

Support groups for relatives of people living with a serious mental illness: An overview

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Abstract

Relatives of people living with schizophrenia play a vital role in the mental health system, yet their needs are often underestimated or overlooked entirely. Taking care of a relative who has a serious mental illness can place considerable strain not only on the primary carer but also on friends and other members of the family. Support groups offer many carers an avenue through which to 'unburden' themselves among people who have faced similar situations and at the same time provide carers with some sense of control over an otherwise chaotic life experience. This report provides an overview of such support groups while placing an emphasis on factors associated with their success.

History and development of the self-help movement

The concept of self-help is not a new one. Self-help forms of organisation are “especially salient during periods of social fragmentation and unrest and are characterised by loss of relatedness and alienation” (Chapman 1997, p150). This phenomenon can be seen from as early as the 18th and 19th centuries, when unions and friendly societies developed in reaction to the Industrial Revolution. This reaction is indicative of later self-help movements that have historically tended to ebb and flow in response to major social changes. The anti-Vietnam and Women’s movements in the mid 20th century for example, not only marked reactions against authority but also served as catalysts for the more contemporary forms of self-help. These and other disenfranchised groups based on race, ethnicity and disability were formed in reaction to authority and bureaucracy, and typically arose from exclusionary policies and discrimination in larger society (Borkman 1997, Chapman 1997, Constantino & Nelson 1995). Thus, the self-help movement as we know it today has emerged from the needs of individuals and families facing major life crises.

A number of factors that have been emphasised in the literature as being facilitative of the growth of self-help include:

- The erosion of the traditional family format;
- The failure of mental health services to adequately address or meet the needs of those who attempt to access them, particularly those people who belong to a minority group, have lower incomes or are coping with a major disrupting disease;
- A greater acceptance of experientially gained knowledge and social support as useful assets in health maintenance;
- Advances in medical science which have increased the proportion of people who have an improved life-span and concomitant chronic medical problems;
- Various civil and consumer rights movements which have stimulated an increased sense of personal entitlement and empowerment, which in turn has increased people’s desire for personal control over their own health care (Chapman 1997, Jacobs & Goodman 1989).

Size and scope of the self-help movement

The development of contemporary self-help groups has been linked with the 1935 founding of Alcoholics Anonymous (Borkman 1997), however the seeds of self-help as we know it today were sewn in the societal changes of the 1970s. Since then, the self-help movement has mushroomed. There are groups for almost every presenting problem that clinicians confront, with millions of members worldwide (Toro et al. 1988). As Davison et al. describe it: “through self-help groups, millions of Americans attempt to overcome addictions, discuss innovations in insulin treatments, grieve for the loss of a breast, or share fears about the possible progression of HIV” (p205). In fact, by 1990 in the United States alone, it was estimated that six and a quarter million Americans (or 3.7% of the population) participated annually in some form of self-help group (Jacobs & Goodman 1989).

Beginning of the mental health self-help movement

The origins of self-help are closely related to major societal changes and the same can be said for the beginnings of the mental health self-help movement. Following reforms in the nineteenth century, incarceration became the fate (or punishment) of those who were classified as lunatics or inebriates. However, with the advent of deinstitutionalisation in the 1950s, such settings no longer constituted the centre of the mental health system. These days, people experiencing mental illness are increasingly expected to live and receive treatment in the community. Unfortunately, due to lack of public funding, assertive community treatment has failed to live up to expectations, as services are either nonexistent or where available, often lacking in quality. As Grosser and Vine (1991) point out, many families are “frustrated by a system of mental health care delivery that fail(s) to consider their needs a priority, disappointed by the inadequacy of programs for their discharged relatives, and angered by their negative experiences in working with professionals, clinicians and public servants” (in Constantino & Nelson 1995, p56). This lack of services and the resulting frustration of the families who care for their mentally ill relatives, has led to the growth of the mental health self-help movement. In fact, over the past 20 years, the number support groups for family members of people with severe mental illness has grown exponentially. One indicator of this phenomenon comes from data available from the National Alliance of the Mentally Ill (NAMI). In 1979, representatives of 100 family support/advocacy groups came together to form NAMI. By

1996, NAMI had 1,100 chapters and 140,000 members, which represents a ten-fold increase (Mannion et al. 1996, Citron et al. 1999). Carers then, are very much involved in the self-help process.

Definitions and characteristics of self-help groups

The literature is replete with definitions, characteristics and ideologies that have been varyingly attributed to self-help groups. In addition, varying terminology for self-help groups abounds and is often used interchangeably, which can add to the confusion. Generally, however, the terms 'self-help group', 'support group', 'mutual help group' and 'educational support group' can be said to represent similar concepts¹. For the purposes of this review, it should be assumed that 'self-help' and 'support' refer to the same entity.

In the US, some consensus as to how to define these groups was reached following the major public policy event in self-help outlined in the *Surgeon General's Workshop on Self-Help and Public Health* (1988). Here, self-help groups are defined as "collectives of voluntary associating persons who share a common problem; they are self-governing, rely on the experiential knowledge of their members as the group's source of authority, provide mutual assistance which is at least emotional support and do not charge fees" (in Borkman 1997). In a later report published in 1999 by the Surgeon General, self-help was further defined as being: "geared for mutual support, information and growth (and) is based on the premise that people with a shared condition who come together can help themselves and each other to cope, with the two-way interaction of giving and receiving help" (chp.2).

Although there is a broad variety in format, style and ideology among support groups, the process itself remains essentially shaped by the following ideologies and characteristics:

- Groups function within an ethos that highlights and values notions associated with empowerment, experiential wisdom, mutual support, social learning, empathy and shared experience (Borkman 1997, de Balcazar et al. 1989, Chapman 1997, Constantino & Nelson 1995, Davison et al. 2000, Dunne & Fitzpatrick 1999, Jacobs

¹ There have been some attempts to distinguish support groups from self-help groups in the literature (see Kurtz 1990 and Rootes & Aanes 1992) by making professionally-led versus peer-led distinctions. However, this is somewhat clouded by the fact that mental health professionals and nonprofit organisations often aid self-help groups with logistical support, start-up assistance, consultation, referrals and education (U.S. Dept of Health & Human Services, 1998).

