer effectiveness scale

A rating scale was developed to find out how carers perceived their own effectiveness as carers. It consisted of closed-ended questions requiring one to just choose the appropriate response and mark it off with a cross in the provided box. Carers were supposed to rate themselves quantitatively by assigning values 0 – 4, designating strongly agree, agree, uncertain, disagree, strongly disagree to 20 items measuring carer effectiveness (see Appendix D).

### 3.3.5 Program evaluation interview guide

Most interventions have at least some impact on the participants. It was hoped that this intervention program would have a positive impact on the participants of the program. The program evaluation interview sought to find out whether participation in the program actually did help. It gave an opportunity to each participant to comment on the intervention program.

Program evaluation by participants has its advantages. According to Magwaza and Edwards (1991) the person who receives the services is in an excellent position to evaluate different aspects of the program as s/he is the only one who has access to his/her feelings. Also, since the program is specifically designed for the particular participants, they are therefore the best people to assess whether it met their needs.

In the present study, an open-ended questionnaire was constructed. This part was constructed to make it possible to secure precise details of personal reactions. It consisted of items related to the overall impact of the program on the carers of the terminally ill, their own suggestions about the program and whether it should continue or not. It also required a short written qualitative evaluation of the program from the participants (see Appendix E).

### **3.4 Procedure**

This was a participatory-action research, program evaluation type of design, where carers of terminally ill persons acting as co-researchers jointly defined the aims of their group, the themes to be discussed and the meanings of such variables as empowerment and carer effectiveness. The participants were pre- and post-tested on the above variables in individual sessions, which allowed privacy and confidentiality for the participants. Whereas in pre-testing individual sessions, a needs-analysis questionnaire was administered, in the post-testing individual sessions, a program evaluation interview guide was administered. The group ran for a contracted period of 6 weeks with members meeting twice a week.

This is one of the many facilitation methods for fostering community involvement in the process of enquiry into their own conditions and development needs. Freire (1973)'s epistemological framework is an interesting example in that it is dialogical and participatory i.e. research is conceived of as a joint effort of a facilitator (or animator) and a group of people aspiring to understand their own circumstances better, in order to change these, if necessary. Research therefore becomes an intervention in the community setting.

Participatory action research is critical research, driven by action and values. It has the following advantageous aims:

- ◆ It produces knowledge in an active partnership with those affected by that knowledge.
- ◆ It is aimed at improving social, educational and material conditions.
- ◆ It is more practical than scientific.
- ◆ It aims to bring about a change rather than just gain knowledge.
- ◆ It is relevant to community needs.
- ◆ It mediates between individual and collective needs in that it is instrumental in promoting communal participation.
- ◆ It promotes a good relationship between the researcher and the researched.
- ◆ Instead of the researcher knowing about participants, s/he knows with them. In this way, participants are not called subjects.
- ◆ It has been described as bottom-up research instead of top-down research (Freire, 1973).

It follows the following phases:

- Definition of problems, whereby questions arise through participation
- Data collection and analysis, where participants are directly engaged. This involves a dialogue and reflexivity among themselves as well as with the researcher.
- Utilization of results where community members have access and control over their own findings. It enables communities to act on their own behalf.

Results can then be disseminated by the participants in popular as well as academic forums.

### **3.5 Techniques for data analysis**

#### **3.5.1 Quantitative data**

Firstly the data was treated with descriptive statistics, where percentages and sample means were calculated. Then, to deal with the possibility of the problem of sampling error, hypothesis testing was done using a t-test for small dependent samples. The results of these calculations will be presented in the next chapter (chapter 4).

#### **3.5.2 Qualitative data**

A combination of thematic content and discourse analysis was done to identify themes, summarize and categorize responses to open-ended questions. Morgan (1988) recommended this approach which involves using themes and direct quotations as it adds strength when compared to analyses, which use only one of the two methods. Details of the meetings and themes that came up in individual and group sessions will be summarized in the next chapter.

### **3.6 Résumé**

The study elicited the needs of the carers of terminally ill persons in individual sessions. These were discussed among participants in the mutual aid group meetings. The procedures of the present study have been laid out, including the scales and questionnaires that were used to collect data during pre- and post-testing sessions. The main strength of the research is that it encouraged participation from the community. The next chapter presents and analyses data.

## **CHAPTER FOUR: PRESENTATION AND ANALYSIS OF DATA**

### **4.1 Introduction**

This chapter presents the responses from all tools used to collect data. The responses from biographical data are presented and briefly discussed. The themes that emerged from individual interviews and group meetings are presented, analyzed and discussed qualitatively. Then numerical values are assigned from responses to the power maps and carer effectiveness scale and these are analyzed and subjected to a t-test for small dependent samples.

### **4.2 Presentation of data**

#### **4.2.1 Biographical information**

The mean age was 23.33 years with ages of the carers ranging from 20 to 32 years. Twenty seven percent (27,27%) of the participant carers (n = 3) were non-matriculated and 72,72% (n =8) were matriculated. All the participants except one had received formal training in caring. The length of service in the caring role ranged from 4 months to 2 years. The project has a co-ordinator, 2 counsellors, 5 peer educators, 2 youth workers and 1

drama co-ordinator. The number of clients seen ranged from 1 to 30 and deaths of clients ranged from 0 to 6.

#### 4.2.2 Individual interviews

The purposes of the initial, individual meetings were for the researcher and the participants to get to know each other before the group started, elicit and analyze their needs, pre-test, choose topics to be discussed in the following 12 sessions and contract as a group. Needs were listed and a time-table was drawn up, which was made of topics to be discussed. Participants also volunteered to facilitate different sessions. The themes that came up from different sessions were as follows:

##### 4.2.2.1 Meaning of caring

There were three themes that were revealed by the participants' responses to the question: 'what does it mean to you to be a carer?' First, 54,55% of the participants reported that being a carer meant sacrifice for the other and the community, knowing one had made a contribution. 81,82% of the carers seemed to derive pleasure from giving help where it was needed, helping the ill people (who could not help themselves) cope with the illness. To 45,45% it meant sympathizing, and giving up one's time for the other and being patient with them, which was what they needed most.

Second, 54,55% reported that they did it for themselves and their own growth. Caring meant knowing one could be sick one day and need to be cared for, and when that time comes, one will accept help without guilt. Carers reported that caring for an ill person gave one an opportunity to deal with difficult situations in life and grow from them (45,45%). Moreover, one learns a lot from the experiences that ill people share and it becomes a challenge to want to do more and learn more.

