

**COPING WITH MENTAL ILLNESS :**  
**A CASE STUDY IN INITIATING A**  
**SUPPORT GROUP IN MAMRE**

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## ABSTRACT

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The aim of this dissertation is to provide a detailed description and partial evaluation of a support group for psychiatric out-patients and their relatives in Mamre. The first nineteen sessions of the support group are described in detail, and the evaluation information was obtained from the participants at the evaluation workshop held in February 1992, as well as the facilitator's observations.

The nineteen group sessions were usually held once a month, but not every month, between June 1990 and February 1992. The sessions were all held on Sunday afternoons and usually lasted two to two-and-a-half hours.

All known psychiatric out-patients in Mamre and their families were invited to all the meetings. Attendance varied, but a group of approximately 11 regular attenders emerged over the nineteen sessions. Three community workers also joined the group at various stages and became regular participants in the group.

The preliminary evaluation of the group revealed that the group is functioning within the working phase of group development, and that the group provided a number of benefits to the regular participants. The evaluation also highlighted issues of autonomy, heterogeneity and non-adherence. Suggestions for further research and group aims, focusing around these issues, are made.

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## BACKGROUND TO THE STUDY AND OVERVIEW

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This study has its origins in 1988 when I became a family member of "the mentally ill". This first hand experience of the devastating effects of schizophrenia on my close relative, and on the family, was the beginning of a professional interest in this field. The most striking feature of the experience was the sense of isolation and ignorance we experienced as a family.

An opportunity to talk to others in similar situations came in the form of my psychology honours thesis, when I interviewed parents on living with the illness (Benjamin, 1988). The aim was to use the research to initiate a support group, but the respondents were unwilling to participate in this. Two years later I was offered the opportunity to be involved in initiating a support group in a different community. Until that point, I was only aware of two things :

1. That support groups for mentally ill people and particularly their families, was being enthusiastically encouraged in the literature, and
2. that, as a family member of someone with schizophrenia, I believed that this work was necessary and important.

The opportunity to be involved in initiating a support group came in the form of the MA (Clinical Psychology) Community Psychology Project (MACPP) in 1990, which in turn grew out of the Mamre Community Health Project (MCHP).

The MCHP is a long-term, community health project initiated in Mamre<sup>1</sup> by the University of Cape Town (UCT) Department of Community Health and the Medical Research Council. Appendix One provides a broad overview of the research and intervention goals of the MCHP.

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<sup>1</sup>A full description of Mamre, a village 48km from Cape Town, is given in Chapter Three.

As part of the MCHP, 31 psychiatric patients and their family members resident in Mamre were interviewed by Tracey Miller (UCT Psychology Department) about their illness experiences. The names of the respondents, out patients at Lentegour Psychiatric Hospital<sup>2</sup>, were obtained through the Community Psychiatric Nurse for the area.

After an analysis of the data, the need for intervention was raised, which gave birth to the MA (Clinical Psychology) Community Psychology Project (MACPP), out of which grew the present study. The MACPP encompassed the first 3 meetings of the group, and is detailed in a report by Benjamin and Leon (1990).

This dissertation undertakes to document the experience of initiating a support group for out-patients of Lentegour Psychiatric Hospital and their families in Mamre.

Although the literature was enthusiastically encouraging support groups, very few projects had been written up in detail and at that point, none in South Africa that I could find. It was with surprise that I found mention of a support group for patients (as early as the 1970's) in Minde (1974). This group was known as the "Friends of Komani" (Minde, 1974) in Queenstown and was reported to have improved the patients' well-being.

A further difficulty was that much of the work around mental illness and the family focuses on schizophrenia in particular and the population of psychiatric patients in Mamre is more diverse. However, some attempts have been made to look at other disorders eg, depression, alcoholism, etc (See, for example, O'Callaghan 1986).

In terms of the applicability of the schizophrenia literature for

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<sup>2</sup>Lentegour Psychiatric Hospital was opened in 1985 under the jurisdiction of the House of Representatives to serve "Coloured" patients. Since 1992, the service is no longer based on racial classification, but along geographical regions.

this project, two important points should be noted :

- \* the diagnosis of schizophrenia was made in the case of the majority of the patients in the present study (see Appendix Two).
- \* more importantly, key disabling symptoms eg. withdrawal, lack of motivation, violence, etc, which occur in many cases of schizophrenia are often similar to those of other disorders. Newton (1988), for example, states that the problems raised by schizophrenia and depression are often similar.

The broad aim of this dissertation is to describe fully the first 19 sessions of the group. The preliminary evaluation of the group, which will constitute an important part of the dissertation, is essentially concerned with the development of the support group, not with its impact in terms of individual clinical outcomes. The focus is therefore on process (or formative) evaluation as opposed to summative or outcome evaluation.

The dissertation should be conceived of as a working document, providing an opportunity to reflect on a continuous process, and to plan for the future.

## **OVERVIEW OF CHAPTERS**

The introductory literature review places the study in context of the historical movement towards community care and essentially offers a theoretical argument in favour of support groups. Chapter 2 takes an indepth look at the rather vague concept of social support, and support / self-help groups, and their links with mental illness and community development.

Chapter 3 discusses the rationale for and methodology of the present study, with detailed discussion about the case study and

action research methods, as well as the question of evaluation.

Chapters 4, 5 and 6 essentially detail the operations of the group over the first 19 sessions (which includes the evaluation workshop). This leads to the Discussion chapter, which highlights the major trends emerging from the study, and the Conclusions and Recommendations for further research. In the Postscript, I will also detail some personal feelings regarding this experience, as I feel that this is an integral aspect of this kind of exploratory work.

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## CHAPTER ONE : INTRODUCTION AND LITERATURE REVIEW

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### INTRODUCTION

The deinstitutionalisation movement starting in the 1950's and 1960's (See Benjamin, 1988; Hatfield, 1987; Mangan, 1988; Orford, 1992) has resulted in more and more patients moving out of institutions and into their families' (and the community's) care.

The impact of this movement on both patients and families is now widely acknowledged within the mental health field, and, as a result, the question is no longer whether or not the (chronic) mentally ill should be managed in the community, but how mental health professionals can best provide and aid community care.

A wealth of literature on various forms of interventions exist, ranging from the earlier writings of Anderson, Hogarty and Reiss' (1980) psychoeducational approach, to the later examples of the USA and Italy where the implementation of community services as alternatives to hospitals has been legislated (See Mangan, 1988 and Orford, 1992).

The aim of this chapter is to highlight :

- 1) the effects of deinstitutionalisation on patients and their families, and
- 2) the role of support and education which continue to be pinpointed as two major needs of the victims of mental illness.

### THE EFFECT OF DEINSTITUTIONALISATION ON THE MENTALLY ILL AND THEIR FAMILIES

Classically, mental illness has been viewed as being caused to varying degrees by disturbed family relationships or members eg Fromm-Reichmann's "schizophrenogenic mother" theory, Bateson's double-bind hypothesis, etc (Hatfield, 1987). But the

relationship between mental illness and families is no longer viewed in simplistic terms of cause and effect.

On the one level, mental illness affects patients and families in similar ways. As pointed out by Orford (1992), living with a psychiatric disorder involves chronic strain for *both* the disabled or ill person, *and* the close relative or carer. Stigma (Goffman, 1963) serves as another example which (arguably in subtly different ways and with different consequences) plagues both patients and families.

On another level, patients and families affect each other in complex ways. The notion of "Expressed Emotion" (EE) (Hatfield, Spaniol and Zippel, 1987 ; Hogg, 1993 ; MacCarthy, 1988 ; Macmillan, 1992 ; Mangen, 1988 ; Mintz, Liberman, Miklowitz and Mintz, 1987 ; Mueser, Gingench and Rosenthal, 1993 ; Newton and Craig, 1991 ; amongst others) is a case in point.

The concept of EE is inferred from a score on the Camberwell Family Interview (CFI) which is usually administered at the time of the patient's admission (Hatfield, et al, 1987). The CFI consist of five scales<sup>3</sup> which are used to rate relatives' attitudes and responses during the one to two hour interview. The number of criticisms made by the relative, together with the quality of emotional overinvolvement expressed, designates them as high or low EE. High EE is usually defined as one or more of the following : a) six or more critical comments ; b) marked emotional overinvolvement or c) presence of hostility (Mintz, et al, 1987 ; Hatfield, et al, 1987).

EE is seen as involved in a complex interaction with the patient's behaviour (Macmillan, 1992 ; MacCarthy, 1988) ; premorbid relationships and family burden (MacCarthy, 1988) all of which affect the course of schizophrenia.

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<sup>3</sup>See Mintz, et al (1987) for an indepth discussion of the scales.

Mueser, et al (1993 : 252) add:

EE is influenced by the social impairment, the burden experienced by relatives, their understanding of the illness, and the utilization of social support. EE, in turn, impacts on patient functioning.

It is important to bear these complexities in mind, since an attempt will be made here to discuss the impact of deinstitutionalisation on patients and families separately.

### **The Mentally Ill and Deinstitutionalisation**

Deinstitutionalisation essentially means life in the community for patients, which is often seen as a rather "bleak" prospect (MacCarthy, 1988). A pamphlet distributed by the Cape Mental Health Society<sup>4</sup> (CMHS) entitled "*Requirements for People with a Psychiatric Illness*" aptly describes life for patients :

Whilst their medical needs are being met, many problems face these people. Employment is difficult to obtain, not only because of stigma, but also because the work demands are often beyond their capabilities. Psychiatric illness affects social behaviour so family contacts, social and recreational options are often limited. Many mentally ill people exist on disability pensions only, which are inadequate to maintain a reasonable standard of living.

Even for those living with their families, life is far from satisfactory, as pointed out by MacCarthy (1988 : 207) :

People in need of continuing care who live with family or friends rather than alone or in hostels seem to represent the success stories of community care. However, these people rarely live a 'normal' life in the community. More often they remain confined within the boundaries of their homes. High unemployment, housing

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<sup>4</sup>Cape Mental Health Society is a private, registered welfare organisation, serving mentally handicapped and mentally ill people and their families. It was established in 1913 and is the oldest mental health society in South Africa. The Society is affiliated to the Federation Council for Mental Health.

shortages and a scarcity of long-term state-funded residential placements partly account for this. Neither patient nor family are likely to be offered alternatives, whatever their quality of life.

(See also Bernheim, 1982).

As in the case of families, the consequences of mental illness for patients often pose bigger problems than the psychotic breakdown itself. This is perhaps nowhere clearer than in the case of unemployment.

The mentally ill are often excluded from the labour market by forces beyond their control. Unemployment, in turn, leads to higher levels of depression, anxiety and general distress; and a concomitant lowering of self esteem and confidence (Orford, 1992). In the process, ex-patients are excluded from a immensely meaningful experience, as Jahoda (1988: 17-18) shows :

Whether one likes or hates one's job, it structures time for the day, the week, the years ; it broadens the social horizon beyond family and friends ; it enforces participation in collective purposes; it defines one's social status; it demands reality-orientated activities...the enforced categories of experience provided by employment meet fairly enduring human needs for time structure, activity, social contacts, participation in collective purpose, and knowing where one stands in society. (Cited by Orford, 1992 : 66).

Hence, as a result of deinstitutionalisation, "leaving the hospital is far from the end of the rehabilitation process" (Bernheim, 1982 : 634) for patients, and the ex-patient requires "resources to which he could turn for help in making the necessary readjustment to ... community life." (Durham, in Gottlieb, 1981 : 18).

#### **Families of the Mentally Ill and Deinstitutionalisation**

The problems faced by families with a mentally ill member are manifold, ranging from the experience of the illness and/or

patient ; professionals and institutions ; to socio-political and ideological issues.

MacCarthy (1988) distinguishes between "objective stresses" eg financial difficulties, loss of autonomy and exposure to disruptive and frightening behaviours and "subjective distress" eg what relatives report or attribute to their role. The latter is similar to Arey and Warheit's (1980) notion of "subjective burden".

