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CONSUMER PERSPECTIVES OF THE ROLE OF SELF-HELP AND TRADITIONAL SERVICES IN THE LIVES OF PEOPLE WITH SCHIZOPHRENIA

By

Barbara Marie Hughes

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ABSTRACT

CONSUMER PERSPECTIVES ON THE ROLE OF SELF-HELP AND TRADITIONAL SERVICES IN THE LIVES OF PEOPLE WITH SCHIZOPHRENIA

By

Barbara Marie Hughes

Over the past two decades, there has been increasing use of self-help groups by people with serious mental illness. With the rise in the quantity and utilization of self-help groups has come an increase in formal studies and analyses as well as anecdotal reports. As a result, our understanding of the role that they are playing in peoples' lives is beginning to emerge. Yet we know little about how self-help members utilize these services in their efforts to cope with the illness, how they view the similarities or differences between self-help and traditional services, or how a self-help group's ideology and vision may influence their beliefs and behaviors in their movement toward recovery.

This research represents a secondary data analysis of forty-five qualitative interviews with participants in a self-help group, Schizophrenics Anonymous (SA). An interpretive and narrative framework guided the examination of how participants described the similarities and differences between self-help and traditional services; the extent to which they use self-help in conjunction with other sources of support in their recovery efforts; and an examination of the group's "community narrative," or basic story, particularly its view on the role of traditional services and its relative degree of fit with members' personal narratives. Thematic and inductive content analyses were used which involved a reduction of the empirical materials, a setting level analysis, an analysis of traditional service utilization, a cross-case analysis, and a within-case analysis.

This study has brought the consumer perspective to our understanding of self-help and traditional services. There are three major findings. First, consumers' reports converge with previously identified differences between self-help and traditional services advanced by professional literature and published consumer reports. These include differences between the knowledge bases and the setting characteristics. Second, descriptions from members of SA revealed that they integrate both self-help and traditional services in their efforts toward recovery. Each member described how they utilize at least one traditional service, psychiatric medication, and many others described how they integrated additional forms of traditional service into their recovery programs. Finally, the findings suggest that community narratives influence personal beliefs and behaviors and that this influence is communicated clearly and consistently within the organization.

This study suggests questions that the field may want to examine in regard to other population groups, such as those dealing with substance abuse and gambling addiction. Such studies would help to reveal the consumer perspective of these impacted individuals, a voice frequently missing in the literature. This future research agenda reflects the greater role for self-help and other client driven services in members' recovery anticipated in the coming years. As our understanding of the role of self-help and traditional services in members' lives increases, so too will our ability to assist clients by better understanding the role of self-help in their lives, being cognizant of the messages we impart about self-help, being familiar with the community narratives of self-help groups within our communities, and making appropriate referrals to self-help groups for our clients.

DEDICATION

I dedicate this work to anyone who has come to appreciate the role of self-help groups in their lives, and particularly to the founder of Schizophrenics Anonymous, Joanne Verbanic, the members of Schizophrenics Anonymous, and the staff of the National Schizophrenia Foundation. I appreciate your willingness to share your journey with me in hopes of lighting the way for yourselves and others. I am humbled by your courage and dedication and grateful for your generous time and support.

Furthermore, I dedicate this work to my children, Jennifer and Jordan. If ever there was a time to take a step of faith and make amends for all that I have not been to you, this is it. May these words, and the effort that went in to making them come together, be a small token and reminder of my indebtedness to you for your love and willingness to stay by my side. You have also been exemplar models of the kind of unconditional love and support to which I can only hope to aspire. The two of you are my undisputed heroes and friends.

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This work represents the culmination of five years of effort in pursuit of a lifelong goal. As in so many things in life, our greatest accomplishments are just that, great, because of the multitude of support, encouragement, and assistance contributed by so many. Clearly, my family and friends have been a major source of support and encouragement, particularly my children, Jennifer and Jordan. It is for them that I embarked on this journey, and it is because of them, that I was able to persevere.