Third, because of the stigmatization of people living with the Aids virus, caring for them gave 36,36% of carers a chance to show love, support, acceptance and care which in turn helped them to deal with the disease and accept themselves as they were and their circumstances.

#### 4.2.2.2 The joys of caring

Regarding the joys of caring, four themes emerged. First, helping seemed to bring joy and satisfaction to the carers. It was not only caring for the ill that brought satisfaction to 72,73% of the carers but also making other people aware of what they need to know (giving them psycho-education regarding HIV/Aids and how to take care of themselves).

Second, being appreciated by the clients that one has helped brought joy (81,82%). One was not only appreciated by the clients, however, even the

families and the community members at large did appreciate. Being appreciated gave one recognition and validated one's efforts.

Third, 54,55% of the participants also reported that growing from the experience of caring brought joy. Because of the challenges of caring, one ended up looking for more information, by networking with other carers and professionals, thereby growing in knowledge. The mere sharing of experiences with other people working in the same field, made a positive difference. One also learnt a lot from ill people because of the experiences they shared.

#### 4.2.2.3 The frustrations/challenges of caring

The challenges of caring came up in four themes. First, 81,82% of the participants reported that some terminally ill people sometimes demand more than carers can offer (the carers could not meet the clients' expectations). This could be due to two factors i.e. limitations of the project itself (or the scope of that particular helper) or there are those that pose unreasonable demands even if the scope of the helper is known to them. This might have led to frustrations and feelings of helplessness in 36,36% of carers who then felt they had failed that client. An example of this was when a counsellor did a home visit bringing a counselling service and found that the client urgently needed what could be provided by the

home-based caregivers (food, medicines, his or her house to be cleaned, etc.).

Some participants (72,73%) reported that it was extremely difficult to counsel a hungry person or a person in excruciating pain. Therefore, although supplying such concrete/material needs like money and food might be out of the scope of a counsellor, he or she could not do his work effectively without them. There are some terminally ill persons who would ask the counsellor to find a job for them so they could be able to provide for their children. In such cases counsellors found that an ill person could not even turn on his/her bed without assistance. Some participant carers (36,36%) reported that some ill people were not aware of their emotional needs. They were only aware of their concrete needs and the project did not cover these.

Second, denial by ill people and / or their families that the person is HIV positive was a frustration for the carers. In some cases carers were rejected either by the ill person or the family members as they brought help to the home of the ill person. This caused frustration. Another source of frustration was seeing a client leaving carelessly because of denial that he was infected. Because of this, they got re-infected with sexually transmitted diseases. One felt like one had wasted one's time coaching

them how to live positively with the virus, when one met them at the clinic.

Third, 63,64% of the participants reported that death of clients they had been taking care of was a source of pain, bringing feelings of loss and grief. Sometimes they could not handle those feelings and it affected the quality of work negatively.

Fourth, there was a report by 54,55% participants that it was frustrating to be in the support group, which had people who did not attend regularly. Another frustrating factor was that the support group was not about sharing of experiences, problems and coping skills anymore. Rather it was more about funding. One participant reported that it was even difficult to bring in a new client to the group because s/he would not be supported emotionally.

#### **4.2.2.4 Special needs and expectations from the mutual aid group program**

The carers reported a list of special needs and after prioritizing the time available, and the urgency of the needs of the participants, it was agreed that the following topics would be dealt with. The other needs would be attended to in the follow-up program:

- Stress and its management
- Grief and loss
- Dealing with isolation
- Communicating and developing trust with professionals
- Avoiding getting over-involved with the client's problem
- Guilt, anger and other emotions
- Financial issues
- Looking after oneself - preventing burnout
- Standards against which they can evaluate themselves and their work
- Developing a healthy self-esteem
- Asking for help
- *Courage to help their clients face their problems and find their own solution*

### **4.2.3 Group meetings**

The group meetings were about topics outlined in 4.2.2.4 above. The methods used were discussions, short lectures (in cases where there was new information), brainstorming of ideas, sharing of how others were coping. Some discussions challenged the way that carers were doing things and their attitudes and perceptions. All members had a chance to lead one session, and the preparations were done together with the researcher who provided information if any was needed. The group

unanimously agreed that caring for a terminally ill person was an awesome responsibility, which might be overwhelming at first or if one did not have a support system. It was agreed that one could not satisfy all needs of the clients, but one should work within one's scope and if the client needed more than that, networking (referrals) could never be overemphasized. They also agreed that caring, helping and sacrificing oneself was equally rewarding especially when one saw an improvement in the state of health and well being of the person s/he was caring for. It was also agreed that carers should take good care of themselves and prevent burnout and stress instead of waiting until one suffered. Regular exercise, eating well and sleeping well were recommended.

Carers learnt how to deal with their difficult emotions and Carer Information Sheets were compiled, produced and issued to all members of the group (see Appendix F).

#### **4.3 Quantitative analysis of data and results**

The data obtained from pre- and post-testing of the two variables (empowerment and carer effectiveness) were first treated with descriptive statistics and then, to deal with the problem of sampling error in research, hypothesis testing was conducted. A t-test for small dependent samples was used to test hypothesis:

at 0.01 level of significance,

$$t_{\text{crit}} = 2,99$$

degrees of freedom (df) =  $n-1 = 11-1 = 10$  (where  $n = 11$ )

In the sampling distribution of the present research, the rejection area will be in one tail, i.e. beyond +2,99 because the researcher expected the improvement of the level of empowerment and carer effectiveness.

#### 4.3.1 Empowerment

Power-mapping is not a psychometrics of the individual, but a flexible method for representing important aspects of his or her social environment. Maps were used to guide the researcher and the participants to map the circumstances in terms of both the power and resources available to him or her (assets) and the extent to which s/he is subjected adversely to the proximal power of others (liabilities). The maps helped provide a visual summary of the participants' current position, helped target areas for concerted action to increase power, to measure and illustrate outcomes of this mutual aid group (Hagan and Smail, 1997).