The mere presence of the mentally ill family member is said to have a disruptive effect on family life (Arey and Warheit, 1980; Bernheim, 1982), and may influence the family's "subjective burden" (Arey and Warheit, 1980).

Some patients returning from hospital may display florid symptoms of psychosis (eg. delusions and hallucinations). Inappropriate affective responding, activity level and social skills (Bernheim, 1982) may be additional problems. O'Callaghan (1986) adds socially embarrassing behaviour, social withdrawal and underactivity to the list of potential problems. Willis (1982) sums up the problems families with a mentally ill member are faced with : from seemingly "trivial" eg lack of grooming, to lack of motivation, refusal to take medication, drugs, violence and suicide. In addition, as pointed out by Bernheim (1982), families often have to contend with worsening symptoms, rehospitalisation and finding community resources for the mentally ill member. Hence, the consequences of the psychotic breakdown often pose bigger problems than the episode itself (Patmore, 1987).

Furthermore, psychiatric services are often experienced by families as inadequate in meeting all their needs [see Group for the Advancement of Psychiatry (GAP), 1986 ; O'Callaghan, 1986 ; TARRIER, 1991 and Willis, 1982]. Inability to empathize, lack of appropriate training, and the lack of community support, contribute to rendering professionals less capable of supporting

families (GAP, 1986).

The amount of help received by families is often too little (O'Callaghan, 1986) and usually administered by the local General Practitioner, who often has little time for families.

Ideologically, it is argued that the philosophy of civil rights to the patient does not consider the well-being of the family (GAP, 1986). Hatfield, et al (1987 : 224) holds that the message given to families by deinstitutionalisation, is "under no circumstances should the patient be hospitalized", which results in additional pressure on the family to keep the ex-patient in the home.

Birchwood and Smith (1990 : 29) also note the uneasiness expressed by families about the increased burden placed upon them by the community movement, and the concern that they are regarded as an "inexpensive community resource". [See also Lewis and Frey (1990) for a detailed discussion of the role and feelings of families.]

The effect of all these factors on families include deterioration in the family members' mental and general health (O'Callaghan, 1986), confusion (Barrawclough and TARRIER, 1987), isolation, fear, loneliness, stigma, shame, anxiety, guilt, depression, etc (Benjamin, 1988 ; Newton, 1988 ; Willis, 1982). Financial burden, especially when rehospitalisation occurs ; reduced social and leisure life (O'Callaghan, 1986) with little opportunity to lead a 'normal' life ; and disruption of the family's social networks (Benjamin, 1988 ; Willis, 1982) are additional consequences.

These consequences, in turn, impact on the family's ability to adhere to intervention programmes (TARRIER, 1991) which will be explored in the Discussion chapter.

Willis (1982 : 618) sums up the experiences of families :

When all the...problems are considered, it can be seen that deinstitutionalization has in some ways made life for the families of the chronic mentally ill more difficult...But most of us...would rather that our...relatives had a chance to be rehabilitated in their own communities than to be interned for a lifetime in a mental institution. We need, however, all the help we can get in coping with these problems...

The "help" required by ex-patients and their families is the focus of the rest of this chapter.

## **THE ROLE OF SUPPORT AND EDUCATION**

### **The Role of Support**

There is little argument that support is essential to families and patients in order for them to cope with mental illness and deinstitutionalisation (see Benjamin, 1988 ; Brugha, 1991 ; Craig and Newton, 1991 ; GAP, 1986 ; Newton, 1988 ; O'Callaghan, 1986 ; Orford, 1992 ; Patmore, 1987). The call for supporting patients and their families is not surprising, since support is seen to result in reduced rates of relapse and ultimately reduced admissions to hospitals, hence maintaining deinstitutionalisation.

Despite the conceptual difficulties with the notion of support, it is generally considered to have a strong link with health (Orford, 1992).

This section will detail some of these arguments, as well as those in favour of support groups (and self help groups) and education. The often unclarified notion of support is the topic of the next chapter.

### **Support and Ex-Patients**

Orford (1992 : 75) discusses the relationship between social support and health in terms of the two major models in this

field.

The "main (or 'direct') effects model supposes that social support has an effect independently of level of stress : it can 'promote good health, both in the absence and in the presence of stressful life events'" (ibid). Cassel (in Gottlieb, 1981), an early articulator of the relationship between social support and health protection, is a proponent of this model.

The "stress-buffering model...suggests that social support works by diminishing the potentially harmful influence of stress : where no stress exists, social support has no effect" (ibid). Support, during stressful times, could reduce the risk of psychiatric illness (Brugha, 1991 ; Craig and Newton, 1991).

Other authors have noted more specific arguments in favour of supporting ex-patients. Mangen (1988 : 176-177), noting the impairment of social skills and small social networks that affect the mentally ill, argues that services must offer continuing care clients the opportunity to enhance their social competence and to develop a new social network.

Craig and Newton (1991 : 505) add :

Support does not refer to the provision of goods or services for ex-patients in areas where they are relatively well provided and competent, but to ways of meeting needs that the ex-patient cannot meet himself, to finding emotionally supportive environments, and to ways of helping him become independent rather than dependent.

#### Support and the Families of the Mentally Ill

The stress of living with a mentally ill person is not easily removed and therefore the family's coping strategies have to be increased. According to Heller, et al (1984) the family's resources must be increased by linking families to social support networks.

Hatfield, et al (1987), looking at relapse in schizophrenia and the role of intervention, conclude that "the common ingredient in successful programmes may be that they...offer support to families."

But, more importantly, supporting families relates to their role as caretakers of the mentally ill. As pointed out by Craig and Newton (1991 : 506) :

Many people who have had major psychiatric illness need ongoing support, but even the most flexible of community psychiatric support programmes have time limits, and the risk of relapse may return when this support is removed...Only more permanent changes to the environment, such as the way key family members relate to the sufferer, can hope to achieve the kind of long-term protective benefits desired; this is the kind of protection which was previously only seen to be possible through maintenance drug treatments. Such approaches are not advocated as alternatives to pharmacological treatments, of course, but as an additional essential element of management.

### The Role of Support Groups

In a paper discussing support and personal relationships in relation to psychiatric disorder, Brugha (1991 :154) states that "the most acceptable general statement on management and policy at the present time is that of...encouraging those who appear to need additional support to participate in self-help groups, sharing their difficulties and problem-solving strategies with 'fellow-sufferers'."

Narrow, Regier, Rae, Manderscheid and Locke (1993 :106) found that for "a large number" of people with mental and addictive disorders, support networks of friends, relatives, and self-help groups were important sources of care.

More specifically, support groups for ex-patients are seen to be effective in reducing social isolation, increasing cohesiveness and improving reality testing (in the case of psychosis) (Kaplan and Sadock, 1988).

Kaufman, Freund and Wilson (1989 : 7) highlight another valuable function of support and self help groups :

Self-help and peer mutual support promote the development of a positive social identity. Through the self-help process, consumers establish social identities that reflect their value as members of the self-help group. The positive social value is often distinct from their devalued status in most social groups outside of the self-help community. Members have the opportunity to examine both the positive and negative aspects of their experiences as "mental patients" through discussion with peers. Members explore their experiences with one another in a social climate that supports and values their experiences and also tolerates manifestations of emotional disability.

Furthermore, given the inadequate supply of community support systems such as halfway houses, sheltered work environments, etc. (Bernheim, 1982), social support groups may serve as an additional resource, and in some cases, the only resource, available to ex-patients.

For the families of the mentally ill, O'Callaghan (1986) proposes three levels of services - support groups occupying the first level, family therapy the second level and separation from the family the third. Two of these levels are also seen as important in reducing the levels of EE in families, as pointed out by Newton and Craig (1991 : 505) :

EE can be lowered in two ways : either the contact between the individual and relative can be reduced, by finding alternative places to spend much of the day, or relatives can be helped, through participation in educational groups and family therapy to find more supportive ways of relating to the patient.

### **The Role of Education**

A second major need often stated is that of education. Education includes information, advice or guidance on various aspects including resources, the illness, financial aid, management of difficult behaviour, the future, etc. It would seem that education provides for families (and patients) more than just

knowledge. As pointed out by TARRIER (1991 : 479) :

There is evidence that the benefits of educating relatives is not in the acquisition of knowledge itself but in the non-specific effects of reducing anxiety, worry and perceived burden.

Patmore (1987) agrees that education is a stress relieving strategy, while Maforah (1987) adds that education is important in reducing stigma and encouraging community participation. Averill (in Heller and Swindle, 1983:97) highlights another important characteristic of education :

...information frequently can be varied when little else can, with potent effects in terms of stress regulation.

Test and Scott (1990) also highlight education and the inclusion of families as two important principles in successful community care programmes.

Mueser, Bellack, Wade, Sayers and Rosenthal (1992) raise the important issue of who determines what patients and families are educated about. In their own study, they found that generally, all groups of respondents were most interested in learning basic information about the illness (eg. medication, early warning signs) and generic coping strategies (eg. stress management).

## **SUMMARY**

In the first part of this chapter, the effects of deinstitutionalisation on the mentally ill and their relatives were highlighted. Excluded from meaningful activities like employment, the mentally ill generally face a bleak and unfulfilling existence. Included through deinstitutionalisation in the care of the chronic mentally ill, families face a life of wide-ranging stress and strain. Both have to contend with inadequate support structures.

The second half of this chapter examined the role of support and

education in alleviating some of the burden faced by the victims of mental illness.

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## CHAPTER TWO : SOCIAL SUPPORT, SUPPORT GROUPS AND COMMUNITY INTERVENTION

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The previous chapter highlighted the importance of support and education for patients and their families. While education appears relatively straightforward, the notion of support continues to be something of an enigma. This chapter will attempt to clarify this concept in terms of current thinking.

### **SOCIAL SUPPORT**

Heller and Swindle's (1983 :89) warning that "social support currently is in danger of becoming a magic term to explain anything and everything about helping behaviour", still seems to be applicable today. They point out that the problem in the field is conceptual rather than methodological, and, as a result, we do not really know how support works (Egan, 1990 ; Heller, Price, Reinharz, Riger and Wandersman, 1984 ; Newton, 1988). However, models have been proposed, but before we examine one of these, the concept of social networks needs clarification.

Social networks refers to the "social connections available in the environment that vary in terms of structure and function" (Heller and Swindle, 1983 : 100). In an attempt to clarify the concept of social support, Heller and Swindle (1983) propose a model in which social support is seen in terms of an interaction between the social network and person occurring across time. Heller and Swindle (1983 : 91) add :

... support levels achieved by an individual are a function of the availability of supportive structures in the environment interacting with individual skills and competencies in accessing and maintaining supportive relationships that present themselves in the environment. Support received at any point in time depends not only on support currently available, but also on the individual's prior history of support availability, accessing and maintenance skills in interpersonal relationships, and past support-seeking behaviour.

Tolsdorf (1975) and Syrotuik and D'Arcy (1984) both cited by Orford (1992 : 78) also emphasise this interactive relationship, stating that "while social support has implications for psychological well-being, the reverse is also true with one's psychological condition affecting the availability and utilisation of support".

But what is this support that is provided by social networks? At the risk of oversimplifying the extensive literature, a summary of network characteristics which make them supportive follows. We will see later that many, if not all, of these properties have been incorporated into support or self-help groups.

Brugha (1991 : 115, 116) defines support in two categories :

Broad definitions encompass a wide variety of forms of care that come to individuals through the action of others and that handicapped people, such as the chronically mentally ill, may not be able to provide for themselves eg. shelter, nourishment, occupation, clothing ...Narrow definitions...emphasise the specific 'personal' provisions of social relationships and particularly their more subjective components e.g. confiding, intensity and reciprocity of interaction, or reassurance.

Networks can be supportive by offering or providing functional support (ie. tangible help eg. money, services) ; informational support (ie. advice, knowledge) and emotional support (Newton, 1988).

Hirsch (in Heller, et al, 1984:162) holds that socializing and social reinforcement are two additional forms of support that networks can offer. This refers to the notion that individuals use others as standards of comparison to shape their own behaviours and attitudes (Heller and Swindle, 1983).