& Goodman 1989, Kane et al. 1990, Kurtz 1990, O’Riordan 1989, Rootes & Aanes 1992).

- The emphasis is placed on social support and mutual aid with members both providing and receiving help, while also serving as role models (Constantino & Nelson 1995, Kane et al. 1990, Meagher 1998).
- Groups reject professionalisation and bureaucratisation (the primary characteristics of service organisations) in favour of autonomy and solidarity (the primary features of mutual-benefit associations). This rejection places the emphasis on the value of democratic and egalitarian principles (Chapman 1997).
- The democratic nature of groups involves self-governance, equal rights within group processes, leadership at the pleasure of the group, free expression of thought and feeling, independence from external rule, internal system of checks and balances and de-emphasis of rank and privilege (Chapman 1997, Jacobs & Goodman 1989, Rootes & Aanes 1992, Wintersteen & Young 1988).

Demographics

Much research has been conducted into the characteristics of people who attend support groups. Davison et al. (2000) conducted a study in which it was found that support seeking was highest for diseases viewed as stigmatising and that people who felt their illness was embarrassing, socially inappropriate or disfiguring were more likely to seek the support of others with similar conditions. They offer this explanation:

“The experience of illness is a profoundly social one. Suffering elicits intense emotions and hence the desire to talk to others. Through interpersonal exchanges, patients develop an understanding of their illness: They may talk to friends, relatives and professionals about what their diagnosis and treatment may entail. Over the course of their particular illness, relationships are strained or broken, and new ones become valuable, such as those with doctors, nurses or physical therapists. For some, the condition itself constitutes a dangerous secret that erects a barrier between themselves and their support network. Thus, patients’ experiences of illness both influence, and are influenced by, the social fabric that surrounds them” (p205).

Festinger's (1954) social comparison theory states that individuals seek to have and maintain a sense of normalcy and accuracy about their world. In times of uncertainty, affiliative behaviours increase as people seek the opinions of others about how they should be thinking or feeling. Social comparison is intrinsic to the health care setting, where anxiety levels are often high and information, when available, may not be delivered in a format that patients readily understand. Diagnosis, treatment, side effects of medication and other kinds of disruption prompt people to talk to others undergoing a similar challenge (Davison et al., 2000). Furthermore, the reluctance of people to discuss such intensely personal problems in 'normal' social situations and the deeply held feelings that others who have not experienced a comparable crisis cannot truly understand, increases the need to actively seek out support groups (Wintersteen & Young 1988).

Overall, the literature concurs on the characteristics of people who attend support groups. These figures are representative on the whole of white, middle class females who have higher than average education levels. Similar findings are reported for family members who attend support groups due to a mentally ill relative (Borkman 1997, Mannion et al. 1996, Norton et al 1993). In these 'carers' groups, more parents participate than their siblings, spouses or adult children, and members report smaller social networks than non-members (Mannion et al. 1996).

Who are the carers?

"Few people become carers by making a rational decision about what they are going to do with their lives, rather, "the caring role creeps up on them, as it becomes clear that their relative is going to need help for much longer than anyone imagined" (Berry 1997, p17).

In the field of mental health, self-help groups have been developed by two different stakeholder groups: people who have experienced mental health problems, (who refer to themselves as 'consumers', 'survivors' or 'service users', depending on their country of origin an/or their particular stance²) and parents and family members of people with mental health problems. Relatives (including friends, family and spouses) in turn are commonly

² The US Surgeon General's report into mental health (1999) makes the point that some people reject the term 'consumers': "to some, being a consumer erroneously signifies that service users have the power to choose services most suitable to their needs...(and) contend that consumers neither have choices, leverage, nor power to select services. Instead, some consumers refer to themselves as 'survivors' or 'ex-patients' to denote that they have survived what they experienced as oppression by the mental health system" (chp.2).

referred to as 'carers', 'relatives', 'family' or 'secondary consumers', terminology which is still being modified as the mental health forum develops. Still one further step removed are the groups for human service workers who face the daily stress of working with those who are seriously ill or dying (Jacobs & Goodman 1989). Sometimes, groups involve and include all three stakeholders.

In 1997, the National Schizophrenia Fellowship in the United Kingdom (NSF) conducted a study into the demographic characteristics of carers. They revealed that around one and a half million people in Britain spent 20 hours per week or more looking after someone who has a mental illness (most of these people were identified as having schizophrenia). Some 60% were women and their average age was 60. Only 3% were in full time employment (Berry, 1997).

The vital role that carers play cannot be overestimated. Since deinstitutionalisation and the resulting emphasis placed on community care, there has been an increased assumption that families will take on much of the responsibility for the care of the person diagnosed with schizophrenia (Brady 1996). Deinstitutionalisation has also been premised on the use of unpaid labour of volunteers, who are mainly women, in the home or in private organisations (Chapman 1997).

Much of the literature available today emphasises the role that carers play in the wider mental health spectrum. Carers are referred to as the "glue that holds the system together" (Chapman 1997, p149), the "paraprofessionals who play a significant role in the service delivery system" (Abramowitz & Coursey 1989, p236), the "coordinators of services and advocacy for their handicapped relative" (Winefield & Harvey 1995, p140) and the "primary source of care for persons with a severe mental illness...they provide housing, financial aid, companionship and emotional support" (Pickett-Schenk et al. 2000, p413).

Abramowitz and Coursey (1989) estimated that by 1982, 250,000 chronically mentally ill patients in the United States were discharged to their families. Other studies have estimated that between 40-60% of people with schizophrenia return to live with their relatives (Brady 1996, Norton 1993). The NSF estimated that the money carers of people with schizophrenia save the British government every year is in the region of three billion pounds (Berry 1997). It is obvious therefore, that the present policy of treating the mentally

ill in the community simply could not exist without the family members who almost always bear the main burden of care.