In order to find out whether the help provided was useful in the reduction of distressing symptoms, and resulted in an increase in overall well-being, whether participation in the mutual aid group program empowered individuals, it was necessary to consider the relative power status before and after contact with the service. Therefore numerical values were

assigned on a five-point scale of 0–4 (see 3.3.3) in order to compare those constructed at the beginning of the program and subsequently (Hagan and Smail, 1997). The results of pre-testing and post-testing for the 11 participants were compared using a t-test for small dependent samples as follows:

**Table 4.3.1: A table displaying the results of the change in empowerment as perceived by participants**

Participant	Pre-test	Post-test	D	D <sup>2</sup>
01	37	39	2	4
02	33	35	2	4
03	35	40	5	25
04	34	36	2	4
05	29	32	3	9
06	27	30	3	9
07	29	34	5	25
08	32	35	3	9
09	35	39	4	16
10	35	37	2	4
11	28	35	7	49
<b>Sums</b>	<b>354</b>	<b>392</b>	<b>38</b>	<b>158</b>

$$\text{Pre-test mean} = X_1 = 354 / 11 = 32.18$$

$$\text{Post-test mean} = X_2 = 392 / 11 = 35.64$$

It was hypothesized that the level of empowerment of the carers would improve after they were involved in the mutual aid group program. The difference between the post-test and pre-test means is significant, due to the impact made by the mutual aid group program.

$$\begin{aligned}
 t_{obt} &= \frac{\sum D}{\sqrt{n \sum D^2 - (\sum D)^2 / n - 1}} \\
 &= \frac{38}{\sqrt{11 \times 158 - 38 \times 38 / 10}} \\
 &= \frac{38}{\sqrt{1738 - 1444 / 10}} \\
 &= \frac{38}{5.42} \\
 &= 7.01
 \end{aligned}$$

therefore  $t_{obt} = 7,01 > t_{crit} = 2.99$

$t_{obt}$  of the value of 7,01 is significant at the chosen level of significance .01 Therefore the researcher retains the research hypothesis Also, from inspection of the table 4.3.1, it is clear that all participant scores improved from pre- to post-test conditions.

#### 4.3.2 Carer effectiveness

In order to find out whether the help provided was useful in improving the perceived effectiveness of carers, whether participation in the mutual aid group program had a positive impact on individuals, it was necessary to consider the relative effectiveness before and after contact with the

service. Therefore numerical values were assigned in order to compare those constructed at the beginning of the program and subsequently. The results of pre-testing and post-testing for the 11 participants were compared using the t-test for small dependent samples as follows:

**Table 4.3.2: A table displaying a change in carer effectiveness as perceived by participants**

Participant	Pre-test	Post-test	D	D <sup>2</sup>
01	63	66	3	9
02	52	58	6	36
03	56	58	2	4
04	57	58	1	1
05	50	55	5	25
06	48	55	7	49
07	51	55	4	16
08	51	57	6	36
09	56	60	4	16
10	55	61	6	36
11	51	59	8	64
<b>sums</b>	<b>590</b>	<b>642</b>	<b>52</b>	<b>292</b>

$$\text{Pre-test mean} = X_1 = 590 / 11 = 53.64$$

$$\text{Post-test mean} = X_2 = 642 / 11 = 58.36$$

It was hypothesized that the effectiveness of the carers improved after they were involved in the mutual aid group program. The difference between the post-test and pre-test means is significant, due to the impact made by the mutual aid group program.

$$\begin{aligned}
 t_{obt} &= \frac{\sum D}{\sqrt{n \sum D^2 - (\sum D)^2 / n - 1}} \\
 &= \frac{52}{\sqrt{11 \times 292 - 52 \times 52 / 10}} \\
 &= \frac{52}{\sqrt{3212 - 2704 / 10}} \\
 &= \frac{52}{7.12} \\
 &= 7.30
 \end{aligned}$$

$$\text{therefore } t_{obt} = 7,30 > t_{crit} = 2.99$$

Because of  $t_{obt}$  of the value of 7,30 at .01 level of significance, the researcher retains the research hypothesis. Also, from inspection of the table 4.3.2, it is clear that all participant scores improved from pre- to post-test conditions.

#### **4.4 Program evaluation**

The program was rated as excellent by 82% of the participants and good by 18% of the participants. They reported that it empowered them with skills to cope with their own feelings and those of the persons they were caring for.

They also reported that the program was helpful to their clients because they were now more ready to face the challenges of their work and also because they knew that they had this source of support (the group) to fall back on in case of problems. The program was also helpful in improving the level of personal empowerment as well as perceived effectiveness as carers. The problems with a support group that had been reported to be 'stagnant', not moving forward, was reported to be moving, since they gained more skills in running a support group and how to vary methods of running it.

The main problem was that the level of participation in the sessions had not been the same. There were some members of the group, who were actively involved and some were not that active. This could be attributed to personality differences because the members who were a bit inactive were consistently so, except when they were leading sessions. Another problem was that the participants felt that the sessions were not enough,

that all their needs should be addressed and the solution to this was that the program would continue as had previously been planned.

It was also suggested that the groups be run for other projects in the same organization as well as other organizations that care for the terminally-ill. Eight of the members of the group committed to starting mutual aid group programs elsewhere. The way that the group was run encouraged participation. Everyone was recognized as important and as a valuable source of support. No solutions were imposed, but alternatives were discussed at length. Each member had a chance to reflect on sessions at home and practice new skills with their clients to see if they actually worked and decide whether to adopt them or not. The way they did some things were questioned at some points, but they were ready to rethink their strategies and to be flexible where it called for that. Therefore they learnt action and acted on the basis of learning.

#### **4.5 Résumé**

The themes from the sessions have been presented and analyzed. It is evident that the study yielded positive results. The mutual aid group program empowered the carers and improved their effectiveness in caring. However, the study is not without limitations. The next chapter points these out, makes recommendations for future research and concludes the study.

## **CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS**

### **5.1 Introduction**

This chapter concludes the present study, on the basis of the literature reviewed, the mutual aid group that ran for twelve sessions, pre and post-testing of the participants, and the testing of the hypotheses. The main findings are the core of this chapter. Limitations of the study and the implications thereof will be articulated. Recommendations for future studies in this area of health promotion mark the end of the project.

### **5.2 Summary of the main findings and their discussion**

#### **5.2.1 Themes from sessions**

Carers derive pleasure from caring for others who cannot help themselves. This happens before they receive any token of appreciation. Being involved in caring seems to lead to growth that comes from gaining more experience and getting more information from ill people as well as other professionals. It can however be frustrating when the needs/expectations seem to be more than what carers can provide because of the limitations of the project or unreasonable demands posed on them. One particular frustrating element to deal with in clients and their relatives is denial of sickness, as it leads to the rejection of the help brought by the

carers. It is devastating to experience death of a client and face one's own grief issues while helping the family of the deceased.

The group meetings took the form of lectures, brainstorming ideas, discussions and role-plays. Sessions were led by the carers. It was unanimously agreed that one cannot satisfy all the needs of the clients. Therefore one should be as professional as possible, using the system of referrals effectively. The result of those sessions was the production of the Carer Information Sheets presented as Appendix F.

### **5.2.2 Empowerment**

There was a significant improvement in the level of empowerment perceived by the participants. The participant carers gained influence over events and outcomes of importance to them (Fawcet et al., 1994).