However, even if social relationships are able to provide considerable support, Egan (1990 : 388) points out that they can also be stressful, adding that "too little support can actually

be alienating, while too much social support can be suffocating".

Furthermore, Newton (1988 : 151) points out that "social ties may differ radically in function and should not be considered to provide some unitary benefit in terms of concepts such as emotional support ... in some instances, ... supportive relationships can have a negative impact on well-being".

Egan (1990) adds a further problem with social support : the kinds of communication skills needed are not necessarily available in the population. Often sympathy and empathy are confused, and the latter not necessarily communicated, which could contribute to making supportive relationships undesirable. However, in a support group forum, issues in communication can be addressed, while maintaining the supportive relationship.

In terms of understanding coping, it is important to note that support seeking can occur in response to a threat and could result from "an appraisal that more help or information is needed" (Heller and Swindle, 1983 : 100). As pointed out by these authors :

Support seeking can be part of normal adaptation, but also can be a sign of inadequate coping or a breakdown in network resources, particularly when it occurs outside of an indigenous network.

(See also Newton, 1988 : 155).

Newton (1988) discusses support in terms of chronic stress, pointing out that "(natural) informal networks" are valuable in coping with chronic strain, while offering little protection against acute stress.

## **SELF HELP / SUPPORT GROUPS**

To some degree, the differential definitions of support and self-help groups is an academic issue - their shared benefits and goals seem more striking than their differences. They appear to

differ fundamentally in their relationship with mental health professionals.

Although not overtly stated, support groups seem to necessitate the involvement of a facilitator, usually a mental health professional. Nichols and Jenkinson (1991 : 11) describe support groups as consisting of 4 to 12 members plus a facilitator. The group has to share a common, identified need, and members must be capable of giving reciprocal care to one another. In each of Harter's (1988), Willis's (1982) and Leung, Rastogi and Woods's (1989) papers on support groups, a mental health professional initiated and remained actively involved in the groups.

The definition of self-help groups, on the other hand, is more accessible. Orford (1992 : 224) quoting Katz and Bender (1976) define self-help groups as :

... voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions. (my emphasis)

The role of professionals in self-help groups is grounded in one of its unique characteristics ie. "the natural antithesis between the philosophies of self-help and professional care" (Emerick, 1990 : 401). This author explains further :

... one of the major historical functions of self-help groups has been to politicize their members - to broaden narrow, individualistic orientations to problems into a group perspective in which personal problems are inextricably linked with broad-based socio-political and economic problems. Needless to say, most health-care professionals, by contrast, are trained to think and act in highly individualistic and biological terms.

However, Orford (1992) includes programmes where the initiative

an ongoing leadership has come from professionals (for example, programmes to improve the social networks of people returning to live in the community after psychiatric hospitalisation) as lying at the one extreme of self-help groups, thus narrowing the gap between support and self-help groups around this issue.

Kaufman, et al (1989), similarly, propose a model of self-help that includes professional involvement, while Emerick (1990) points out that the degree of professional involvement in self-help groups will depend on the nature of the problem the group addresses, as well as its political and structural characteristics.

The group for psychiatric out-patients and their families in Mamre is regarded as a support group. However, as will be seen below, support and self-help groups share similar benefits, and hence this dissertation will not be limited to the literature on support groups.

### **The Functions of Support / Self-Help Groups**

Support groups are based on the assumption that practical, highly specific emotional support after the event, and from new social relationships, is helpful (Newton, 1988).

At the most basic level, support groups offer members simply a chance to talk.

While it is recognised that support groups may not be beneficial to everyone (Egan, 1990), they are seen as having many advantages. As pointed out by Heller, et al (1984:165) :

By meeting with others in the same situation, those in distress can share effective coping strategies and information, and can provide support and reinforcement for each other. Furthermore, the 'helper therapy principle' suggests that the act of providing help may be beneficial to the helper as well.

Support groups for people with similar experiences can thus provide for its members others from whom they can learn to cope

(Terkelson, 1987) as well as access to tangible resources.

The benefits and functions of support and self-help groups are summarised in relation to key references in the table below.

**TABLE ONE : GROUP BENEFITS AND FUNCTIONS**

Support Groups (Nichols and Jenkinson, 1991)	Self-Help Groups (Orford, 1992)
	Emotional support
Provision of role models	Imitative behaviour
	A powerful ideology
Growth of knowledge	Relevant information Ideas about ways of coping
Helper therapy principle (Heller, et al, 1984)	Opportunity to help others
Cohesion	Social companionship
Hope instillation	Sense of mastery and control
Universality	
Corrective recap of the family group	
Catharsis	

These benefits will be discussed in further detail in the Discussion chapter.

Thus, support or self-help groups, perform specific functions in terms of the needs of their members. At the same time, they are based firmly on community intervention principles.

Early arguments in favour of support groups were based on the need to make the traditional treatment system more appropriate and accessible to the poor and disadvantaged, and more closely articulated with informal resources and primary institutions in

the community (Gottlieb, 1981 : 20).

Maforah (1987) refers to support groups as "community rehabilitative services", and contends that support facilities would increase referral and support while reducing reliance on hospitals.

Support groups can complement professional help while having additional advantages over professional services. Members can achieve friendships on equal terms, and if the members' experiences and environments are similar, support groups are more likely to foster members' coping skills (Newton, 1988:162).

Furthermore, support groups can avoid casting the client into a dependent role (Maforah, 1987 ; Newton, 1988) and provide an opportunity for community psychologists to help people develop skills which give them access and control over their environment ie. empowerment (Egan, 1990 ; Heller, et al, 1984 ; Orford, 1992; Levine and Perkins, 1987).

Support groups emphasize the belief that "people who have the problem know a lot about it from the 'inside', from experiencing it" (Egan, 1990:103). This ideology is centrally important since one of the difficulties with some family intervention programmes is the assumption that relatives know nothing about mental illness, which serves to alienate families and encourages non-adherence to family intervention programmes (Tarrier, 1991).

Support groups fall within Rifkin's (Katzenellenbogen, Hoffman, Joubert, Pick, Yach and Klopper, 1988) self care approach to community participation in health. As such, they provide the opportunity for people to meet their own health needs, while encouraging community participation.

While too much support, according to Egan (1990) may relieve people of self-responsibility, the process of establishing a support group may encourage empowerment and community

development. It is felt that this process can become a community supportive programme in terms of Buch's (1985:85) definition :

Community supportive programmes are those which favourably influence the long-range welfare of the community, that help it stand on its own feet, that genuinely encourage responsibility, initiative, decision making and self reliance at the community level, and that build human dignity.

### **SUMMARY**

Social support refers to an interactive process between environmental and personal characteristics. It is not beneficial to all, and some people will not use supplied support networks outside of their natural support systems. The implication drawn from the literature is that people with impaired natural systems and facing acute stress may benefit more from support groups. Support groups are also seen as promoting empowerment and community development.

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## CHAPTER THREE : RATIONALE AND METHODOLOGY

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A full description of Mamre is provided which will provide the basis for the rationale for the group. A map of the South Western Cape region, showing the geographical relation of Mamre to Atlantis and Cape Town, forms Appendix Three.

### **THE RESEARCH CONTEXT**

(extracted from Hoffman, Yach, Katzenellenbogen, Pick and Klopper, 1987 : 5)

Mamre is a village of approximately 5000 inhabitants along the Cape West Coast, 48km from Cape Town and 5km north of Atlantis, which is a recently developed dormitory town to Cape Town. Mamre had been a government cattle post from 1697.

The Rural Coloured Areas Act 24 of 1963 legislation controls Mamre, and the village is run by an elected Village Management Board. In 1971 the Divisional Council of the Cape (DCC) was given responsibility for the health and environmental services in the area.

Mamre was chosen for the MCHP for several reasons. It is a well established community with strong traditions and many of the descendants of the original families continue to live in the village. It is a community in transition - piped water has only recently been introduced and electricity and water-borne sanitation will probably be introduced in the near future [both have subsequently been introduced]. It is also an easily accessible (less than 1 hour's drive from Cape Town), well defined and circumscribed area which makes local study feasible and practical.

This nature (ie. a well-established, dynamic and accessible community) particularly favour the establishment of a support group, which is reinforced by the community's difficulties in accessing psychiatric care.

## RATIONALE

A major factor favouring the initiation of a support group in Mamre relate to its difficulties in accessing psychiatric care.

In the greater Cape Town area, three state hospitals, ie. Stikland<sup>5</sup>, Valkenberg<sup>6</sup> and Lentegour, provide inpatient treatment of acute (psychotic) symptoms, and out-patient follow-up and support to ex-patients. Organizations like CMHS (based in Cape Town) offer support through information, recreational and social work services, and sometimes accommodation, to psychiatric in-patients and especially those living in the community.

There is no organised community system, and very little intervention by mental health workers in community settings, especially with the chronic mentally ill. In the literature under review in this paper, there are no examples of support groups initiated by mental health professionals locally.

Miller and Swartz (1990) discuss the impact of difficulty in gaining access to psychiatric care, on ex-patients and families in Mamre.

These difficulties include:

i) Distance from psychiatric hospitals which makes treatment difficult and expensive to obtain. Before 1992, psychiatric patients in Mamre had to attend Lentegour Hospital as it served "Coloured" patients, which is the furthest of the three state

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<sup>5</sup>Stikland Hospital, the closest psychiatric hospital to Mamre, opened in the early 1960's, initially under the jurisdiction of the Department of Health, and since 1986 under the Cape Provincial Administration. It catered only for white patients and hence not for Mamre residents until 1992, when its service became based along geographical areas.

<sup>6</sup>Valkenberg Mental Hospital falls under the jurisdiction of the Cape Provincial Administration. It was established as a mental institution in 1891, and was "desegregated" in 1990.

hospitals from Mamre. If psychiatric emergencies occur, distance is even more limiting as transport is often impossible to obtain (especially at night). Miller and Swartz (1990:4) add:

the distance between services and families may impair treatment, rehabilitation and follow-up after discharge. It is likely to deter families from visiting hospitalised patients and attending counselling and education sessions at the hospitals, making it less likely that they will be supportive of and compliant with treatment. In the case of an emergency or the unexpected development of side-effects, families may have to seek help from a non-psychiatric medical practitioner closer to home, perhaps resulting in contradictory or inappropriate treatment.

ii) Lack of resources for handling aggressive or suicidal patients, as the police are often not able to deal with this effectively. Miller and Swartz (1990:7) explain :

The police are sometimes requested to take a family member to hospital...The police cannot however always be relied upon, for a number of reasons. The police station in Mamre does not have a police van, and they have to borrow a van from Atlantis (the neighbouring town) in order to help in this way. Perhaps they are (understandably) reluctant to focus attention on themselves by escorting a reluctant patient on foot through the village where many people know each other....In addition, the police are reluctant to take patients to hospital without a doctor's instructions.

iii) The community psychiatric nurse (who is only able to visit Mamre one day per month) is often not able to follow-up patients who have missed appointments. Furthermore, if patients are not compliant for a while, they are taken off her active list, i.e. then there is no potential psychiatric help available at all.

iv) A further difficulty affecting all the households is that the available sheltered employment - Orion in Atlantis - caters more for mentally handicapped than psychiatrically disabled people.

## METHODOLOGY

The methodological underpinning of this study is that of a case study approach, with action research and participant observation principles. In order to provide further understanding of the researcher's approach and methods, and to point out the limitations of the study, the methodology will be discussed in further detail.

A case study is defined as an :

...indepth, qualitative description and analysis of the behaviour of a single individual, group or organization, or community or of a collection of individuals or collectivities which are dealing with a specific type of event or situation.

(D'Aunno, Klein and Susskind, 1985 :439-440, their emphasis)

Its distinctive characteristic is its small number of subjects. One of the best methods of organising social data, the case study maintains the unitary character of the social object under investigation while highlighting events and processes over time. Furthermore, it has another positive feature, as pointed out by Orford (1992 : 125) :

...a positive feature of case studies is the very emphasis that is usually placed upon the experiences of those most directly involved in the phenomena concerned, and a greatly reduced distance between researcher and researched in comparison with more traditional approaches.