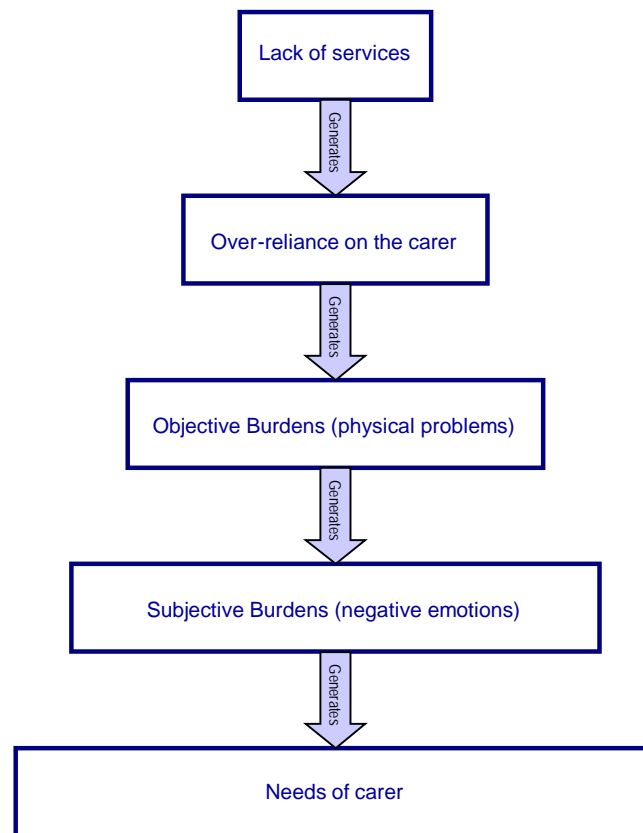
Burden of care

Such reliance on the families of people with a mental illness inevitably results in some form of 'burden' experienced by carers. This burden is unique to carers of people with a mental illness. As Karp (2000) explains:

“Although their sickness might dramatically disrupt the logistical routines of everyday family life, physically ill people are ordinarily deeply involved in getting well and returning to their presickness social roles. In contrast, mentally ill people often cannot abide by the usual rules of social settings, may engage in behaviours considered socially repugnant, sometimes deny that they are ill, and frequently treat their caregivers with hostility instead of gratitude” (p7).

Being a 'front line' carer for someone with schizophrenia can create considerable costs for families and often involves the family unit in a long-term stress that threatens the physical, social and mental wellbeing of all family members (Dunne & Fitzpatrick 1999, Kane et al. 1990, Pickett-Schenk et al. 2000, Toseland 1990). Carers are often thrown in the deep end, with little or no formal training in mental illness. They also face a lack of information about the disorder and its medication, a lack of resources and treatment facilities and, at times, a lack of responsive professionals (Abramowitz & Coursey 1989). These very real obstacles place both objective and subjective burdens on family members (Chapman 1997). Objective burdens are actual physical problems such as those associated with financial hardship or disruptions to household and social functioning, while subjective burdens are the associated feelings of anguish, guilt and loss. As can be seen from *Figure 1: Burden of Care* below, burden of care directly stems from the role carers play in the wider mental health spectrum. A fundamental lack of services in the community leads to an over-reliance on family members, which in turn generates physical and emotional problems for carers. This provides the basis then, from which the needs of carers can be identified.

Figure 1: Burden of Care



Objective burdens

There is general consensus in the literature as to the nature of both the objective and subjective burdens placed on carers of people with schizophrenia. The objective burdens can include:³

- *Economic losses*: such as financial and employment difficulties, as well as loss of opportunity and potential for the carer (Abramowitz & Coursey 1989, Brady 1996, British Columbia Ministry of Health 1993, Berry 1997, Chapman 1997).
- *Impaired physical health*: in a study conducted by the NSF in 1997, over 70% of carers surveyed felt that their health had suffered because of their caring role.
- *Disruption of relationships*: family relationships can suffer because the relative's behaviour can be extremely difficult to cope with and symptoms can be very

³ It is important to note that not all carers will face the same burdens – much is dependent on the unique circumstances of each individual.

disruptive (Abramowitz & Coursey 1989, Brady 1996, British Columbia Ministry of Health 1993, Chapman 1997).

- *Reduced social networks*: this is due in part to the disruption of normal social and leisure activities as well as to the stigmatisation that often occurs hand-in-hand with a diagnosis of mental illness (Abramowitz & Coursey 1989, Brady 1996, British Columbia Ministry of Health 1993, Chapman 1997).

Subjective burdens

Subjective burdens experienced by caring family and friends has been directly linked to the experience of objective problems (Cuijpers & Stam 2000). Subjective burdens are more emotional in nature and include feelings of anxiety, stress, guilt, shame, self-blame, depression, fear, anger and confusion (Abramowitz & Coursey 1989, Berry 1997, Brady 1996, Chapman 1997, Wintersteen & Young 1988). Caring for someone with schizophrenia can be both time and energy consuming; family and friends are often relegated to second place and the carer's own plans and ambitions are more often than not put on hold, which can lead to feelings of anger and resentment (Berry 1997). Grief is also very common. Grief as it relates to carers of people with schizophrenia, often manifests as the adjustment of coming to terms with the disintegration of personality in the family member:

"There is always the sense of loss, almost like a death. Schizophrenia cuts down young people just as they are realising their potential and the person left often seems a pale shadow of the person they were before. There is a grieving that needs to be done for this lost person, a grieving that will help the carer adjust to the new person the sufferer has become" (Berry 1997, p26).

Other experiences include lowered self-esteem and increased isolation and withdrawal due to stigma and reduced social networks (Brady 1996, Wintersteen & Young 1988).

Carers' needs

As the burden of care is directly related to the emotional and physical costs of caring for someone with schizophrenia, so too then are the carers' needs, which stem from the role they are forced to play within the mental health system and its contemporaneous burdens. It follows then, that the needs of carers fall into two distinct categories: the need for

assistance with problems stemming from objective burdens (for instance, information and coping strategies etc.) and the need for assistance in coping with the associated subjective emotions (learning to come to terms with feelings of guilt, anger, fear, depression, shame and grief). Carers not only need information and advice about how to cope with their ill relative, they also need emotional support.

It is also crucial to recognise that the needs of individual carers change over time:

“Sometimes in the rush that happens before someone is finally diagnosed as suffering from schizophrenia, the feelings connected with caring are pushed aside, as if they matter little. After the diagnosis, there are so many practical things to deal with, as both carer and sufferer adjust to the new life of learning to live with the illness. It is only after the immediate problems are sorted out that carers find the time to reflect and ponder about the emotions involved. Recognising these emotions is as important to caring as working out the practical side” (Berry 1997, p25).