### **5.2.3 Carer effectiveness**

The study promoted carer effectiveness of the participating carers of terminally ill patients.

### **5.3 Limitations of the study**

One limitation of the present study was the lack of mix of types of carers. There were only counsellors, youth workers and peer educators, and no home-based caregivers, nurses and other professionals. There was also no mix of ages, only the youth. All participants worked for the same project, therefore the sample was regarded as biased.

Also, the results of this study could have been confounded by some variables like the fact that participants were like co-researchers. That could have affected the way they self-reported the effect of the group on them.

Lastly, the literature on non-professional caring is lacking and this led the researcher to rely heavily on the very few references available. This poses a challenge for future researchers.

### **5.4 Recommendations**

The following recommendations are made:

- ◆ More groups of this kind (to promote health at a tertiary level) still have to be formed all over the country because of the HIV/Aids pandemic. Carers need support.

- ◆ Those health professionals working with communities should be alert and sensitive to the needs of communities they serve, in order to start such groups. In these groups mutual advice and support is valuable in order to work through painful emotional experiences.
- ◆ The government should be encouraged to fund such projects, which promote health.
- ◆ Likewise the business sector should also be encouraged to fund such projects and also to create awareness in the workplace about the contribution that can be made by healthy people towards increasing productivity.

## **5.5 Conclusion**

It is evident that the less powerful members of society are more susceptible than others to mental health problems (Thorncroft, 1991). Those that have the most demands on them and the least resources with which to cope (e.g. carers, women, the unemployed, the disabled, lower socio-economic class members and single parents) suffer the most (Hagan and Green, 1994). However, if they are in supporting relationships, in which they are given an opportunity to be heard (at the tertiary level of health promotion) their solutions for living are improved and their health, strength, skill and human rights increased. Such interventions improve meaning, self and social realization and actualization and other higher level survival needs (Maslow, 1971; Edwards, 2002) among those in helping professions.

South Africans are currently in the process of restitution, nation building, reconciliation and reconstruction. Community psychology attends to the needs of the so-called 'victims' of the previous system, resolving past neglects and attending to new concerns and crises. Therefore, community psychologists are change agents facilitating the process of social change in post-Apartheid South Africa. The challenge facing community psychologists is to contribute towards building a secure and stable society from fragments left by Apartheid.

The present research was in line with values of community psychology, which regards whole communities (not only individuals) as possible clients. Some of its aims are illness prevention and alleviation of problems / psychological symptoms through health promotion and empowerment. In this study, this was achieved through social action by individuals, communities and community psychology professionals working together in collaboration. The main goal was improving human condition and promoting psychological well-being. This was achieved by applying knowledge and methods of study, research, intervention and evaluation from the broader disciplines of psychology and social sciences in community context.

It is the researcher's hope that the present research has made a valuable contribution to health promotion of the South African population, through the social action model. It is also hoped that the reader will be conscientized to the

importance of caring, helping, healing for all citizens, especially those regarded as 'at risk for mental problems'. It is hoped that health professionals will be challenged to assist communities in altering the imbalances in power and wealth. This will be done through taking measures that will make individuals in communities better able to control their own lives. This cannot be achieved unless in part they gain access to and possession of available resources.

This mutual aid group program was nested within an existing community organization. Therefore, it is guaranteed that the structures will be left in place even if the researcher withdraws her participation. The mutual-aid group for carers empowered participants to be able to empower other carers. Most of the carers committed themselves to start more groups of the same kind, thereby cascading the skills that they learnt in the mutual aid group program. This will be done under close supervision of the current researchers.

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**Appendix A: Biographical Information**

1. **Identification number** .....
2. **Age** ..... years, ..... months
3. **Your educational level** .....
4. **Your formal training in caring** .....  
.....  
.....
5. **When did you start the caring profession?** .....
6. **Your role(s) in this project** .....  
.....  
.....
7. **How many terminally-ill clients have you seen in your caring profession?** .....
8. **How many have died? ..... children**  
..... **Adult females**  
..... **Adult males**

**Appendix B: Needs Assessment Questionnaire**

**1. What does caring for (terminally) ill persons mean to you?**

.....  
.....  
.....  
.....

**2. What are the joys of caring?**

.....  
.....  
.....  
.....

**3. What are the frustrations of caring?**

.....  
.....  
.....

**4. List your needs as a carer of the terminally-ill persons.**

.....  
.....  
.....

**5. What do you hope to contribute in the mutual aid group in terms of your expertise and your experience?**

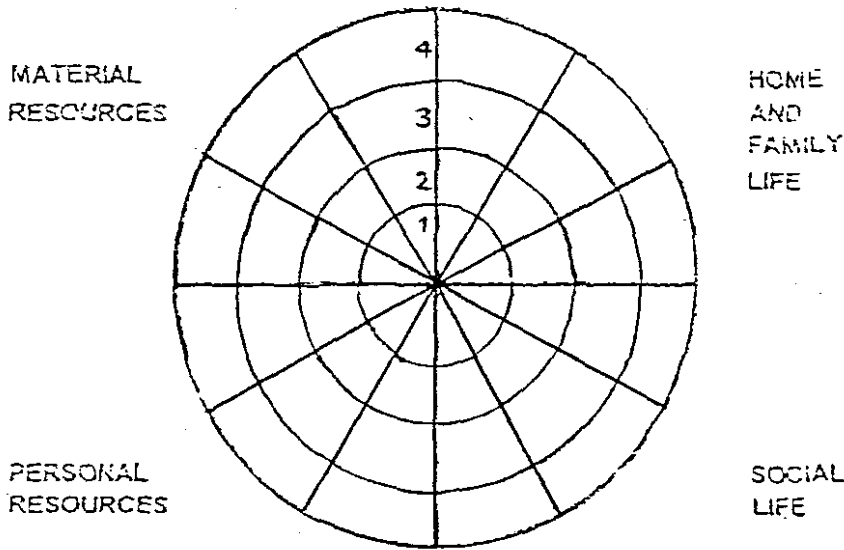
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**6. What do you hope to gain from the mutual aid group?**