However, it is partial in nature. As pointed out by D'Aunno, et al (1985 : 442 - 443) :

In the case study there is no ultimate truth ; there is only the experience of those involved filtered through the conceptual lenses and empathic capacities of those conducting the study.

The following characteristics of the present study conform with

action research principles :

1. Collaboration between researcher and participants
2. The research is conducted in a naturalistic setting ie. within the group which is held at the MCHP office in Mamre.
3. The aim of the study is "...knowledge building with the aim of engaging members ...in order to be of practical help to them " (D'Aunno, et al, 1985 : 422).
4. The data are used for two main purposes - to gain insight into the members' responses to change and their ways of coping with it, thereby enriching knowledge and theory about social processes ; and to help the researcher assess the functioning of the support group and identify any modifications needed.

As a member of the support group, accountable to the group, the researcher also has a role similar to that of a participant observer. As such, some of the researcher's experiences within the group will also be referred to in a minimal way.

It is not unlike the role adopted by Wollert, Knight and Levy, cited by Orford (1992 : 233) :

They believed that professionals' contacts with self-help groups were often, 'hurried and evaluative, focused on the professional, and asserted the professional's superior status'. Their own contact, by contrast, was, 'long-term, nonevaluative, group-centred, and characterised by a respect for the group's right to accept or reject our input' (p.136)."

Rogers (1951) best sums up the orientation of the researcher in her role as facilitator within the group :

- confidence in the members' ability to be responsible for themselves
- responsibility to the group members, not for them.
- acceptance of individuals and of the group
- the use of mainly reflection and clarification to facilitate group process.

## **EVALUATION**

As part of the present study involves an evaluation, this issue merits some discussion here.

This study uses formative as opposed to summative evaluation. Orford's (1992 : 121) defines this in the following way :

Formative evaluation does not attempt to reach a summary statement about outcome, but rather seeks to aid the development of the programme by discovering ways in which the programme is operating that make it more or less likely that it will achieve its aims. The emphasis is upon process rather than outcome.

Nichols and Jenkinson (1991) hold that evaluation is of benefit to the group leader, to its members, and others beyond the group. As already mentioned, the evaluation of this project, is aimed primarily at benefitting the first two categories.

Techniques of evaluation vary (see Nichols and Jenkinson, 1991) and are closely linked to objectives. As stated by these authors (1991 : 146) :

If the objection (sic) was simply to create a situation where previously isolated people were given an opportunity to talk and provide mutual support, this can be assessed by cautious observation within the group and a little gentle questioning.

The evaluation of the present project is based on this concept and achieved through "cautious observation" by the facilitator and "a little gentle questioning" in the form of a workshop.

The decision to involve members in the planning and implementation of the evaluation workshop was based on the principle of empowerment. Pratt and Gill (1990) argue that encouraging participants, with staff help and support, to develop and pursue questions about their own program, serves as a tangible demonstration of empowerment by demystifying the process of design and fostering a greater sense of program ownership.

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## CHAPTER FOUR : PARTICIPANTS AND PROCEDURE

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The 19 group sessions were held between June 1990 and February 1992 and included the evaluation workshop. The content of the sessions is detailed further in the following two chapters. In this chapter, the participants and procedure will be discussed.

### **PARTICIPANTS**

The names of the 31 psychiatric out-patients interviewed by Tracey Miller (Psychology Department, UCT) about their illness experience were obtained from Miller and these patients and their families served as the potential pool of participants for the support group. Protocols on these patients were also obtained from Miller, providing additional information about the patients and their family circumstances. This information is used in Tables three and four, in this chapter.

### **Attendance**

Attendance varied over the eighteen sessions with at least fifteen people attending each of the first six group meetings. At the first meeting, more than 30 people, at the second meeting, 21 and at the third meeting, 18 people attended. A steady decline in attendance occurred over the remaining sessions. However, there were occasional bursts in numbers eg at the Christmas Party held in December 1990, more than 20 people attended.

By the latter sessions, the group consisted of about 11 regular attenders, together with two or three community workers and the facilitator. At most of the sessions, an occasional or infrequent attender (see Table two, overleaf) would also be present.

Initially, one Community Worker was present at all the sessions. Over the 19 sessions, two additional Community Workers joined the group.

**TABLE TWO : ATTENDANCE**

	PATIENTS	FAMILY MEMBERS <sup>7</sup>
REGULAR	5 (7) <sup>8</sup>	3 (4)
OCCASIONAL	2	2
INFREQUENT	11	11
NEVER	13	unknown
<b>TOTALS</b>	31	unknown

**KEY:**

Regular attendance refers to participants who attended almost all the sessions. Most of these participants tended to forward apologies when unable to attend a session.

Occasional attendance refers to participants who attended more than 5 of the 19 sessions, or who at some stage over the 19 sessions attended regularly. An example is K, who attended at least 5 sessions at various times over the 19 sessions, and whose input at the Evaluation workshop was valuable.

Infrequent attendance refers to participants who attended at least one but not more than 5 sessions. Many of these participants attended the first 3 sessions. An example is that of M and a family member, both of whom attended only the evaluation workshop.

Never refers to members who did not attend any of the 19 sessions.

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<sup>7</sup>Figures refer to individual family members, not household.

<sup>8</sup>The figures in parentheses are explained in the text.

Table two (previous page) summarises attendance by patients and family members. The figures refer to the 31 patients included on Miller's list. In addition to the 9 regular participants, 2 patients and one family member not included on Miller's list, also attended the group regularly. This is represented by the figures in parentheses.

### **Regular Attenders**

Because the "regular attenders" were the most consistent and influential participants over the 19 sessions, they deserve more indepth discussion.

Table three (overleaf) summarises the pertinent information regarding these participants.

### **Nature of Problems Experienced**

The difficulties experienced in the 31 households, extracted from Miller (1990), are summarised in Figure one (to be found immediately after Table three). The difficulties represented by the letters A to F are not mutually exclusive.

The reader's attention is drawn to the following trends which are highlighted by the figure :

- \* 62,5% of those experiencing severe problems did not attend any of the sessions, including the evaluation workshop.
- \* none of those experiencing financial problems and inadequate care and support attended the group regularly.

These trends will be explored in the Discussion chapter.

### **PROCEDURE**

The meetings were all held on Sunday afternoons and usually lasted two to two-and-a-half hours. With the exception of the last two sessions, both held in February 1992, all the sessions were held at most once a month, with some longer breaks inbetween (see Table Three, Chapter five).

**TABLE THREE : REGULAR ATTENDERS**

NAME	BIOGRAPHICAL DATA	DIAGNOSIS	NATURE OF PROBLEMS	FAMILIAL / HOME CIRCUMSTANCES	ATTENDANCE BY FAMILY MEMBERS	ADDITIONAL NOTES
KA	52 years, single, unemployed	Schizophrenia Alcohol abuse	Severe	3 Of 10 household members are unemployed. Patient receives good care but feels frustrated and unhappy as family members shout at him. He is seen as lazy, selfish, a burden. He cannot handle money, must be reminded to wash and gets involved in bad company.	Sister attended regularly	Behavioural problems addressed in group.
AA	54 years, single, unemployed	Epilepsy	Severe / Boredom / Fear and worrying	Patient needs constant companionship. He has a poor memory and is short-tempered. Mother worries about his sex-life as he often 'chats up' girls (although there has been no complaints about this).	Mother regular attender	Relationship issues approached in group.
AM	71 years, widowed, unemployed	Depression	No major problems	Has difficulty in walking to clinic because of an injured knee. Would like to stop taking medication because while she's still taking them, she feels sick and will only feel completely well once she's discharged.	Never	Likened her experienced of the group to that of a family.

**TABLE THREE CONTINUED**

NAME	BIOGRAPHICAL DATA	DIAGNOSIS	NATURE OF PROBLEMS	FAMILIAL / HOME CIRCUMSTANCES	ATTENDANCE BY FAMILY MEMBERS	ADDITIONAL NOTES
FP	35 years, single, unemployed	Mental handicap		Patient is shy and withdrawn, and tends to keep her feelings to herself. At times she suddenly becomes cross and hysterical. She is well cared for, has good support on all levels, and appears to be functioning well.	Never	
DB	19 years, single, unemployed	Schizophrenia		Financial problems. Conflict between father and older brother (related to alcohol abuse). Very frightening episode related to side effects of drugs. Mother feels that admitting problems implies that she is not satisfied.	Mother regular attender	ONLY MOTHER, NOT PATIENT, ATTENDED
LF	43 years, married, unemployed	Neurosyphilis	Severe	Patient can't work, gets cross quickly, talks a lot, hears and feels things, has been very aggressive in the past and is always scared that his mind will slip. His wife feels depressed about the future, gets cross with him, treats him like an adult but he needs to learn to be responsible.	Never (although she has stated that she would like to learn how to handle him better)	

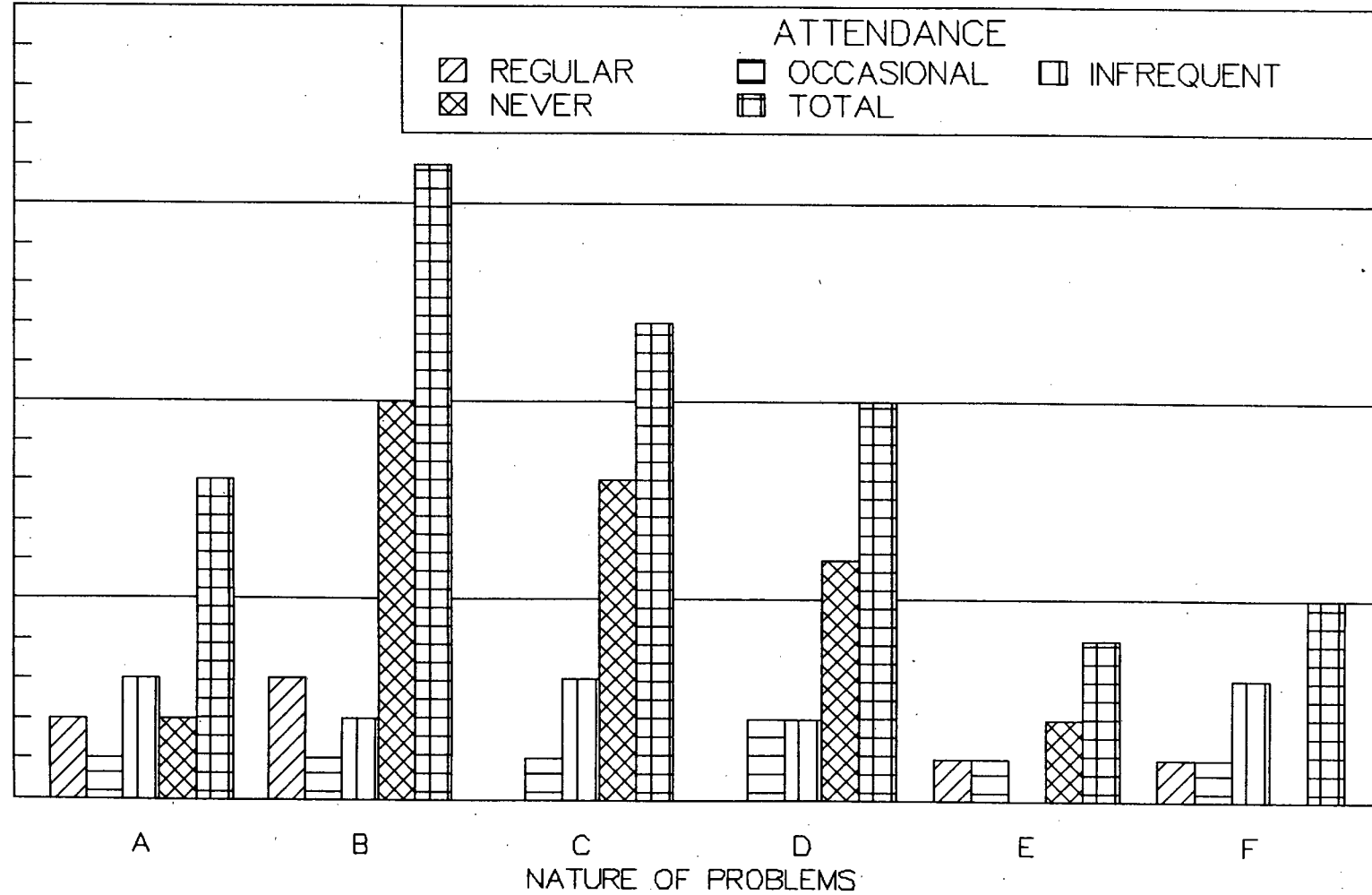
**TABLE THREE CONTINUED**

NAME	BIOGRAPHICAL DATA	DIAGNOSIS	NATURE OF PROBLEMS	FAMILIAL / HOME CIRCUMSTANCES	ATTENDANCE BY FAMILY MEMBERS	ADDITIONAL NOTES
CB*	32 years, single, unemployed	Schizophrenia Dagga abuse	Severe	Very poor relationship with family members. Expressed a wish to find alternative accommodation.	Never	Facilitator and community worker provided individual support and assistance when CB faced the threat of a possible criminal charge
JA*	+ - 21 years, single, unemployed	? Schizophrenia	No major problems	Patient is withdrawn, doesn't communicate easily	Mother regular attender	Patient became increasingly more verbal towards the end of the 19 sessions.