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Chapter 1

INTRODUCTION

Over the past two decades, there has been increasing use of self-help groups by people with serious mental illness. With the rise in the quantity and utilization of self-help groups, our understanding of the role that they are playing in peoples' lives is beginning to emerge. There is growing literature, both conceptual and empirical, that describes how self-help groups assist and influence their members. Much of this literature has focused on distinguishing between the role of self-help and that of traditional services in assisting individuals with their recovery from mental illness. This literature has identified many of the effective mechanisms of mutual help and has distinguished them from the mechanisms of change employed in traditional mental health interventions.

While this is important to our understanding of self-help, it is clear both from the empirical literature and from published consumer reports of their experiences with mental illness that many mental health consumers utilize both traditional services and self-help, either simultaneously or sequentially, in their efforts to cope with their mental illness. Yet we know little about how self-help members utilize these services in their efforts to cope with the illness, how they view the similarities or differences between self-help and traditional services, or how they view the compatibility or incompatibility of these approaches in their movement toward recovery.

McGuire (1988) argued that people find many different ways to create 'packages' of services that draw upon multiple sources of help, self-help and traditional services among them. Some people use self-help as an alternative to traditional mental health services, because of dissatisfaction with their service delivery experience. Others use it as a supplement to traditional service delivery. Because of these different reasons that people utilize self-help and how they may incorporate other services into their recovery programs, what these individual 'packages' look like will vary with people's experiences and needs.

Most of the literature about self-help to date has primarily been written by professionals who have focused on how these groups have developed to provide a system of support for their members. Within this literature, there has been an emphasis on articulating and demonstrating the differences between self-help and traditional services. While this has been helpful in understanding the effective mechanisms of self-help, this literature has focused on self-help as an independent system of care.

Professionals also cast traditional professional conceptions on people whereby they are viewed as recipients of services or treatment. This implies the application of a medical or human services model that is defined more by the purposes of the professional community than by the context in which people live their lives (Rappaport, 1993). People are seen as the recipients of treatment and services, and there exists a vast power differential between the professional and the consumer. The consumer possesses little to no control over their treatment program, and people are viewed as "simply" having problems such as illness, disease or social dysfunction. This conception is not consistent with the self-help ethos that often rejects members' views of themselves as recipients of services, but rather adopts a new ideology and a transformation of identity, or sense of self, according to a narrative provided by the organization (Antze, 1976; Cain, 1991; Kennedy, 1991; Levine, 1988). Professional conceptions of people as recipients of services or treatment will undoubtedly influence the perspective of the professional examining self-help and will impact their ability to understand consumer service utilization.

There is no empirical literature that examines, from the perspective of the consumer, how participants use self-help in conjunction with other sources of support in their recovery efforts. This latter perspective is important because it would provide first-person accounts of members' experiences with self-help in combination with other services. These first person accounts will advance our understanding of how self-help groups operate, how members themselves understand and describe their packages of support, and how their experiences in a self-help group impact and are impacted by their experiences with other systems of support.

One of the factors that may influence how self-help group participants utilize traditional services is the group's ideology about the problem and its solution (Antze, 1976). Self-help groups can be conceptualized as communities for living (Rappaport, 1993). As a community, a self-help group develops a narrative, or story, that reflects the group's goals, beliefs and philosophy. This community narrative is, in part, developed from the individual stories (personal narratives) and the experiences of its members. A member's individual story or personal narrative contributes to, and is, in turn, shaped by, the adoption of the community narrative of the setting in which they are involved (Rappaport, 1993).

One of the components of a self-help group's community narrative is its view on the role of traditional services in recovery from mental illness. Community narratives across self-help groups vary widely with regard to the role of traditional services. Some self-help community narratives convey wariness or skepticism about the effectiveness of traditional service delivery. Other self-help groups have a neutral stance on the utilization of traditional service delivery, neither encouraging nor discouraging members' utilization of those services. Finally, some self-help groups encourage the utilization of traditional services. Whether or not a self-help group supports the utilization of traditional service delivery is likely to impact a consumer's view and use of those services.

We know that people's lives are complex and the sources of support that they receive can vary dramatically. An awareness and understanding of the 'packages' of services that people create will allow us to look beyond the differences between self-help and traditional services to understand the array of options that consumers can draw upon to best meet their recovery needs. Securing this understanding from the experience of self-help group participants, the very people who weave these 'packages' of services, will heighten our understanding and awareness of service access and utilization.