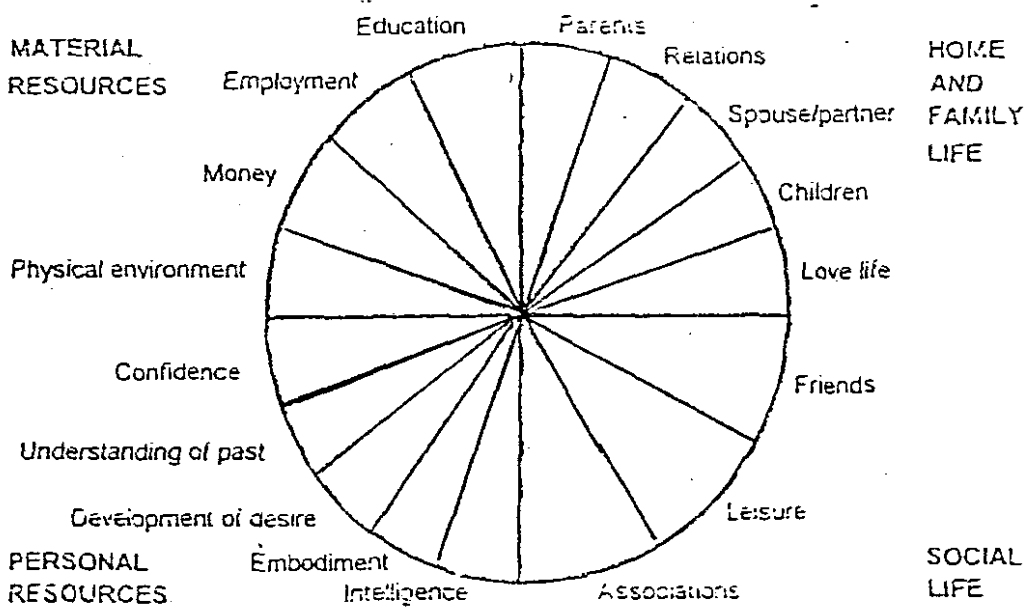
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**Appendix C: Power maps**

**Figure 1: Skeleton Power map (From Hagan and Smail, 1997)**



**Figure 2: Terrain of proximal powers and resources (From Hagan and Smail, 1997).**



## Appendix D: Carer Effectiveness Questionnaire

This questionnaire tests how you feel about your work in terms of the level of burnout and your effectiveness as a carer. Please rate yourself as sincerely as you can by marking the appropriate space with an X. SA= Strongly Agree; A= Agree; U= Uncertain; D= Disagree; SD= Strongly Disagree

	SA	A	U	D	SD
I'm emotionally exhausted by my work					
I can't be a source of emotional support at home					
I'm irritable most of the time					
I feel emotionally drained by my work					
My work takes from me but does not give anything back					
I'm looking for another job					
I feel stretched to the limit by my work					
I'm in this job because I need the money					
I'm so used to my work that I don't feel anything anymore					
I work for the sake of doing something					
I need a break					
My clients don't mean anything to me					
I don't look forward to going to work like I used to					
I feel useless in this job					
I don't feel proud of my work anymore					
I am contemplating resigning					
I don't enjoy doing my work anymore					
I am about to quit					
Sometimes my clients irritate me					
I find it hard to cope with the demands of my work					

## Appendix E: Program evaluation interview guide

Please evaluate the mutual aid group program as sincerely as you can. Please tell how you feel about and think of it. Feel free to express your views as they are important for all co-researchers to know whether it made an impact in your life and your circumstances.

1. Did the mutual aid group program meet your needs?

--	--

2. How would you rate the mutual aid group program?

Excellent
Good
Fair
Poor

Why?

.....

.....

.....

3. Do you think the mutual aid group program was helpful to your:

clients

--	--

Personal empowerment

--	--

Effectiveness as a carer

--	--

4. What would you say were the main problems of the mutual aid group program?

.....  
.....  
.....

5. Would you like the mutual aid group to continue?  
Why?

.....  
.....  
.....

6. What suggestions would you give to improve the mutual aid group program?

.....  
.....  
.....

7. Comment on the mutual aid group program in your own words.

.....  
.....  
.....

## **Appendix F: Carer Information Sheets: From carer to carer**

Each Carer's situation is unique and every Carer will have different needs for information and support. We have also learnt as Carers that our needs change over time so some of the issues raised in the information sheets may not be relevant now, but might be later.

### **Major issues for Carers**

Stress

Grief

Isolation

Communicating and developing trust with professionals

Guilt, anger and other emotions

Financial issues

Looking after yourself - Preventing Burnout

Developing a Healthy Self-esteem

Asking for help

### **Stress**

What is stress? Essentially, stress refers to the application of some force or pressure to do something. We all need some level of stress in our lives, or we wouldn't get anything done. However there are times when we feel too much pressure, we don't know how to respond to it, it builds up and before

we know it we are feeling 'stressed'. The good thing is that there are ways of managing stress so that it does not affect your health and well-being.

As a Carer, it is important to work out what pressures you are experiencing that may build up to cause stress.

Do you keep pushing yourself and have unrealistic expectations of what you can achieve?

Are there daily tasks that you find particularly difficult?

Do you feel constantly tired?

Are you always striving to meet the needs of other people, putting them first?

Do you take time out from the things that place you under pressure?

### **Reducing Stress**

Here are some tips on how you can effectively deal with stress.

**Talk it out**

*When something worries you talk it over with someone you can trust.*

Talking it over may help you to see things more clearly, which then might make it easier to do something about.

**Take small steps**

What was insurmountable whole, becomes a manageable group of pieces.

Don't try to do it all at once, break a task down and do the most important things first.

Don't try to be a 'super-carer'

No-one can be perfect in everything. Set realistic goals and ask for support.

Make time for recreation/ exercise.

Allow time for time-out. Having a break will allow you to return feeling so much better. Physical exercise helps to 'burn' off tension.

Resolve conflict

State your feelings and position as calmly as possible, and listen to the other's point of view. Talk it over and try to resolve the conflict.

Give in sometimes

Stand your ground on issues of which you are sure and which are important to you, however, you could sometimes be wrong. Be willing to admit this as it can sometimes gain you support from others.

Eat well

Provide yourself with the fuel to keep going. Increase intake of healthy, nutritious foods and reduce sugar, fat and caffeine.

Learn to say 'no'

Try to avoid being 'used up' or taken advantage of.

## Practice relaxation

Regular relaxation practice will lower stress. Chose something that you will enjoy and want to do regularly. Massage, yoga, relaxation tapes are just a few of the options.

## **Grief**

Many people associate grief with death and do not take into consideration the experiences of loss that can create similar reactions to the loss of a loved one through death. We grieve when we lose something we care deeply about, such as:

Shared plans and activities

Relationships

Hopes for the future

Friends and community life

Work or career

Holidays

Personal time to ourselves

Security

## **Special Aspects of Grief for Carers**

Grieving for Carers may go on for a long time, years, a lifetime. Carers are constantly in touch with grief. They feel the effect of disability or illness on the person they care for. Grief is caused by the changes in their lives and their relationships including that with the person they care for. The demands of caring also add to the sense of loss and grief.