\*Not included on Miller's list.

FIGURE ONE : NATURE OF PROBLEMS IN RELATION TO ATTENDANCE

NUMBER OF HOUSEHOLDS



**KEY TO FIGURE ONE :**

**A:** No major problems

**B:** Severe problems

[which includes violence, aggression, short-temperedness, encephalitis, stealing, marital difficulties, alcohol use (both patients and family members), lack of social support network, and poverty].

**C:** Inadequate care and support

(includes lack of emotional support from family members, lack of financial support, lack of interest from family members, poverty, and unkempt home surroundings).

**D:** Financial problems

**E:** Fear and Worrying

**F:** Boredom / Poor school performance /

shy, anxious, depressed / total dependency. The case of total dependency refers to a 57-year-old, single, unemployed woman diagnosed with schizophrenia who is apparently completely dependent on a neighbour and lives in the neighbour's back yard.

The date for each meeting was determined at the preceding meeting in consultation with the group and the Community Workers.

### **Notification**

Notices of the meetings were sent to the 31 households included on the Miller's list every month. An example of the notice forms Appendix four. Participants were also asked to verbally encourage family members and friends to attend. Initially, notices were sent to two group members for delivery in Mamre. Eventually, one of these members, AA, took sole responsibility for delivery of the notices, and later still, made posters advertising the meetings which were displayed at strategic locations in Mamre. (The change in the notification procedure reflected in part the development of the group, as well as that of AA).

### **Format**

Of the 19 sessions, the second, third and nineteenth sessions took the form of workshops, involving small group discussions followed by feed back to the larger group. The third and fifth sessions involved didactic input. The ninth and fifteenth sessions were activity sessions in which members focussed on the making and pricing (respectively) of needlework and creative items. The sixteenth session was the Christmas party. These sessions are discussed in further detail in the following two chapters.

The 12 remaining sessions consisted of general group discussions, followed by tea, closure of the group through summary of the major discussion points, a reiteration of decisions made, and prayer.

### **Methods of Imparting Information**

Didactic input occurred in two group sessions. Most of the educational input occurred informally, however, with any issue being used to impart information. For example, when the end of

the year approached, a member raised worries about the use of alcohol over this period. This provided an opportunity to discuss issues like stress (and its management) and the incompatibility of alcohol intake and medication.

Over most of the sessions, concerns raised about behaviours and feelings would be used to discuss the symptomatology of various mental illnesses, and/or the side effects of medication.

Another educational strategy was that of teaching patients (and family members) the names of the medication they were using.

The question of stigma was also a major concern for members, and enjoyed much discussion in the group. At one particular meeting, the facilitator challenged the group to look at their own stereotypes regarding mental illness.

At the same time, the facilitator attempted to model listening skills within the group, mainly through the use of clarification and reflection, and occasionally by facilitating communication between members. The facilitator also focused on modelling concern and empathy. For example, in one meeting, AA seemed very preoccupied and worried, but refused to talk about what was happening. The facilitator expressed concern about him, while stating her respect for his decision not to talk about what was happening, and encouraged other members to share possible difficulties in talking about problems.

#### **Methods of Facilitating Group Development and Providing Individual Support**

The support of group development by the facilitator is discussed below (ie. raising issues around control and independence ; encouraging the group to take increasing responsibility and toward autonomy). Support of individual members usually occurred in relation to individual difficulties (and again provided the opportunities for modelling concern, empathy and supportive behaviour). In most cases, the group was encouraged to support the individuals concerned, although in some cases, the facilitator made specific suggestions. For example, a family member raised concern about behavioural difficulties experienced

with a patient, and after some discussion within the group, the facilitator suggested a behavioural programme as a means of addressing the concerns. Both the family member and the patient agreed to this, and over the next three sessions, were asked to report back on the progress of the intervention.

Another example is that of AA, a patient who raised relationship problems with his mother, Mrs L. Both were encouraged to express their feelings concerning the difficulties, and the group proceeded to give practical advice to them. As they were the first members who used the group to discuss difficulties, they were also asked about their experiences of using the group in this way. Issues concerning confidentiality, and fear of the consequences of talking in the group, were raised, and gave the group the opportunity of stressing these rules within the group (ie. confidentiality, not taking issues outside the group unless agreed to by parties involved, etc.)

The relationship difficulties between these members continued but both felt that there was a slight improvement over the 19 sessions.

In another case, concerning an infrequent attender, the group suggested a practical solution to encourage her to attend meetings. Some members decided to accompany her as she was reluctant to attend meetings on her own.

In one case, involving CB, a previous Section 28<sup>9</sup> patient, the facilitator and community worker intervened on an individual basis when there was a possibility that he could face a charge of assault. CB was asked to establish whether or not a charge had been laid before further action could be discussed. It emerged that a charge had not been laid, but CB's problematic home circumstances were highlighted and discussed. He eventually moved home.

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<sup>9</sup>Section 28 refers to a patient that has been committed to a psychiatric institution via the penal system, by the order of the Minister of Health. Also known as a "President's Patient" [Government Gazette, April 1973, Vol 94, No. 3837].

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## CHAPTER FIVE : GROUP PROCESS

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The group process is summarised in Table four (overleaf).

The aim of the MACPP, which constituted the first three sessions of the group, was to lay the foundation for a support group, and to facilitate contact with the community.

In the first meeting, Tracey Miller fed back the results of her study on the experiences of psychiatric patients and their families. The rest of the meeting consisted of participants directing questions about practical and financial issues at the community psychiatric nurse who was also present. Another meeting was requested by the participants, as well as more information about mental illness.

The second and third meetings took the form of workshops, consisting of small group discussions and report-back sessions in the big group. Small groups consisted of between 4 and 7 members including psychiatric patients and family members. Group leaders, chosen from amongst the participants, were responsible for facilitating discussion and reporting back to the larger group.

The aim of the second session was for members to get to know one another better and to share knowledge about their experiences of psychiatric illness, both from a patient and family member point of view. This was facilitated with a set of guiding questions (Appendix five). The small group discussions focused on sharing information about symptoms of mental illness, medication, stigma and fears of and for the patients. Causes of mental illness suggested in the small groups included head injuries, home circumstances and family relations, stress and pressure, and early childhood experiences, although a large number of people said they didn't know what had caused the illness. In the report-back forum, advice about management was exchanged. These included management of epilepsy and the importance of recreation,

**TABLE FOUR : GROUP PROCESS**

DATE	FORMAT	GROUP PHASE	CONTENT / MAJOR THEMES	ATTENDANCE FACTORS	INDIVIDUAL DEVELOPMENT	ADDITIONAL NOTES
1990 June	Feedback General discussion	Orientation	Aims : Feedback of Miller's study / Lay foundation for support group	Very good attendance		MACCP
July	Workshop		Information sharing Getting to know each Other Similar problems			
September	Presentation/ Workshop		Need for mutual support "Toesigskomitee" "Dra mekaar se laste"			
October	Discussion		Offer practical help Understanding of support group	Change in venue		
November	Didactic		What are support groups			
December		Exploring	Committee Interpersonal problem		AA and Mother	
1991 March	Discussion	and testing	Control / Leadership issues	2 members of committee no longer present	Tea to members	

**TABLE FOUR CONTINUED**

DATE	FORMAT	GROUP PHASE	CONTENT / MAJOR THEMES	ATTENDANCE FACTORS	INDIVIDUAL DEVELOPMENT	ADDITIONAL NOTES	
April	Discussion	Working Phase	Making of articles	1 more community worker	Talents within group highlighted		
May	Activity						
June	Discussion		??	Facilitator absent			Group meets on its own!
July			Own stigma / stereotypes	Another community worker	Behavioural intervention		KA and sister
August			KA and sister				
September			Articles				
October			Attendance Symptomatology Stress of December period				
November			Discussion / Activity	Preparation for selling of articles (eg pricing)			
December	Party		Importance of group Profit of R600	Increase in attendance	AM speaks AA withdrawn		Huge success

**TABLE FOUR CONTINUED**

<b>DATE</b>	<b>FORMAT</b>	<b>GROUP PHASE</b>	<b>CONTENT / MAJOR THEMES</b>	<b>ATTENDANCE FACTORS</b>	<b>INDIVIDUAL DEVELOPMENT</b>	<b>ADDITIONAL NOTES</b>
1992 January	Discussion	Working Phase	Coping with new year	Change in venue		Incorrect notices! Decreased attendance
February			Brainstorming how to encourage attendance		AA and notices	
February	Evaluation Workshop		Evaluation of group Is group really safe?	Better attendance	AA speaks CB's crisis JA starts speaking	Mrs L absent

faith and prayer (which reflects the religious nature of Mamre as a community), and co-operation with professionals. Members expressed their appreciation for the opportunity to get to know one another and noted with surprise that they all had similar problems. The wish for another meeting was expressed again and ideas for the next meeting were brainstormed in the large group.

The third meeting took the form of a presentation on mental illness by Dr Leslie Swartz (UCT Psychology Dept) and included information on symptoms, causes, management, the role of professionals and prognosis. In small group discussions (see Appendix six for the guideline questions) following the input, appreciation for the information was expressed.

The importance of co-operation with professionals, especially around medication, was stressed. The focus of the general discussion at the end of the meeting was on the need for mutual support of families. In line with this, a support group was suggested by one member and agreed to by others. At this stage, the present author undertook to pursue this suggestion further.

The fourth and fifth meetings focused on support groups in more detail, with didactic input from the author in one session. The aim of the fourth session was for the facilitator to gain clarification about the suggestion of a support group and to facilitate the participants' defining the concept in terms of their own needs. The idea of "carrying each other's burdens", of people helping one another with practical difficulties relating to psychiatric illness (eg. helping people with grooming and self-care, visiting households and offering practical support), predominated. In the next session, the facilitator gave a short talk about support groups. The concepts of "support" and "group" were defined, and examples of support groups discussed. The functions of support groups (support, education, practical assistance, etc) were listed, and the basic principle of control by the members stressed. The fact that the group does not only have to concern itself with problems, but can also focus on positive aspects of coping, was also stressed.

The discussion around support groups continued in the sixth session, with questions about organization and leadership, and the facilitator's role, being raised. Mr S, the father of a patient, raised the key issues of dependency, control and leadership. The group, following Mr S's suggestion, decided to elect a committee consisting of a chairperson, vice chairperson, secretary and treasurer. The facilitator's role was defined as that of resource, both within and outside of the group, ie. input and liaison.