When a relative is first diagnosed with schizophrenia, there is a sense of urgency that often accompanies the carer’s need for information on schizophrenia and its treatment, as well as the need for information as to what services exist and are available for their relative’s use (for example sourcing accommodation and rehabilitation facilities). In addition to this, there is a crucial need for effective coping strategies as relatives grapple and come to terms with the inherent behavioural problems associated with schizophrenia. As time moves on and the sense of urgency passes, carers begin to recognise their own emotions and the need to share their isolating experience with others who have found themselves in similar situations. Still further down the line, carers may begin to feel the urge to help others who are faced with schizophrenia in their own families. This may evolve into a desire to actively advocate for the mentally ill (by lobbying the government for improved services and/or increasing awareness of mental illness in the community to reduce stigma) or it may manifest itself through the carer becoming a long-term member of a support group or as a speaker within a psychoeducational setting. *Figure 2: The Changing Needs of Carers* on page 13, highlights these changing needs over time and suggests possible outlets/interventions in meeting these needs. It introduces the distinction which should be drawn between ‘beginner’ carers, who are new to the concept of schizophrenia in their own family, and ‘advanced’ carers, who have many years

experience and have developed their own kind of expertise in the area of mental health. The diagram presents these carers as being on either side of a time-line continuum, while emphasising that most carers are likely to be somewhere in between.

This concept is evidenced in Winefield et al.'s (1998) qualitative study, which involved interviewing carers at various stages on the caring continuum. They found clear differences between a 'two-year carer', who was still very much in information-gathering mode and a 'twenty-year carer' who was ready to put their energies into political action. Carers with middling amounts of experience were dealing with yet other issues. One carer of ten years clearly expressed the grief and sense of loss that many feel upon finally accepting the chronic nature of their relative's disability. They concluded that carers with less than five year's experience wanted more information about the illness and medication compared with longer term carers, and were less interested in lobbying to improve services. After ten years, acceptance grows and, after that, a readiness for political activism replaces hopes of a cure.

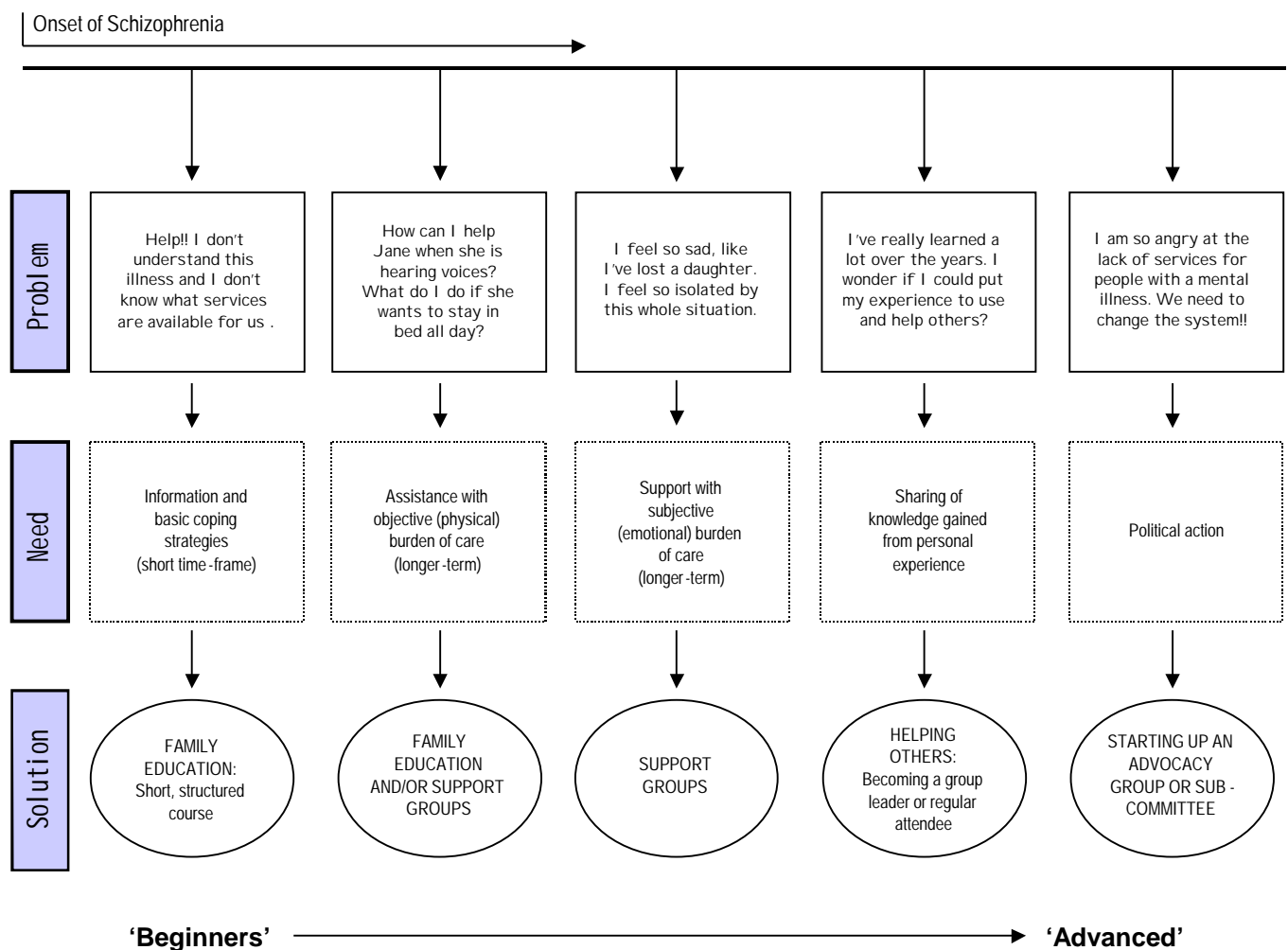
The concept of the different stages and therefore differing needs of carers is also evidenced in Wintersteen and Young's (1988) study, which also concludes that: "families move through predictable stages of coping, and gradually turn from an inward to an outward orientation. As they come to accept the illness and move ahead, they need less support and more opportunities for positive action" (p24).