Losses within the caring context keep on occurring, such as a set back in the condition of the caree, family and friend's support disappearing. Even a small matter of not being able to celebrate a special event can trigger fresh grief. Grief can feel like a punching bag - you think you have coped and then it returns and hits you again.

The person you are caring for is also experiencing grief and as the Carer you will more than likely bear the brunt of that grief. You may be faced with supporting someone else through all the emotions and symptoms of *grief while trying to deal with these yourself.*

The process of grief will be different for every individual but there are some commonalties of grief reactions that most people experience. These can include;

Disbelief and denial

Release of emotion - tears, laughter

Feeling sad and alone

Physical symptoms - headaches, nausea, continuous cold and flu like symptoms

Losing concentration, forgetfulness, questioning own sanity

Real and assumed guilt

Anger, blame and resentment

Loss of interest and energy

Dealing with grief - acknowledging it and working through its course - is essential for your mental and physical health.

### **What can you do about grief?**

Acknowledge its existence - grief is a normal part of the caring journey.

Put something positive in your life - try to balance the loss with something that makes you feel good.

Recognize your limits and accept help.

Beware of withdrawing emotionally and physically.

Find and use skilled help - talking to counsellors, attending a course or support group will assist you to work through the feelings and emotions.

## **Isolation**

Isolation doesn't just happen, it grows gradually.

Isolation is:

Not being able to get out of the home.

Having no one to talk with.

Having no one to share thoughts and fears with.

Feeling different, cut off, alienated.

Never being touched.

Having no one to call on for help.

Feeling unconnected.

Isolation is very destructive. It separates you from the rest of the world, from the help and friendships you need. You need to do something about it, not only for your own quality of life but also for the person you are caring for. You can become isolated from your friends, family and community because:

They feel uncomfortable coming into your home.

They don't understand your responsibilities.

They don't understand the role of Carer.

They only see your coping exterior.

They don't see your needs.

They don't know what to talk about.

Because they feel that it is too hard and they are frightened that it might happen to them.

**Tips to assist you to prevent isolation:**

Identify the people, activities and interests that you have or had that are valuable to you.

Resolve not to let these go, or begin to rebuild them. Some things may have to go but try to maintain those that are of greatest importance to you.

Make a plan to keep and rebuild those things.

Share that plan with someone who can help and support you to make it happen.

If you have become isolated, getting back into the world will be difficult.

Reach out to a friend, another Carer or support person to begin with. Just going out for a coffee may be a big first step. Starting small and building from there is a good plan.

**Communicating with professionals**

When you are caring for someone, you often have contact with a broad range of professional people who provide support and services to you and

the person you are caring for. It can be daunting at first, to have many different people, with different expertise and advice to give, come into your lives. There may be times when you feel that your home has turned into Rundle Mall, because you have so many people coming and going. There may be times when you don't even remember who the people are, or what they are there to do. This is common and especially in the early days, you might have to ask people where they are from and what support they will offer you and how they work with the other support people you are in contact with.

The following list may help you when it comes to communicating with these people so that you are asking the right sorts of questions to the right people.

**Medical Practitioner:** Could include your local/ family GP. They are able to provide information about the disability or condition, its effects on the person and those around them, and also offer support in linking with appropriate and available services.

**Physiotherapist:** Someone who supports and promotes movement and mobility.

**Occupational Therapist:** Someone who supports independence in everyday tasks. This may require adaptation of equipment or the development of skills to manage as much independence in daily living tasks.

**Speech Therapist:** Someone concerned with the evaluation, diagnosis and treatment of speech and language problems.

**Psychologist:** Someone concerned with the assessment of understanding and personality as well as interpreting a person's behaviour.

If you do have contact with many different professionals it might be helpful to follow the following tips:

**Keep Records:** Write down who comes, when they come, what they say or advise. Make a list of people, what they do, where they are from and their telephone numbers.

**Ask Questions:** If you are not sure what role a particular person plays, ask them. If you don't think you need a particular service ask why you have been referred. If you feel that you have needs that aren't being addressed ask what other support services you could be referred to.

**Write Questions Down:** before a meeting with a professional support person, think

about the issues or questions that you have and write them down so that you don't forget anything that is important to you. Also write down the response you get so that you don't miss the answers. If you have problems: There may be times when you don't get along well with the support people you are in contact with. If this is the case it is better to deal with it sooner rather than miss out on feeling good about the support you are entitled to. Talking through the problem with someone you trust and feel comfortable with will help you work out how to deal with the issue. Find out what the grievance procedure is with the organization and follow the process for airing your concern. If you continue to have problems there are advocacy services that can support you.

### **Guilt, anger and other emotions**

Justified guilt occurs when you do something that violates realistic moral standards and personal values, such as stealing, taking advantage of other or allowing a mate to abuse a child. It is a fact that people frequently feel guilty when there is no objective basis for them to do so. It is not violating moral standards to have an afternoon off shopping, however Carer often feel guilty about doing this or even thinking of doing it.

When you are feeling inappropriately guilty any or all of the following things may be happening. You see yourself as the only one who can help

and therefore you should take responsibility. The person in need often appears helpless. The message is communicated that, "if you really care, you will do this for me" or you give yourself this message.

## **Emotions**

Emotions are bodily sensations in response to a thought, which is a response to a belief. It is an automatic reaction. Emotions just are, they are neutral, neither good nor bad, wise or unwise. You don't have control over your emotions. The action taken as a result of an emotion may be wise or unwise. You do have control over the way you act in response to the emotion you are feeling.

There are four main types of emotions i.e. joy, fear, sadness and anger. Emotions are neutral, but can be expressed constructively (healthily) or destructively (unhealthily).

How to express your emotions constructively:

**FEAR** Admit it, seek re-assurance, learn to trust, deep breathing, pray, flee, fight.

**ANGER** Own it, speak out ("I feel angry". Not "you make me angry"), physical exercise (no hurting others!), yell, talk about it. There is

enormous energy in anger, it can be used to fight injustice, seeking to improve your own situation.

**JOY** smile, laugh, dance, skip, hug, party, cry.

**SADNESS** cry, sigh, moan, admit, then try to do something to change your mood, seek support.

### **What happens to unexpressed emotions?**

The energy that emotions create gets bottled up and becomes a stress. The result can be the body expressing the emotion in other ways - headaches, backaches, illness, sarcasm, depression, vindictiveness, blaming others. To be healthy we need to allow ourselves to feel and accept our emotions and to express them constructively. Dealing with our emotions is an important part of caring. Counselling is available to assist.