Due to various difficulties, including a busy time of year (ie. Christmas/New Year period) there was a long break between the sixth and seventh sessions - November 1990 to March 1991 - which again raised issues around control. More specifically, the facilitator posed the question about what happens to the group if the facilitator, or the community worker (whose workload dictated casual involvement in the group) were unable to attend a session. The group decided to meet anyway, but expressed the need for continued assistance from the facilitator and community worker in co-ordinating the meetings. At the same time, the facilitators encouraged a gradual shift in control of the group by handing over the responsibility of supervising tea for the meetings to the group. Mrs L, a family member, eventually became the person responsible for this.

Although the suggestion that the group undertake activities within the group had been raised before, it was at this time that a major shift occurred when a group member (a family member) announced that she could get materials from the factory in which she worked, for use by the group. The idea of making articles (like pillows, scatter cushions, dolls, trays, etc) was enthusiastically agreed to by most of the members, and it was decided that the following session would take the form of an activity session. The initial idea underlying the making of articles was that of occupying members', especially patients', time.

The activity session highlighted talents within the group, notably Mrs L and Mrs B, both family members. Eventually, the idea of selling the articles was raised (prompted in part by the group running out of tea and needing more!) and progress with the selling of articles became a standard item on the agenda of the group. It was eventually decided to sell the articles in Mamre just before Christmas, and the meetings in November and December 1991 focused almost exclusively on preparation for this. The result was a profit of R600, which was placed in the group's kitty for use by individual members in cases of emergency.

At the same time, two important developments occurred alongside each other. Firstly, two of the people who had been elected to the committee, were involved in a motor vehicle accident and eventually stopped attending meetings. At the same time, the number of people attending continued to decrease steadily. In discussing these changes within the group, participants noted that a core of regular attenders had emerged in the group, and felt that they could take increasing responsibility for the maintenance of the group, without necessarily having to establish a committee. The importance of notifying all members of meetings was stressed, and the concern regarding non- or poor attendance was raised.

A third important development during this period was the attendance by two more community workers.

Two further special events occurred during 1990. In June, the group met without the presence of the facilitator for the first time. The reason for this was to encourage independence of the group. A community worker who attended this meeting, reported that it had been successful. At the session following this, the group members also expressed satisfaction with the meeting. Secondly, in December, the group held a Christmas party with each member contributing eats or drinks. One of the community workers made a speech in which she praised the group for their efforts and expressed her view that the group was a huge success, even

though many people whom she felt could benefit from the group, did not attend. One of the patients, AM, also made a speech on behalf of the patients thanking family members, the community workers and facilitator for their participation in the group. She likened her experience of the group to that of a family, and gave a moving speech about the importance of the group in her life.

Nineteen-ninety-two brought with it a change of venue for the group with the turn out at the first meeting being poor due to the address being printed incorrectly on the notices.

The idea of an evaluation was raised by the facilitator for the purposes of this research, as well as for the benefit of the group i.e an opportunity to review and plan ahead. In order to plan the evaluation, the group met twice during February, the second meeting being the evaluation workshop. At the first meeting in February, the importance of trying to get as many people as possible to attend the evaluation workshop, especially people who did not come regularly so that group can get some idea of what difficulties people faced, was discussed. It was decided to make and display posters, and to send out notices inviting people for tea and cake, in an attempt to boost attendance. The evaluation workshop is discussed in detail in the following chapter.

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## CHAPTER SIX : THE EVALUATION WORKSHOP

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The evaluation workshop lasted two hours. Seven regular and five non-regular attenders formed the small groups. Two regular attenders forwarded apologies.

Each group discussed guideline questions (see below), and later reported back in the larger group. A community worker acted as facilitator in each small group, and the researcher spent some time with each group. The third community worker joined the general discussion.

### OUTCOME OF SMALL GROUP DISCUSSIONS

The translated notes made by the small groups are provided in this section, which is then followed by further discussion :

#### Regular Attenders

##### 1. Experience of the group

- \* Friendship Circle
- \* Little interest shown after beginning
- \* Educational
- \* Groupwork led to change
- \* Pleasantness of meetings
- \* Look forward to meetings
- \* Meetings once a month too little
- \* Families show too little interest

##### 2. What can be done?

- \* Meet more than once a month
  - \* Needle and handwork...
  - \* Singing group...
  - \* Gardening...
  - \* Confidentiality
- PS : Safety of group

In reviewing the experience of the group, members felt that a "friendship circle" had been established. They saw the group as a "pleasant time" and stated that they looked forward to meetings. They found the meetings informative and a chance to talk about common problems. They also felt that group tasks provided them with an opportunity to change together.

They raised concern about the decline in the interest in the group amongst the broader psychiatric community in Mamre. In particular, they noted the lack of interest from family members. They suggested that the group meet more than once a month, and include other tasks (eg gardening and a singing group).

The principle of confidentiality was reiterated as important to this group, and difficulties around giving each other feedback, raised. Members were asked whether they felt that group was "safe" enough for them to give each other constructive feedback (negative or positive) and the facilitator noted that although group members agreed that the group was safe enough, they didn't really give one another negative feedback. This led into questions about the repercussions of this being raised eg. fear of spoiling relationships. It was felt that this needed further investigation in the group.

### **Non-Regular Attenders**

#### 1. Reasons why they don't attend regularly

- \* Other responsibilities
  - husband crippled
  - sister has epilepsy
  - belong to another group  
(sometimes meet on same day)
- \* Shy, people call attenders "mad"
- \* Family problems
- \* Reluctant to come alone

2. What can we do to make it easier for people to attend?

- \* Confidentiality
- \* Motivation
- \* Activities eg outings
- \* More information about illness

3. What do you want from the group?

- \* More support
- \* Money for emergencies
- \* Unity in group, working together
- \* Motivation
- \* Interest

In discussing the question of what difficulties they experienced in attending meetings, all stated home responsibilities and family problems as the major factor. One member explained that she had to care for a crippled husband which made it difficult for her to leave the home, while another noted worry over his epileptic sister.

The second major factor noted was that of conflicting needs. Some of these members said that they also belonged to other groups or organizations who sometimes meet at the same time as the present group.

The third factor discussed was stigma, with all the members expressing shyness about attending the group for "mad people". One member described being teased by other people, which made him feel ambivalent about attending meetings.

When asked what would make it easier for these members to attend the group meetings, they all felt that the principle of confidentiality would encourage them to attend. One member said that if he knew everything he said would be confidential, he would feel more secure.

These participants all saw the group as a resource in cases of emergency, and as a place for getting "attention", a sense of "unity" and "motivation".

They continued to discuss practical suggestions for group activities, much of which were either in operation in the group (eg. making and selling articles) or had been suggested previously (eg. patients contributing to a group fund).

### **Group Discussion**

In the general discussion following small group discussions, each group fed back on their discussions. The issue of confidentiality, a concern raised in both groups, was discussed in more detail. Difficulties relating to self-disclosure ie. raising an issue in the group in the presence of a family member / patient, and then having to deal with possible consequences (eg. fear of being reprimanded/being exposed) outside of the group. At this stage, Mr A raised issues in relation to his mother (who was not present) and the difficulty with dealing with the issue without her presence was stated.

Tea was followed by a summing up of the workshop, and the need for further discussion on the issues raised was noted.

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## CHAPTER SEVEN : DISCUSSION

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The evaluation workshop provided valuable insight into the regular participants' experience of the group, and difficulties faced by the non-regular attenders, both of which will be explored further in this chapter. Particular attention will be drawn to issues of autonomy, heterogeneity and adherence as they are felt to be crucial factors affecting the success of group.

### **GROUP DEVELOPMENT**

Van der Walt (personal communication) suggests evaluating group development by assessing levels of member participation.

At the first level, members merely benefit in some way or another from being present in the group.

The second level of participation is that of members being involved in the running of the group or the implementation of group goals. That is, members are involved in maintaining the practical operation of the group. Examples of this occurring in the group is the responsibility taken by individuals for tea and notification. Active participation through discussion serves as another example.

The third level refers to members being involved in the planning of the group. This was encouraged increasingly over the first 18 sessions. An example of this is the planning of the evaluation workshop in which all the regular members were involved in determining the workshop format, and brainstorming how to encourage participation.

The fourth and final level of participation refers to the group's ability for self evaluation. Again, the evaluation workshop serves as an example of this. Members were able, albeit to a limited extent, to reflect on the group and express feelings about this. A further important aspect of participation at this level is members' ability to lend constructive criticism, which

again they were able to do to a limited extent (see Chapter six). Furthermore, and perhaps more importantly, members were able to discuss difficulties relating to this.

By definition, the support group can be seen as currently functioning in the "working" (Yalom, 1975 ; 1983) or "established" (Whitaker in Nichols and Jenkinson, 1991) phase of development, which is characterised by :

1. sustained work on tasks by the members, and
2. by the facilitator transferring responsibility for interaction within the group, and for the operation of the group, onto members.

The first characteristic is evident in the preceding chapters, but with the second, some difficulties need to be highlighted.

Firstly, because of the question of the safety of the group which emerged clearly in the evaluation workshop, it is felt that members are not yet able to interact fully within the group. The group's concern with confidentiality and expressed fears of the repercussions of self-disclosure also point to the group's struggle with safety.

Secondly, the group is not able to take full responsibility for the operation of the group yet, although there are factors favouring increasing responsibility.

The establishment of a committee can be regarded as an attempt towards autonomy by the group. The failure of the committee was largely due to two key members no longer attending the group, but may also have been due to the fact that the committee was established too early in the development of the group. The model proposed by Kaufman, et al (1989) suggests that the members in a group may not be at the same level of development at the various stages of the group, which may be a further factor here. One of the key members mentioned earlier was actively involved in leadership in other groups in Mamre, which resulted in him obviously being more capable of taking a leadership role. The extent to which he would have been able to sustain the group,

given the fact that the majority of the other members were not at the same level of individual development within the group, will unfortunately remain an unanswered question.

Thus, in summary, the group is able to sustain work on tasks and is moving towards increasing responsibility. The emergence of a core of regular attenders, and the fact that most of these individuals have started to take increasing responsibility for the group, are two favourable factors for further group development. The establishment of another committee may be apt at this stage of group development.

#### **GROUP BENEFITS**

The literature notes with enthusiasm that support and self-help groups can provide a number of benefits to its members. We will now turn to the participants for their views.

The experience of the group as that of a "friendship circle" expressed in the evaluation workshop, can be seen as referring to the notion of **cohesion** (Nichols and Jenkinson ; 1991 : 16) and Orford's (1992) self-help function of social companionship.

As pointed out by Newton (1988), support groups are more likely to be needed by people who share similar difficulties. This is clearly a factor in the case of psychiatric out-patients and their families in Mamre. Not only is the experience of mental illness shared, but environmental conditions unique to Mamre (see Chapter three), may act as an additional cohesive agent.

Furthermore, Mamre is an established community with a history of meeting their own needs through community structures. An example of such a structure is the "Vriende Van Alkoholiste" (VVA), which is a support group for alcoholics.

A possible further facilitative factor of cohesion is the notion

of *gemeinschaft*, which is traditionally associated with rural communities. Davis and Ziegler (1990) reviews a program which they felt capitalised on this characteristic.

On the other hand, however, Orford (1992 : 74) points out that "the assumption that densely knit networks are necessarily related to greater support and better health under all circumstances" should not be taken for granted. When taking into consideration the large percentage of households experiencing inadequate care and support (38,7%), as well as severe problems (51,6%), in this study, this point becomes quite significant.

The notion of **universality** refers to the experience of similar problems. Interestingly, this is not listed as one of Orford's (1992) functions of self-help groups. This was clearly expressed in the evaluation workshop (see Chapter six), where members expressed appreciation for the opportunity to discuss common problems. This was also clearly evident in the first few group meetings where members noted with surprise that others were experiencing similar problems (See Chapter five).

However, the question of heterogeneity deserves further scrutiny here. Patients and their families participating together appeared to have both positive and negative effects.

Mueser, et al (1993 : 252) points out that "short-term educational family treatments for schizophrenia offer a small benefit to relatives, but not to patients, perhaps in part because patients are often excluded from these treatments", implying possibly that both should be included.