Furthermore, in a recent qualitative study, Karp and Tanarugsachock (2000) mapped the changing emotional needs of carers, based on fifty in-depth interviews. They found that carers' emotions changed drastically over time, from confusion (pre-diagnosis), to relief (upon diagnosis), hope (for the relative getting better), grief (at the realisation that the illness was permanent), anger and finally acceptance.

It is therefore critically important to acknowledge these changing needs of carers when attempting to develop interventions aimed towards relatives of people with schizophrenia and other serious mental illnesses. Directing a 'beginner' to a support group where they could well be confronted with worst-case scenarios or where they have to sit and listen to how people are feeling when what that person really needs is information and coping skills delivered in a structured and timely environment, could prove disastrous. Conversely, placing an 'advanced' relative in a psychoeducational program geared towards explaining

the basics of schizophrenia when all they really need to do is to talk to others in similar situations and develop social networks is also unlikely to prove helpful. Moreover, some relatives may need neither of these approaches. They may have ‘done the groups and bought the tee-shirt’ and are now interested in channelling their energies into the wider community in the form of advocacy.

Figure 2: The Changing Needs of Carers



What are the potential benefits of support groups?

The benefits of support groups have been widely documented in the literature. The fundamental therapeutic qualities to be potentially gained include: opportunities for disclosure, empathic connection, shared goals and psychological adjustments to life

challenges. Support groups underscore the medical value of meaningful, group-based programs whose focus elicits psychological and physical health benefits (Davison et al. 2000). In the words of Jacobs & Goodman (1989):

“The new member, who frequently has felt stigmatised and criticised (or at the very least isolated and not understood), frequently finds immediate acceptance as a member of the group. That sometimes stunning experience seems to be a vital step toward making the cognitive, emotional, and behavioural changes necessary for more effective functioning and improved quality of life” (p538).

Benefits that can be derived from participating in support groups are directly related to the perceived needs of carers. If attendance is timely (i.e. at an appropriate stage in the carer’s life, as described above in *Figure 2: The Changing Needs of Carers*), then benefits can be gained on both the objective and subjective levels, that is, information and coping skills can be developed, as well as emotional support given and received.

Direct outcomes which assist with the objective burdens of caring for someone with schizophrenia fundamentally include the provision of education and information. Through this, carers’ knowledge of schizophrenia is increased and the illness is demystified. As well, an increase in the knowledge of services available is experienced along with the enhancement of the problem solving capacity of carers. Practical advice and suggestions for coping with difficult behaviour are provided, new ways to think, to feel and to deal with life experiences are discovered, and a shift in the illness attributions perceived by members from blaming themselves to the view that their relative’s problems are due to a biological disorder is engendered (Brady 1996, de Balcazar et al. 1989, Carney 1988, Citron 1999, Dunne & Fitzpatrick 1999, Kassis et al. 1992, Kurtz 1990, Kurtz 1992, Mannion et al. 1996, Norton et al. 1993, Rootes & Aanes 1992, Sheridan & Moore 1997, Wintersteen & Young 1988).

Outcomes associated with the subjective burdens directly stem from the sharing of experiences and the sense of peer support fostered in a group environment. These include being able to compare predicaments, decrease negative emotions, form friendships and re-establish social networks. It involves arriving at the realisation that one is not alone, sensing a common understanding, being provided with renewed hope and being exposed to positive role models (Brady 1996, de Balcazar et al. 1989, Citron 1999, Dunne &

Fitzpatrick 1999, Mannion et al. 1996, Norton et al. 1998, Sheridan & Moore 1997, Winefield et al. 1998, Wintersteen & Young 1988). Members who have had similar experiences identify and ally themselves with one another, which makes people aware that they are not alone in their struggles. Moreover, people who have had similar experiences are in a powerful position to understand and accept new and existing members (Rootes & Aanes 1992). This kind of peer support is often the only resource available to family members experiencing the loss and emotional distress involved in coping with a mental illness in their family (British Columbia Ministry of Health 1993) and is therefore of paramount importance to carers.

Are there any weaknesses in support groups?

Like any intervention, support groups are not without their weaknesses. One of the major problems cited in the literature is the sense of pessimism that can arise through carers telling their worst-case scenarios. Part of a study conducted by Karp and Tanarugsachock (2000) included the documentation of long-term observations of a relatives support group. They note:

“Newcomers also learn something from veterans that visibly upsets them. They actually wince, shake their heads in disbelief, and sometimes audibly gasp when they learn many of the regulars have been dealing with the ill person in their life for years, sometimes decades. Although the talk of the regulars is peppered with optimistic references to new drugs, new treatments, and the progress made by a loved one, their expressions of hope seem fundamentally contradicted by their own biographies” (p16).

Obviously, relatives cannot be shielded from the truth forever but there must be some timeliness in its delivery; as emphasised earlier, attending a support group at the wrong time in a carer’s life can be decidedly unhelpful and discouraging. Other problems cited in the literature, which need to be watched for, include:

- Over-dominance of leaders and/or members;
- Level of training (or lack thereof) of coordinators;
- Possibility of the creation of dependency on the group;
- The expression of intense feelings which can overwhelm members; and

- That some leaders can confuse support with therapy (Dunne & Fitzpatrick 1999, Meagher 1998).

Support groups: which components, when, and for whom?

Family support groups for relatives of people with schizophrenia and other serious mental illness vary in their leadership (e.g. professional, paraprofessional, nonprofessional or collaboration), membership (e.g. inclusion of ill relatives seeking support for themselves), objectives (e.g. emotional support, education, social networking, advocacy), types of support activities carried out during the group and in their affiliation with larger, national organisations (Mannion et al. 1996). Therefore, the ability of a particular group to help a specific individual may depend on that group's climate (Meagher 1998).

Most nonprofit organisations in the mental health arena typically offer 'support groups' as part of their service delivery program. However, just what these support groups offer is incredibly varied and often reflects the aims and objectives of their founding members (even among groups under the umbrella of the same organisation). Support groups for relatives typically function on several levels and often include components of information and advocacy in addition to support. This is often a reflection of the changing needs of its carers. For just as carers have changing needs, so are those needs naturally reflected in the ever-evolving objectives of the support groups which they attend. As groups mature, they tend to shift their focus according to the needs of its carers – usually from the need for information and support to the desire to advocate on behalf of their relatives. Invariably, most groups will be some form of blend of all three functions:

“Groups may go through a natural metamorphosis, in which, as the group matures, the focus moves from individual and family concerns to more action-oriented programs. There is both strength and risk in this. Families move through predictable stages of coping, and gradually turn from an inward to an outward orientation. As they come to accept the illness and move ahead, they need less support and more opportunities for positive action. The risk of course is that they may lose sensitivity to new members who still require support, information and an opportunity to divest themselves of their strong feelings with an accepting context. For this reason, some groups have chosen to offer several different types of meetings, and to encourage active outreach to new members”
(Wintersteen & Young 1988, p24).