When a Carer is experiencing intense feelings it is important that those feelings be managed in a way that is satisfactory for everyone concerned. Everyone manages feelings in a different way. Some people experience only a brief irritation, which quickly passes. Others react strongly and rapidly and find it difficult to control their behaviour. Others find that their feelings build slowly and become resentments that they do not share with anyone.

In managing emotional responses it is important to:

Be aware of the feelings you are experiencing because they do influence your behaviour and judgement.

Understand your feelings and that it is possible for you to be in charge of it.

Find an acceptable way to release strong emotions because they rob us of energy and may lead to feelings of depression, helplessness and/or physical symptoms.

**Options to consider for managing feelings.**

Identify the emotion and notice what it is that you are feeling upset about.

Say to yourself - I am feeling \_\_\_\_\_ (emotion), about \_\_\_\_\_ (situation)

Allow yourself to have feelings. Feelings are natural.

What you do about the feeling is the key.

Act instead of react.

Take a moment to be in charge of the emotion before deciding what to do.

Be aware that you are in charge of the feeling and have choices about your actions.

It may be necessary to step into another room and find privacy and take three deep breaths, exhale slowly and tell yourself to R..E..L..A..X.

## **Financial and Legal Issues**

As a Carer you may be responsible for your own and another person's financial and legal matters. There may be simple and complex situations that need to be dealt with and you may from time to time need the advice from other people with expertise in financial or legal issues.

### **Financial advice**

If you are concerned about your own, or the person you are caring for, financial situation then it is best to seek advice as soon as possible. Financial advisors can assist people to develop a budget and work through any debt problems.

### **Making financial decisions for the person you are caring for.**

In situations where the person you are caring for is an adult and able to express their own wishes then as a Carer you must follow the wishes of the person you are caring for. If you don't follow their instructions or disclose to them information that will enable them to make accurate and informed decisions, then you are at risk of perpetrating financial abuse. If *the person you are caring for can not express their own wishes or have lost the capacity to make decisions affecting their life* then there are some

accepted "informal arrangements" that can continue without any intervention. The person you are caring for can make an advance directive called an enduring power of attorney so that if the situation arises that they no longer have the capacity to make decisions for themselves, they have given someone else the authority to do this.

### **Legal information**

There may be a time when you require legal advice on matters that are affecting you. Making a will, thinking about who can make decisions on your behalf if you became incapacitated or if you are making decisions on behalf of someone else are all very common situations.

Legal advice can be obtained from a solicitor, local community legal centres, or the Law Society. These organizations should offer free advice on any legal problem.

### **Legal issues you might want to think about**

#### **Making a will**

By making a will you are saying who you want to receive your property and possessions when you die. If you die without making a will, it may be more difficult for your family to deal with your estate. Private lawyers can

prepare your Will and/ or give you advice but there may be costs or conditions attached.

### **Advance directives (living will)**

If the person you are caring for has the ability to make their own decisions about financial and other life areas, but due to their condition may at some stage not always have this ability, then it is a good idea for them to make an advance directive. Advance directives enable them to say now, who they would like to manage their affairs if and when they can no longer do so for themselves. There are two advance directives that are advisable for everyone to have in place so that if ever they lose their own abilities to make decisions for ourselves they can say who they want to do this for them. This gives them the control of "appointing" someone they trust and respect to have this authority.

### **Enduring Power of Attorney (EPA)**

An EPA is a document that allows you to appoint a person (Financial Attorney) to act on your behalf in making decisions about property and finances. The word enduring means that your Attorney will continue (or begin) to manage your financial affairs should you become mentally incapable. It is sensible to have more than one Financial Attorney if

possible. The *Enduring Power of Attorney do-it-yourself-kit* contains three forms and provides information about Enduring Power of Attorney and how to fill in the document.

### **Enduring Power of Guardianship (EPG)**

An EPG is a legal document allowing you to appoint your own guardian/s. Your Enduring Guardian would start to make decisions for you, if you were to lose your mental capacity. An Enduring Guardian makes different decisions from those made by a Financial Attorney. An Enduring Guardian makes decisions about you and how your needs and interests can best be met. Such decisions may include:

**Where you will live (you may need to go into a nursing home)**

**Which doctor you should see**

**Who you can go on holiday with and how long**

What if there isn't an Enduring Power of Attorney and/ or Guardianship in place for the person I care for and they are not mentally competent to make decisions? Relatives can deal with some day to day money matters. If a Financial Attorney has not been appointed and major decisions have to be made or property sold, then an application can be made to have a

*Financial Administrator appointed. The financial Administrator can be a family member or an independent trust company.*

If the person you care for, loses their ability to make decisions about other areas of their life, then again in most situations there will be family and friends to make those decisions on their behalf and in their best interest. However situations can arise that require a guardian to be appointed. These can include:

*Family members being unable to agree about care plans.*

*The person you care for or another person disagreeing with the decisions you are making on their behalf.*

### **Looking after yourself - preventing burnout**

Caring can be a long journey for many Carers, not just in "emotional distance" to be traveled but also in time. In some situations caring can be a lifetime prospect, as in caring for a child with a disability or chronic illness. Other situations may be shorter in length, but be extremely intense. Whatever the individual caring situation, all Carers need to develop some strategies to prevent burnout. Before you start caring consider the following:

There is always a choice. Even if at first it seems there is none, give yourself time to explore and consider the options.

Be prepared. This means understanding as much as possible about the disability, illness or condition of the person requiring care and support. Understanding the limitations that it will likely impose on both of you and the impact that caring is likely to have on the rest of the family are important things to consider. Being honest about the things that you are and are not able or willing to do.

Community supports and services should be available from early on, don't wait for things to get desperate or breaking point. Find out what services and supports are available to you now and in the future.

Look at your own motives. Sometimes we take on responsibilities out of a need to be seen as "helpers". We might even have an illusion that we are indispensable, "no one could look after him like I could". We might need to appear worthy, or moral. We might be worried about what other people think if we don't take on a caring role. It might be sheer stubbornness and pride.

Accept that one of your reactions to becoming a Carer will certainly be grief. This can include grief for the sacrifices you are making and also grief for the changed relationship with the person you are caring for. Setting up support (close friend, support group or counsellor) to help you work through this and other feelings will be important.

Let other family members know that you will need their help and appreciate their support. Don't try to do everything yourself.

**To set yourself up for success consider the following:**

Cultivate some objectivity.

Step back emotionally and try to become a witness to what is happening.

Observe what your relative does.

Go back to your motives and actions, but without being judgmental. You may see your own limits, your fear, anger and impatience but don't be hard on yourself.