Nichols and Jenkinson (1991 : 11) suggest that groups "can be formed on a heterogeneous basis as long as there is sufficient common ground between members to allow the uptake of a collective task and sufficient experience in common to allow meaningful sharing, empathy and support". The tasks used by the group certainly brought members together, and it was here that all

members were on an equal footing in terms of responsibility in the group.

However, Harter (1988) states that the presence of patients in meetings create the potential for psychotic behaviour thereby inhibiting the expression of feelings. The reverse was also found to be the case. It is interesting that AA used the group in which his mother was not present to raise interpersonal problems with her.

From the patients' experience, factors relating to mental illness may also inhibit their participation. As pointed out by Brugha (1991 : 151) :

The possibility has also to be considered that symptoms such as pathological guilt, subjective retardation, irritability, and simple ideas of reference, which may be elements of the clinical picture, may significantly inhibit the quality and quantity of social interaction between a patient and his/her social network.

The most obvious difficulty within the group was that of scapegoating and patronising attitudes towards ex-patients by family members. An example of this was KA's sister, a family member, who was eventually confronted in the group by the facilitator for referring to her brother as "they" (meaning patients). Generally, the group was also seen as "for the patients", both by family members, patients and community workers. Often suggestions included activities to occupy the patients' time, or the group was seen as being an effort to help the patients. Perhaps this notion was facilitated by the greater number of ex-patients as opposed to family members in the group. Another possibility is that family members may be reluctant to regard the group as theirs because of the stigma attached to the group.

By far one of the most important functions (and benefits) of a group is that of "**imparting of information**" (Yalom, 1983) or Orford's (1992) function of relevant information and ideas about

ways of coping. Again, this benefit was highlighted in the evaluation workshop where members reported that they found the meetings informative. Of note here is that the educational needs expressed by the participants is similar to that expressed by Muesser, et al's (1992) respondents (cf. page 11).

The group benefit of **catharsis** was also evidenced in the group. Again, this benefit has no analogy in Orford's (1992) self-help functions. An example of this is the use of the group by AA not only to discuss home difficulties, but to express negative emotions towards his mother in the group where she was not present. Another member, JA, also used the group to express his feelings of frustration.

In one incident, another member's likening of the group to a family (see p. 38) can also be seen as referring to the group benefit of **corrective recap of the family group**.

Thus far this chapter has focused on the experiences of the regular attenders in the group. We will now turn to issues raised by the non-regular attenders, which highlights the question of adherence.

#### **ADHERENCE<sup>10</sup>**

The question of "lack of interest" amongst the broader psychiatric community in Mamre remained one of the most important issues of concern within the group.

The issue of adherence has also remained a major concern in the literature. The most frequently quoted rate of non-adherence to family intervention is 8% - 35% (Birchwood and Smith, 1990 ;

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<sup>10</sup>The term 'adherence' has been advocated as a shift away from the term 'compliance' as it connotes voluntary individual effort as opposed to "passive patient obedience" (TARRIER, 1991 : 476).

Tarrier, 1991) but refusal and drop-out rates of 51% and 53% respectively have also been reported (Muesser, et al, 1993). In the present study, 41,9% of the total households were not represented in any of the sessions, which is consistent with the more recent rates reported in the literature.

The small group of non-regular attenders who participated in the evaluation workshop gave some insight into the difficulties faced by the broader group of non-regular attenders. These factors will be looked at with reference to the literature in this area.

Tarrier (1991) suggests that the physical health of relatives ; absence of social support ; competing demands and lack of resources (transport, time, money) are amongst some of the factors that affect adherence. These difficulties were expressed by the non-regular attenders who participated in the evaluation workshop (see Chapter six).

Further possible factors highlighted by an analysis of the group will be the focus of the rest of this chapter.

### **High levels of burden**

Tarrier (1991) suggests that higher levels of burden influences adherence to intervention by families. The following factors suggest that the group of non-attenders were suffering higher levels of burden than those attending the group regularly :

- 1) amongst the regular attenders, neither financial difficulties nor inappropriate care and support were experienced
- 2) the majority of those suffering severe difficulty (56,25%) did not attend the group at all
- 3) non-adherence to out-patient treatment and re-admission rates (see Appendix seven) were highest among the 'infrequent' (44,4% and 20% respectively) and 'never' (33,3% and 60% respectively) attenders.

This is in opposition to the viewpoint of Smyth, Vostanis and Dean (1990 : 419) who found that "patients lost to follow-up are less ill, more likely to be employed and more likely to have the support of a marital relationship, and as such this is not a

cause for concern".

### **The role of education**

The good attendance in the first three sessions (which included didactic input) may have influenced later attendance. In an evaluation of three relative support groups, Leung, Rastogi and Woods (1989 : 419), "...found that the first three sessions were rated the most valuable by members of the group". Their members felt they understood more about the illness and that these sessions fulfilled their needs for attending. These findings were in line with other studies cited by these authors (ibid).

It is also possible that the group members who later dropped out rejected the service because the information offered to them was in opposition to their individualised views about the illness and its management. Mamre's strong religious culture may be pertinent here, and in fact, in the second group session (see Chapter five) some members suggested faith and prayer as a management strategy. TARRIER (1991) suggests that a lack of understanding of the nature and course of the illness or conflicting health beliefs also affect adherence.

### **A 'culture' of non-adherence**

TARRIER (1991) suggests that adherence by relatives would be decreased if they are exposed to an environment that supports non-adherence. In Chapter one it was argued that the patient has a profound impact on the family and the home environment. It is thus possible that the patient who does not adhere to out-patient treatment facilitates a climate of non-adherence in the household. Appendix seven shows that the majority (7/9) of the patients who did not adhere to out-patient treatment attended the group infrequently or never. Furthermore, the 2 people who attended the group regularly and occasionally respectively, were not re-admitted for the period under review and were considered to be functioning well by their relatives.

### **Stigma**

The issue of stigma was clearly a factor in Mamre. All the non-regular attenders who attended the evaluation workshop noted that stigma was an important issue affecting their attendance of the group, and it can only be assumed that this would be a key factor for the broader group of non-attenders.

Hall, Brockington, Levings and Murphy (1993 : 106) point out an important aspect about stigma that relates to community intervention :

In a community-based service, patients are nearer their home and there is, therefore, increased risk of being identified as mentally ill...

### **Re-admission**

Lastly, the impact of re-admissions must also be considered as it would affect patients', as well as possibly family members', ability and motivation to attend the group. As pointed out in Chapter two, as well as by TARRIER (1991), families facing an acute crisis may be more amenable to help while those "experiencing a chronic illness with severe deficits may feel that their actions have no influence on the patient and hence view the situation as impossible to change" (TARRIER , 1991 : 479).

Appendix seven includes the re-admission rates for the period under review. Of the 19 patients who adhered to out-patient treatment and attended the group either regularly, occasionally or infrequently, only 2 were re-admitted at some point during the period under review. One of these remained a regular attender in the group, which leaves the possibility that 1 patient's re-admission influenced adherence. Even if this re-admission led directly to either an increase or decrease in the patient's or family's attendance of the group, the incidence is too low to be considered a major factor in this study.

In fact, what is more striking is the influence the group had on

the re-admission of the regular attender mentioned above. AA was voluntarily admitted for a short period in late 1991 and afterwards fed back to the group that he had felt more positive about this admission than in his past experience. He was given positive feedback in the group for his ability to express and act on his own needs.

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## CONCLUSIONS AND RECOMMENDATIONS

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One of the functions of an evaluation, according to Orford (1992) is to show how a programme is functioning in practice. This dissertation, through the detailed description of the first 19 sessions of the support group for psychiatric patients and their families in Mamre, has attempted to do this.

The broad aim of this project was to initiate a support group for psychiatric out-patients and their families in Mamre. An evaluation of the project has facilitated the establishment of smaller aims towards this broad goal by clarifying the following:

- 1) the group is operating in the working phase of group development
- 2) the group provides a number of the benefits it had hoped to provide to most, if not all, of the regular attenders.

The issues of autonomy, heterogeneity and adherence were highlighted, and it was suggested that each of these impacts on the success of the intervention to some extent. These factors require further investigation, and in the absence of relevant literature, further experimentation within the group.

The issue of heterogeneity must be highlighted and explored within the group. As part of this, the limitations inherent in patients and their families participating together will need to be acknowledged and accepted, but particular attention must continue to be paid to the stereotypes the members themselves hold.

The issue of adherence must be addressed. The analysis of the group has also shown that the experience is not unlike that reported in the international literature with reference to issues of adherence, which is a positive feature that needs to be pointed out to the group. This may in part address the concerns of the group around this issue, and hopefully free the group to continue the good work they are doing. New and creative methods

of notification and encouraging attendance (like offering tea and biscuits and making this clear on the notices, and offering activities like outings to places of interest) should continue to be a focus of the group though. The group's ability to raise funds is evident and could make some of these suggestions possible.

A number of reasons were proposed to explain the lack of interest shown by the broader psychiatric community in Mamre. These theories could be tested and explored through further research with the group of non-regular attenders, which would form a basis for devising strategies to address the lack of interest more directly.

Shepherd (1988 : 99) points out that "evaluation is of little use in isolation" and should always be linked to action. As a working document, this paper paves the way for further intervention within the group. Most notably is the fact that the group is now able to move towards greater autonomy, and that individual members are willing to take on increasing responsibility and leadership. As suggested in the Discussion chapter, the establishment of a committee should be explored further. The first step would have to be to discuss the outcome of this dissertation within the group, and to establish the goal of leadership by the group within the group. Once this is achieved, the energies of the facilitator and the community workers would have to be directed towards supporting this committee, which more than likely will have to be very intensive initially (especially since there would have been a substantial time lapse between the last and next sessions of the group).

Thus, in conclusion, it is felt that the broad aim of this project ie. initiating a support group in Mamre, has been met. The maintenance of the group is the next aim.

As a case study, no attempts are made at generalising beyond the limitations of this project. But I do wish to speculate about

the extent to which this form of intervention could be transferred to other contexts, by highlighting some of the factors which facilitated the success of the project :

Firstly, it has been suggested that a major factor which facilitated the initiation of the group related to cohesion factors (eg. shared experiences of mental illness and the difficulties in accessing psychiatric care, the characteristic of being a small, well-established community with a history of meeting its own needs, etc) unique to Mamre.

It is possible that the number of cohesion factors is as important as their nature ie. not just what is shared, but how much is shared by the members. With regard to the participants in the group in Mamre, their shared experiences included participation in Miller's study (which in turn facilitated initial contact with the community).

Using shared experiences (beyond that of the mental illness) as inclusion criteria for a group, and continuing to highlight these, may thus be a key component to the success of a support group.

Secondly, the existence of the MCHP, and the presence of the local community workers, would have resulted in this intervention being more easily accepted by the community. Linking interventions of this kind to existing (credible) community structures will more than likely lead to their success.

Thirdly, the accessibility of the group was probably another facilitating factor. The importance of offering an accessible service is not new to the literature (see Tarrier, 1991), but always deserves emphasis.

Fourthly, in my experience, the practical (preparation of materials and information for sessions, etc) and economical (traveling, time) requirements of the group were minimal and

should even be less so if the service is also easily accessible to the facilitator. However, it must be pointed out that I had a special commitment to the success of the group (ie. a personal experience with mental illness, the use of the project for an MA (Clinical Psychology) thesis and an interest in community work) which would influence my perception of the personal costs involved.

(This commitment, in turn, may have been a further factor facilitating the success of the group).

Obviously, all of these characteristics may not be present and may influence the success of the intervention in other communities or contexts, but many of these factors could be facilitated. This may necessitate a divergence from the traditional roles of facilitation (see Orford, 1992), which in turn makes another requirement the willingness of the mental health worker to take on this challenge.

Community care is no longer a likelihood of the future, it is a reality of the present. If the mental health profession is to benefit from this reality, then we are obligated to support the new caretakers of the mentally ill (be they the patient him or herself and/or their relatives). It is hoped that through this detailed description of the process of initiating a support group, this dissertation can in some way encourage more projects of this nature. If it can do this, it would have gone a long way towards helping the victims of mental illness and deinstitutionalisation.