Wintersteen and Young point out the potential trap of attempting to meet the needs of all (for in doing so, often the needs of few are satisfied). However, they also point to a solution: instead of trying to achieve everything in the one support group meeting, it seems common sense to offer several different types of meetings. In order to perform at optimum levels, groups need to continually reassess their common goals and objectives and in doing so, find an appropriate way to meet them. Sense of purpose is paramount: so long as groups remain focused about what it is they hope to achieve and they retain some sense of structure in their service delivery, it is entirely possible to meet the needs of different carers. This sense of direction, as Winefield and Harvey (1995) point out, is paramount to the group's success: "groups need an agenda other than... 'tea parties', to increase the sense of purpose and facilitate the satisfactions to be derived from a feeling of progress" (p145).

With these points in mind, several possible functions of support groups are discussed below.

Emotional support

The fundamental characteristic of any support group is, quite simply, emotional support. As mentioned earlier, the terms 'support group' and 'self-help group' are often used interchangeably. It follows then, that the fundamental features of the support process (including general characteristics of and benefits to be gained from) are the same as those of the self-help process outlined previously in this review (see *Definitions and characteristics of self-help groups* on page 4 and *What are the potential benefits of support groups?* on page 13). The supportive aspect of any group necessarily deals with the more subjective burdens by providing an environment where carers can:

- Compare predicaments;
- Decrease negative emotions;
- Form friendships;
- Re-establish social networks;
- Decrease isolation;
- Establish hope; and
- Focus on positive role models within the group.

Information provision

This component should not be confused with psychoeducation or family education programs, as there is a fundamental difference in the way these services are delivered. Educational programs are generally delivered by mental health professionals within a specified time frame, whereas information provision within a support group setting is more ad-hoc in nature and can be provided through a variety of avenues, including:

- Guest speakers, for example clinicians, legal workers and other service providers who talk to the group about their particular field of interest;
- Books and leaflets which are brought along to the meeting by the organising committee; and
- Videos which are shown to the group.

Again, the potential benefits to be gained from the provision of information are numerous and are outlined in full in *What are the potential benefits of support groups?* on page 13. To reiterate, they are directly related to the relieving of objective burdens of care and include:

- Increased knowledge of schizophrenia;
- Increased knowledge of services available;
- Demystification of the illness;
- Enhanced problem solving capacity;
- Increased coping skills; and
- Shifting of illness attributions.

Advocacy

By participating in a shared mission, members of self-help groups sense potential for power and influence. Self-help groups have the ability to influence legislation and the direction of community services, as well as acting to influence the attitudes of people who lack intimate contact with the mentally ill. This in turn can provide relatives with an

increased sense of power and competence (Borkman 1997, Carney 1988, Constantino & Nelson 1995, Dunne & Fitzpatrick 1999, Kurtz 1992, Wintersteen & Young 1988). As can be seen in *Figure 2: The Changing Needs of Carers* (see page 13 above), when a relative embarks on the path of advocacy, they have usually already been through the predictable stages of information gathering and emotional support and are now ready to outwardly channel their energies.

It is interesting to note that in a recent study conducted by Chelser and Chesney (1996), it was found that groups who had professional co-leaders or extensive involvement with professionals were unlikely to have advocacy goals. Among relative-led groups, some engaged in no advocacy whereas others mounted major campaigns to change professional services.

Psychoeducation/family education

As mentioned previously, psychoeducation is distinct from the education normally derived from support groups. The hallmark of psychoeducational programs is education, usually provided by mental health care specialists in some organised, structured format. These programs are designed to educate families about mental illness and its treatment, while also recognising the need for training in communication and problem-solving skills to reduce family tension and to manage the relative's behaviour more effectively (Kane et al. 1990). There has also been a distinction made in the literature between psychoeducational and family education models. Pickett-Schenk et al. (2000) make this distinction:

“Psychoeducation models typically are adjunctive to treatment and focus primarily on client outcomes, while family education models are independent of treatment and focus on improving family outcomes by increasing families' competencies to better cope with their relative's illness. Family education programs are typically short term, varying in length from one-day workshops to three months, and may be led by professionals, family members or a professional-family member team” (p414).

Family education programs are often discussed in the literature as *they relate* to the traditional support group. Many studies and reviews have been conducted in an attempt to ascertain the superiority of one form of intervention over another. However, results inevitably tend to recommend *both* forms of intervention as each have unique advantages over the other. Again, it is useful to place this in the context of *Figure 2: The Changing Needs of Carers* (see page 13). When viewed in this light, it is clearly understandable why

both methods of intervention are recommended. ‘Beginner’ carers often need speedy access to information and basic coping skills, and this is best delivered in a short, tailored program accessible through the family education model. More ‘advanced’ carers, however, may be looking for a supportive environment in which to discuss their situation. This can be gained through the more traditional support groups.

One such study investigating the strengths of family education programs in relation to support groups was carried out by Kane et al. in 1990. Their results, which are indicative of other, similar investigations in the field and are used in *Table 1: Family Education versus Support* below, conclude that family education programs are more suitable as short-term interventions, whereas support groups are better suited as longer-term methods of intervention.

Table 1: Family Education versus Support

Family Education	Support
Information is provided in a timely, structured manner and is tailored to the immediate needs of the family coming to terms with schizophrenia.	Information delivered is more ad hoc in nature, sometimes with the aid of a ‘guest speaker’ on a particular topic of interest, other times through the collective experience of family members.
Information is usually provided by professionals, which can instil trust in the family member.	Information is provided by other family members, which may have more relevance and meaning.
People who do not cope well with uncertainty may find the organised structure more comfortable.	Those with a higher tolerance for ambiguity may favour free-flowing discussions.