Recognise that you're doing the best you can. Have some compassion for yourself and you'll increase your compassion for the person you care for.

Work out a practical plan of action. This may involve reading up on the condition, disability of illness, getting advice and organising help such as home nursing, recreational activities. If you are working towards the future in a practical way you are unlikely to suffer burnout.

Get away - for a weekend, a day or a few hours. This gives you both physical and emotional distance and allows the rejuvenation of body and soul. Try to organise regular breaks. Don't let yourself be dissuaded from having fun by other people's opinion or their disapproval.

Be assertive. Express your needs clearly and calmly.

Practice stress management technique (refer to Stress sheet).

Set some boundaries. Write them down and remind yourself of them from time to time.

Be aware of things that you can and are willing to do, but also be aware of the things that you are not able or willing to do. Be clear to yourself and others about your boundaries.

You can't do everything and no one, especially you, should expect you to. Developing a healthy self-esteem will also assist in the prevention of burnout. (refer to Self-esteem sheet).

### **Developing a healthy self-esteem**

Self esteem, how you feel about yourself, can have an impact on your caring role. If as a Carer you have, or are willing to develop a healthy self esteem then you should find the caring role a more rewarding and fulfilling one. For many of us, self-esteem, or how we feel about ourselves, is dependent on external conditions. It is gauged by comparing our performance with the performance of others and is supported or undermined by what other people think about us. Why should we require others to tell us who we are and how we should feel about ourselves?

If we have healthy self-esteem, we Love ourselves, feel that we are able to deal with life's challenges, know that we are needed and that we have something special to give and are not reliant on other people or activities to make us feel good about ourselves.

The foundation of healthy self-esteem is a deep appreciation of life and the opportunities for growth it presents. This means seeing value and lessons that each situation offers. A person with healthy self-esteem is not afraid to make mistakes, because he or she knows that making mistakes is essential to learning.

Having unhealthy self-esteem means that we need other people's approval or praise to feel good about ourselves. We are dependent on certain situations to make us happy, such as being popular, or making a lot of money. If we let them, these activities can absorb all our time and energy.

If, as a carer, you have unhealthy self-esteem, you may be easily hurt by negative things people say to you, and by events in your life that don't work out as you wish. You may spend a lot of time and energy trying to forget your unhappiness. The stress of caring along with your feelings of unhappiness or dissatisfaction can lead to further complications of depression or emotional withdrawal.

Building healthy self-esteem can be a challenging and difficult task, one which you may need/seek support for. It involves growth and change in many areas of your life, such as:

Recognising and changing attitudes and ideas that act as barriers to healthy self-esteem

Being sensitive to your emotions and to those of others, and cultivating emotional closeness with friends and family

Recognising those physical habits and body language that act as barriers to self-esteem

Improving your physical health through proper diet and exercise

Developing an appreciation for the gift of life, even in difficult circumstances.

### **Asking for help: How to get what you want**

It sounds so simple but it can be one of the most difficult things to do.

Asking for help requires two things:

1. You need to know what you want.
2. You need to know where to get it.

Many Carers are not sure what help or support they can get so they don't think they know what they want. It might help by asking yourself the following question. What would make a difference to you, in enabling you to *manage your caring role*? The answer to this question will help determine the support that you would find most helpful and therefore will

be different for everyone who answers this question and may change over time for you too.

Once you have determined what would make the difference for you then you need to ask for help.

### **Who should you ask?**

Start by looking close - family, friends, neighbours, other Carers. You may find that people are more than willing to help, they just don't know what you need. By giving them a clear task they have the opportunity to help and you get the support you need.

You might want to make an arrangement with a friend or family member, that if they do one task or job for you that you will do something in return for them. (for example, if your sister looks after your husband while you do the shopping each week, you will make a casserole for her dinner that night) If you find that you require help and don't have anyone close that you can ask, there are community support services that could assist.

### **Why you should ask for help**

1. Asking indicates self worth and self-esteem. Asking confirms in our own mind and in the minds of others that we have rights and privileges. It means that you feel you deserve and it starts to create an attitude of expectancy.

2. Asking is important for your health. When you don't ask, you can be overlooked, ignored, left out. That leads to frustration and additional stress.

3. Asking is the first logical step to take in letting your family and friends know what you want. They are not mind readers, you have to give them some clues but don't be too cryptic. It will just frustrate you if they don't get the message, so send it clearly.

4. Asking gives somebody else the pleasure of helping you. In fact, failing to ask is selfish. If you like to help others, then give them the same opportunity. Don't deprive them of the satisfaction of helping you.

People in the most part are more than willing to help if they perceive that you are in need or if they believe that you are already doing everything you can and that you need some extra assistance. Many people are desperate to help but they fear they may impose.

### **When They Need More Care**

There comes a time for some Carers when they realise that they are unable to provide the level of care and support to their loved one that is required.

This may come about due the health of the person being cared for deteriorating over time or because the health of the Carer deteriorates over time, or because of other commitments and pressures that are impacting on the situation. Whatever the reason, coming to the understanding that the person being cared for would benefit from more support or a new environment can be a very difficult and emotional realization.

Residential care is often the next step that is considered when the person being cared for needs more care. Making the decision to move into residential care will involve a complex mix of emotions such as sadness, grief, failure, guilt, anger, relief, self doubt and frustration. Whilst these emotions are often difficult to deal with they are not uncommon and are, in fact, a normal response to the thought of such a lifestyle change.

Talking with trusted family, friends and other support people can help during this time to work through and express your emotions, to gain the practical support to look at what will be best for both you and the person you care for in the long term.

A move into residential care does not have to be seen as the end of your caring role. View it as sharing the care with others. You have not ceased to care or love and your involvement in the continued care of your loved one is of great benefit to both of you. By sharing the care with a residential

facility, you can have more energy for quality, dedicated support because you are less physically involved. You can still be involved in a very practical and meaningful way. For example assisting at mealtimes, going on outings, reading books or news papers will give you an opportunity to still share in your loved one's life as well as getting to know the staff and other residents at the residential care facility.

Residential care facilities often have waiting lists, so it is important to plan ahead and visit a number of facilities to find a few that you feel comfortable with. Being on the waiting list can also be very stressful, not knowing when the move might occur, putting other things on hold until the vacancy comes up. Given that this time can be stressful and time consuming, it is best if this "research" is done at a time when you are not feeling overwhelmed by other facets of your caring role, if this is possible. Again asking for assistance from family, friends and other support people at this time may help you manage during this process.

Enjoy caring for others, your labour in the Lord is not in vain.