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## POSTSCRIPT

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An evaluation of this intervention cannot be complete without mention of some of my personal feelings on the experience.

As mentioned in the beginning pages of this dissertation, my motivation to do this work was based on my personal experience of being a family member of a person with Schizophrenia. I know that I would have appreciated having a place to go to talk about this experience, and hence my need to create this space for others. However, joining a group as a fellow sufferer and attempting to create a support group are two completely different things. In terms of the latter, two of the most frustrating aspects of doing this kind of work were :

- 1) the lack of literature providing a detailed description of support groups, and the consequent arduous task of having to turn theory into practice, and
- 2) my lack of training in working in community-based structures resulting in, amongst others, issues around distance and involvement. Orford's (1992) discussion of the inherent difficulties of professionals working in self-help groups has been a source of endless comfort and valuable direction in this regard.

But perhaps the most frustrating aspect is the fact that this dissertation does not convey the enormous gratification that this project has offered me. Nichols and Jenkinson (1991 : 17) comes close to capturing my experience of the group :

There was a regular afternoon ... with conversation, interest, companionship, laughter - a friendship network through the telephone, a time to look forward to ... and the feeling of being bonded. Somehow the formal analysis of group benefits do not catch this element.

I will admit that I often felt reluctant to trek more than 48km to Mamre (straight after Sunday lunch!) but I always trekked back

to Cape Town with a renewed appreciation of and respect for, quite simply, people. And this, I think, is the most valuable lesson I can learn as a psychologist.

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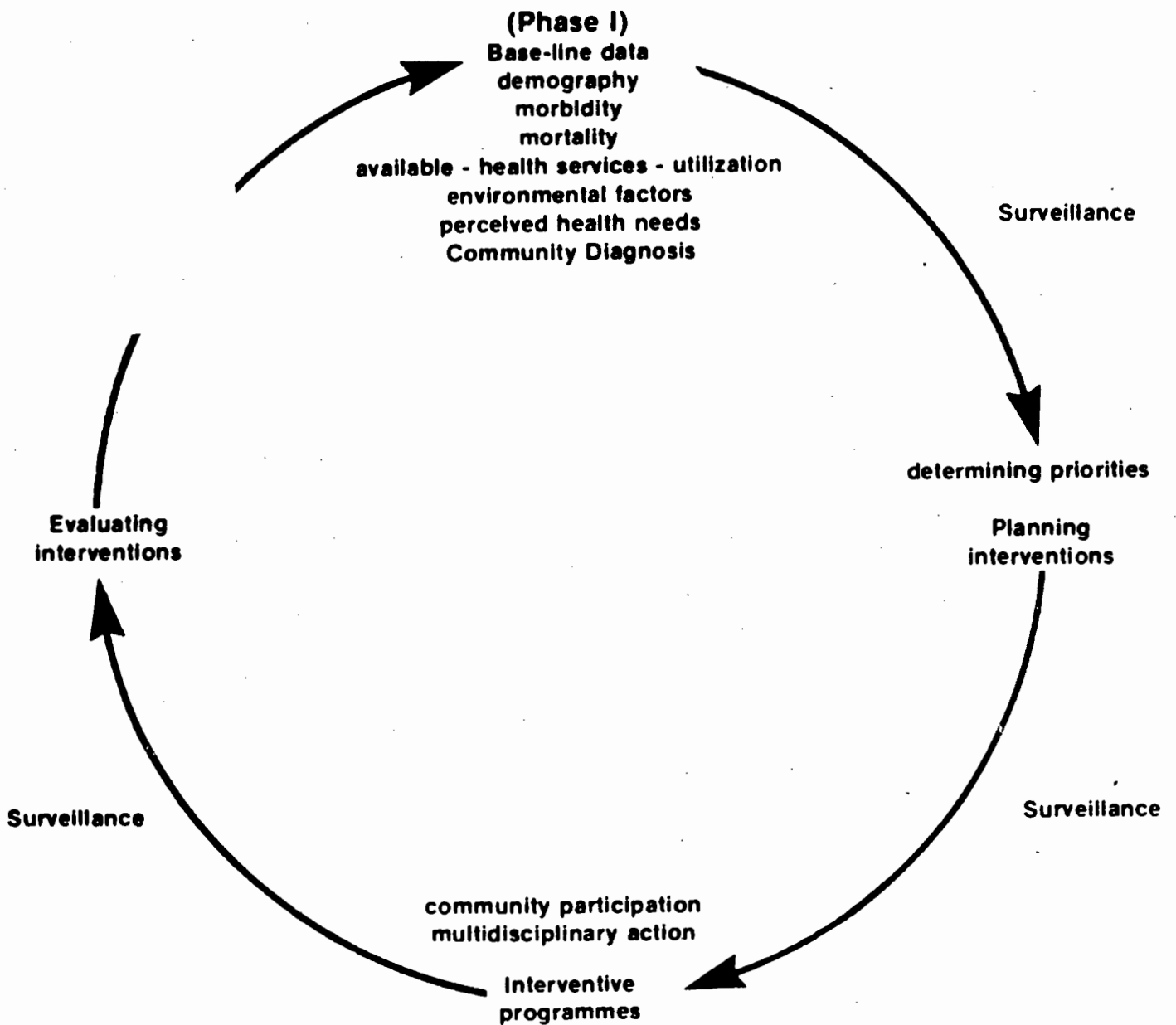
## APPENDICES

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**APPENDIX ONE : OVERVIEW OF RESEARCH AND INTERVENTION**  
**PROCESS OF THE MCHP**

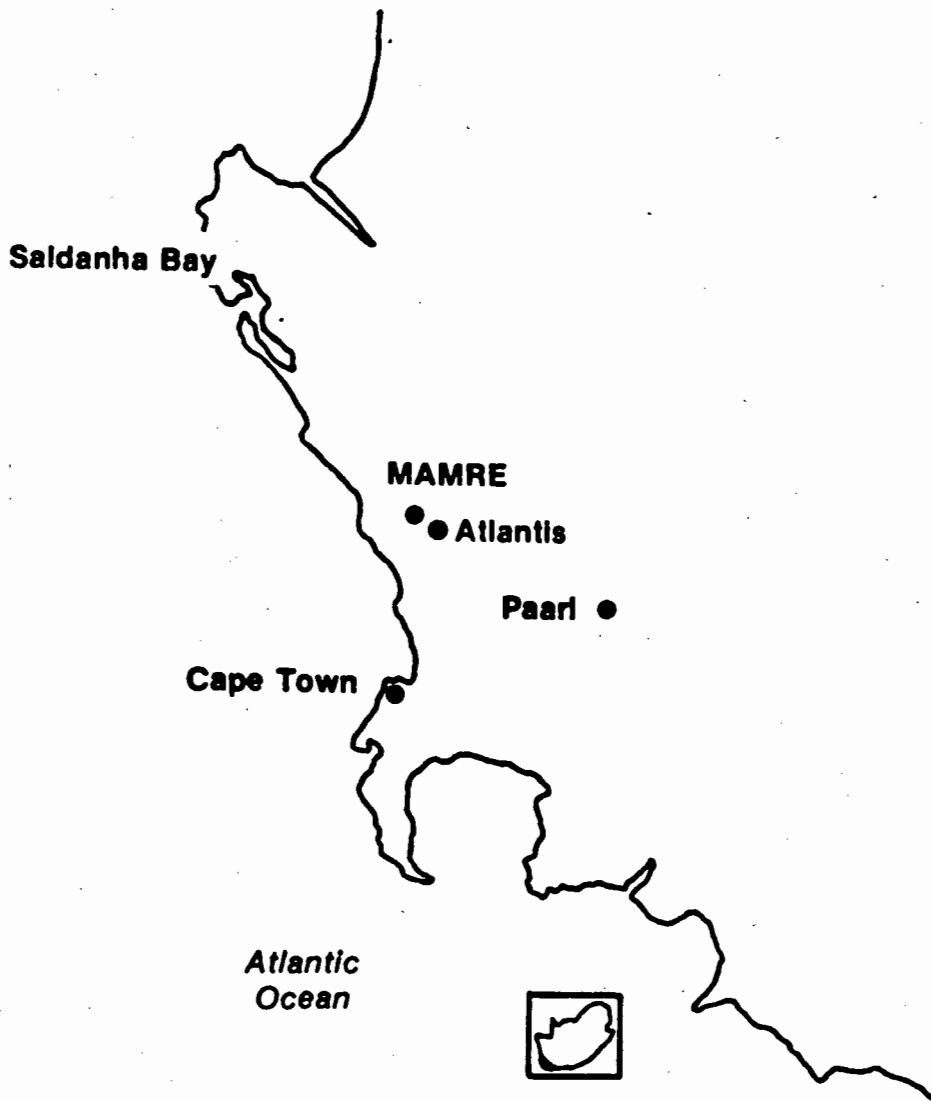


**APPENDIX TWO : DIAGNOSES**

DIAGNOSES	NUMBER OF CASES
Schizophrenia	17
Bipolar affective disorder	1
Hypomanic affective disorder	1
Mild hypomania	1
Major depression	2
Anxiety state with depression	1
Epilepsy	2
Post-traumatic epilepsy	2
Temporol Lobe epilepsy with psychosis	1
Organic mental disorder	1
Neurosyphillis	1
Alzheimers	1
Substance Abuse	3
Alcohol abuse	6
Mental handicapp	1
Acute psychotic episode	1

This information was obtained from the protocols provided by Tracey Miller.

**APPENDIX THREE : THE SOUTH WESTERN CAPE REGION**



**APPENDIX FOUR : NOTICE**

'n Werkswinkel vir psigiatriese pasiente, hul families en

ander belangstellendes sal

op **1 September 1991**

van **2.15 tot 4.00 nm**

by die **OU KLINIEK**

gehou word. Ons sal u graag daar wil sien.

## **APPENDIX FIVE : SESSION TWO GUIDELINE QUESTIONS**

HIER IS 'N PAAR IDEES/VRAE WAT VIR BESPREKINGSPUNTE IN DIE GROUPE GEBRUIK KAN WORD:

1. VERTEL ONS BIETJIE MEER VAN U FAMILIE
2. BESKRYF DIE PERSOON VOOR DIE AANVANG VAN DIE PSIGIATRISIE SIEKTE
3. WATTER SOORT DINGE HET DIE PASIENT GEDOEN, OF DOEN DIE PASIENT NOU, WAT KOMMERDWEKKEND WAS/IS?
4. WAT DINK U HET DIE PSIGIATRISIE PROBLEME VEROORSAAK
5. WAT VERSTAAN U BY 'PSIGIATRISIE SIEKTES'?
6. HOE HET U PROBEER OM DIE PASIENT TE HELP? WAT HET GEWERK EN WAT HET NIE?

**APPENDIX SIX : SESSION THREE GUIDELINE QUESTIONS**

1. WAT IS DIE BELANGRIKSTE DING WAT U VAN DIE PRESENTASIE ONTHOU? WAAROM WAS DIT BELANGRIK?
2. MAAK DIE INFORMASIE 'N VERSKIL IN HOE U VOEL OF DINK OOR DIE PASIENT? INDIEN WEL, VERDUIDELIK.
3. WAT IN DIE PRESENTASIE WAS MOEILIK VIR U OM TE VERSTAAN?
4. INDIEN WEL, WAAROM WIL U MEER INLIGTING HE?

**APPENDIX SEVEN : RE-ADMISSION AND NON-ADHERENCE (OF PATIENTS TO HOSPITAL OUT-PATIENT TREATMENT) RATES**

The re-admission and non-adherence (of patients to out-patient treatment) rates for the period June 1990 to February 1992, in relation to attendance, were as follows :

	RE-ADMISSIONS	NON-ADHERENCE
REGULAR	1	1
OCCASIONAL	0	1
INFREQUENT	1	4
NEVER	3	3

These figures were obtained from the community psychiatric nurse and do not include the 2 patients who attended the group regularly but were not on Miller's list. The information on the re-admission of the regular attender was obtained in the group, and not by the community psychiatric nurse.

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