Individual differences then, in addition to the notion of time frames, play a significant role in deciding which intervention is most suitable for family members.

Education *and* support: the comprehensive approach

Like everything in life, the needs of carers cannot be simply labelled and neatly categorised. Firstly, the needs of one particular carer will almost certainly change and evolve over time. Secondly, individual differences must also be taken into account: what might be a ‘godsend’ for one carer might not be so helpful for the next. Clearly then, carers need a range of options from which to choose. One example of this comes in the form of a group formed under the auspices of Schizophrenia Ireland in Dublin. This group was established following a short-term family education program run by staff of the Eastern

Region Health Authority. Following an eight week course, family members were invited to establish a group of their own in order to address their continuing need for emotional support. The professionals responsible for the delivery of the education program were instrumental in the establishment of the group, yet after one year's duration, they relinquished the ownership, returning it to the members. In addition to this, education programs continue to be conducted on an annual basis. This serves two purposes: new referrals are regularly made to the group and longer-term members are afforded the opportunity of refreshing their knowledge. Furthermore, the provision of this information in a separate, structured manner frees members in the support group environment to shift the focus away from their relatives and back to themselves. That is, during the support group meetings they can focus more on their own emotions (subjective burdens) than on problems centred around their relative (physical burdens).

Measuring success

Are support groups successful? According to Rootes and Aanes (1992), the value of self-help groups in helping people to solve problems is widely accepted. A review of the literature decidedly agrees, although there is some variance as to the *type* of support group studied (e.g. psychoeducation versus support, short-term versus long-term).

Success of support groups has generally been measured in two ways:

1. Impact on the ill relative (indicated by reduced time in hospital and relapse rates etc.) and/or
2. Impact on the carer (indicated by reduced levels of anxiety, stress, depression etc. and an increased sense of personal wellbeing).

Measurement of the efficacy of self-help is problematic from the outset because it is inherently self-selected in nature. However, investigations into the effects of support group participation, even under random assignment, have yielded positive results on the whole (Davison et al. 2000). In a controlled study conducted by Mannion et al. (1996), the idea that participation in a support group positively affects certain key variables in the participant's adaptation to mental illness in a relative was mostly supported. In this analysis, members reported more extensive adaptive coping and less subjective burden than did non-members. Other studies conducted in this vein have also yielded positive

results. Biegel and Yamatani (1986) surveyed members of a mutual help project for families, who reported a perceived high degree of social and emotional support which was directly attributable to their involvement in the self-help group. Medvene and Krauss (1989) reported that membership in a local NAMI chapter engendered a shift in the disease attributions perceived by members from blaming themselves to the view that their relative's problems were due to biological disorders. Norton et al. (1993) concluded that NAMI members perceived greater benefits than non-members. Similar findings have also been reported by Winefield and Harvey (1995, 1998), and Potasznik and Nelson (1984).

Structure and focus appear to be the prominent factors in predicting the success of any group intervention. For example, in a controlled study conducted by Abramowitz and Coursey (1989), a stress-coping framework was used to design a six-session educational support group offering families information about schizophrenia, training in problem-solving and greater access to social support and community resources. Results indicated a significant difference between the experimental and control carers following the intervention. Carers reported significantly reduced anxiety and personal distress and significantly more active coping behaviours. Even more recently, Pickett-Schenk et al. (2000) determined that participation in a twelve-week combined educational/support group increased participants' knowledge of the causes and treatments of mental illness, increased understanding of the mental health service system, and improved morale.

What is it about support groups that people find most helpful? Citron et al. (1999) investigated the factors that were perceived by local NAMI support group members as being helpful. Results indicate that members who felt that information provision and the gaining of support and self-understanding from the group process was helpful, and who were longer-term participants, were more likely to perceive benefits from belonging to that group.

Relationship with professionals

Generally, support groups for families of people with a mental illness can be divided into two categories: groups run by relatives and groups run by (or with the assistance of) health professionals. This variance in leadership is a reflection of the fundamentally different styles and ideologies of carers and professionals, which tend to have their basis in conflicting worldviews. For instance, the education of professionals tends to promote an

ideology that emphasises distance, expertise, and clinical and textbook knowledge, whereas the ideology of self-help groups is based on experiential knowledge, intuition and subjectivity. Furthermore, professionals are highly valued members of society who are well paid and well recognised for their work, whereas family members have often been blamed for their problems, and remain isolated and stigmatised by society (Constantino & Nelson 1995).

Choice of leader (i.e. professionally led or carer-led) is reflective of the variance in attitudes of self-helpers towards the helping profession. Some challenge professional ideology and practices whereas others uncritically complement professional services. Most fall somewhere in between (Borkman 1997, Constantino & Nelson 1995, Wintersteen & Young 1988). In a study conducted by Emerick (1990), survey responses were obtained from 104 groups in the mental health sector and categorised as being 'radical' (anti-psychiatry), 'moderate', or 'conservative' (pro-professional). The radical extreme, which was represented by the National Alliance of Psychiatric Survivors, was separatist from professionals and had an outer-focused model (i.e. legal advocacy and public education). In the moderate and conservative positions were the groups who tended to have an inner-focused model (i.e. support groups and drop-in services) and were more amenable to partnerships with professionals. The majority of groups fell within the 'moderate' category.

Just as carers vary in their attitudes towards professionals and the degree to which they are happy with them, so do the attitudes of professionals towards self-help vary. In several investigations and reviews conducted into the attitudes of professionals towards the self-help phenomenon, the following points have been noted:

- Professionals have admitted to feeling threatened by self-help groups that have anti-psychiatry and anti-professional attitudes (Constantino & Nelson 1995);
- Professional practices reinforce the difference between 'them and us', such as diagnosis and labelling, which alienates professionals from consumers and family members (Constantino & Nelson 1995);
- As a profession, psychologists tend to shy away from self-help because the tradition is to work primarily with more dependent help-seekers or because they are viewed merely as inexpensive, naive adjuncts to therapy – "hand-holding, morale-boosting, do-no-harm meetings of fellow sufferers" (Jacobs & Goodman 1989, p536);

- There is some concern, particularly among psychiatrists, that the philosophy and approach of some self-help groups might clash with the clinical management of the patient and undermine their professional approach (Dunne & Fitzpatrick 1999);
- There is a general consensus that most mental health professionals (in Ireland) see a role for self-help groups in augmenting existing services by providing an after-hours contact point for people and feel that the aims and objectives of self-help groups should be closely aligned with those of the mainstream models of mental health (Dunne & Fitzpatrick 1999).

In 1997, Dunne and Fitzpatrick surveyed the attitudes of Irish general practitioners and found that while practitioners had a generally positive attitude to the principle of self-help, they did not have a clear view on how the self-help movement in general might or should relate to mainstream services. More recently, Dunne and Fitzpatrick (1999) studied the referring patterns of mental health professionals to self-help groups in Ireland. They concluded that “the views of professionals on self-help groups can vary from disinclination to refer patients at all, through caution, neutrality, to enthusiastic support for the self-help option” (p88). Their study incorporated 225 mental health professionals drawn from the staff lists of two regional health boards and included consultant psychiatrists, clinical psychologists, social workers and psychiatric nurses. While this study mainly focused on referral of *patients* to support groups, it seems likely that the general themes that have emerged can be extrapolated to include relatives also. Factors relating to the decision to refer included:

- Clinician’s awareness of the relevant support group;
- The person’s motivation to attend, and their level of need for information and/or support;
- Organisational aspects of the group, including training level of facilitators, whether or not the group was well-established, levels of dedication, commitment and confidentiality within the group, nature of the relationship between the group and mainstream services, regularity of meetings and accessibility (transport, cost etc.);
- Group atmosphere (groups needed to be supportive, open, encouraging and friendly); and
- Group reputation (this was ascertained through feedback from people who had previously accessed the group).

The partnership ethos

In the current climate of burgeoning self-help, it seems imperative to foster the idea of *partnership* between relatives and the helping profession. Parents, siblings and extended family members have a wealth of experience in working with mental illness on a day-to-day basis. Likewise, professionals also bring with them indispensable knowledge and expertise which can be a vital resource for relatives. As Dunne and Fitzpatrick (1999) state: “the challenge would seem to be for the self-help movement and the caring professions to create a partnership which capitalises on the special strengths of each approach while maintaining the integrity of both” (p89).

They go on to state that any developmental links between the medical services and self-help groups would have to proceed with caution and careful planning from the point of view of both parties in order for these partnerships to be successful and productive. Mowrer (1984) notes that what he calls ‘co-option’ of self-help programs by professionals could potentially eliminate those very elements through which the benefits of mutual help are achieved, i.e. equal status between the helper and the helped (all members share the same problem). Potential difficulties to look out for between self-help groups and agencies include agencies minimising the utility of groups, the tendency towards professional domination and risks of rivalry. Equally important are the reservations that family members feel, based on previous experiences with professionals. These issues should certainly not dissuade professionals and support groups from working together, but all parties must meet with an attitude of mutual understanding and respect (Wintersteen & Young 1988).

What role then, can professionals play in the running of support groups? Aside from providing referrals, they can share knowledge and expertise as well as providing tangible support. Involvement can include consultation, initiation of groups, acting as professional advisor to the group or merely attending meetings as a show of support (Kurtz 1990). The role of the mental health professional then becomes one of the “enabler, educator and catalyst rather than one of leader and quasi-therapist to the group...the appropriate professional role to groups identifies opportunities for education and social action, and fosters their collective determination to get on with the tasks at hand” (Wintersteen & Young 1988, p27).

In 1998, Wintersteen and Young developed guidelines for professional involvement in support groups, which are replicated in *Figure 3: Guidelines for Professional Involvement* on page 27. These guidelines were developed as a result of their own study and in conjunction with similar research in the field. They can be applied to both professionals as individuals and professionals as organisations. In essence, they conclude that professionals play a significant, if backstage, role in facilitating the development of the family support movement. They can assist this movement by fostering its growth and independence through the encouragement of lay leaders and local priorities. Professionals should also recognise that in essence, they share a common goal with carer support groups, that is, the desire for an increased sense of well-being and empowerment of family members who care for a mentally ill relative.

Conclusion

Carers play a vital role in our mental health system, yet their needs are often overlooked. Taking care of a relative who has a serious mental illness can place a serious strain not only on the primary carer but also on friends and other members of the family. Support groups offer many carers an avenue through which to 'unburden' themselves among people who have faced similar situations and at the same time provide carers with some sense of control over an otherwise chaotic life experience. Health professionals and non-profit organisations are in an excellent position to facilitate the development of self-help groups, so long as they do so constructively and in the spirit of partnership.

Figure 3: Guidelines for Professional Involvement

1. The appropriate professional role is as a liaison and resource person, not as a therapist. Support group members are there for mutual support, information, and social action, but not to receive therapy from the liaison person.
2. A knowledge of group processes is necessary in order to understand what is transpiring and to assist leaders in carrying out their tasks.
3. The liaison must become familiar with the literature of self-help groups before undertaking this role, in order to keep the group focused and to self-monitor personal performance.
4. Ownership of the group belongs to the members, and is not the service of any agency. Leadership emerges from the group and is selected by the group alone. The group alone is responsible for its success or failure.
5. The liaison can help the group by supplying information, referring new members, and offering advice as appropriate. The liaison takes no action that extends the power of this role or conflicts with the basic purpose of this group.
6. The liaison and employing agency should be aware of the sensitivity of members to patronising or stigmatising attitudes and work to eliminate them from personal or organisational behaviour.
7. The liaison must be able to tolerate the wide range of emotions that will be expressed, without becoming defensive, internalising the comments, or attempting to support or rationalise the mental health system of the behaviour of staff. They may clarify practices of policies as an explanation of events, but should do so in a way that avoids communicating judgement on a group member's words or feelings.
8. The liaison should understand that professionals have much to learn from families, and should be prepared (within the limitations of confidentiality) to serve as a conduit of information to colleagues. The liaison also works with other professionals to increase their awareness of and support for the group.
9. The liaison is aware of talented individuals who may serve on boards or advisory committees, so long as this function does not take leadership from the group.
10. Since social action is one function of self-help groups, agencies should at least be aware that the group may monitor the programs of the agency. This should be seen as a legitimate function, and the agency should neither threaten nor manipulate the group. In fact, the advisor may be aware of a policy on a local or state level that is harmful, and request intervention by the family group.

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