To date, there has been an emphasis in the literature on describing these systems of care as different entities. We also know that our knowledge in this regard has been advanced predominately by professionals. What is needed is a consumer perspective on similarities or differences between these two systems and on how these sources of support are used to promote recovery. This perspective will highlight the role of traditional services in a self-help group participant's recovery.

Knowing that a self-help group's ideology may influence a member, it is important to have an understanding of how a particular group views the role of traditional services. One of the ways to that this is reflected is through its community narrative. With a self-help group member's personal narrative and an understanding a self-help group's narrative, specifically as they relate to traditional service utilization, we can better foster the type of support, understanding and assistance necessary to promote the development of a package of services that meet members' individual situations. This will also foster an appreciation for the fact that different people will create different packages of service (different strokes for different folks) and an increased ability to match a self-help group, as reflected in it's community narrative, to a member's individual perspective, as reflected through their personal narrative. This study was undertaken to contribute to our knowledge in three ways. First, to advance our understanding of self-help as a system of care. While we understand a great deal about the differences between self-help and traditional services, we also know that this understanding tends to be from the perspective of professionals or the published writings of individual consumers. There is a lack of empirical literature that looks at how self-help participants actually experience the differences and similarities between these services and how they might use them in their personal recovery. This understanding is important from a systems perspective because the more we understand about how consumers use and experience these different sources of support, the better we are able to encourage professionals to interact with self-help groups without undermining the role that they play in consumers' lives.

Second, to advance our ability to help promote recovery for individuals with serious mental illness. While we know that people's lives are complex and that the sources of support that they draw upon can vary, there is a lack of understanding about how self-help group participants describe the extent and type of utilization of traditional services and further, how they would describe the differences and similarities between them. By asking for individual stories of support and assistance, we develop an understanding of the extent to which a self-help group's participants draw upon multiple sources of support, and how participants might weave different sources of support into a recovery program. This understanding increases our ability to facilitate and support the decision making processes of self-help group members who develop ‘packages’ of services to attend to their unique situation.

Finally, this research allows us to explore the convergence between a self-help group’s community narrative and member’s personal stories. It adds to our understanding of how self-help groups influence how members think and behave. It allows us to begin to document the range of ways that self-help groups view the role of traditional services. Eventually, as we learn more about other self-help groups and their community narratives, we may be better able to support recipients of traditional services as they seek a self-help group that is consistent with their personal narrative.

Chapter 2

LITERATURE REVIEW

Overview

There has been a rise in the quantity and utilization of self-help groups by people with serious mental illness (Chinman et al., 2002) and with this, the role that they are playing in people's lives is beginning to emerge. The literature has identified some of the effective mechanisms of self-help (Reissman, 1965; Leiberman, 1979; Levine, 1988; Maton, 1988; Powell, 1975; Roberts et al., 1999; Salem et al., 2000) and has distinguished self-help from the mechanisms of change employed in traditional mental health interventions (Morgenstern et al., 1997; Ouimette et al., 1997; Project MATCH Research Group, 1997; Segilman, 1995). However, empirical literature and consumer reports reflect that many self-help members also utilize traditional services, either simultaneous or sequentially. Yet, despite this, we know little about how consumers weave these into their recovery. Most of the literature about self-help groups has primarily been advanced by professionals who have focused on how these groups have developed to provide a system of support for their members. It has also provided a predominately professional perspective on how self-help groups work. There is no empirical literature that examines, from the perspective of the consumer, if and how participants use self-help in conjunction with traditional services in their recovery efforts.

In this review I examine: the increase in both the quantity and utilization of self-help groups; the effective mechanisms of self-help groups; how mechanisms of self-help are different from traditional mental health interventions; the empirical literature of how people utilize both self-help and traditional services; the consumer literature of how people utilize both self-help and traditional services; and, the role of community narratives in shaping consumer's view of traditional services.

Rise in Quantity and Utilization of Self-Help Groups

The number of self-help groups has proliferated, making access to self-help more available to interested consumers. Self-help groups exist in any number of problem areas (e.g., alcohol, drugs, emotions, weight). As Katz (1981) observed over 20 years ago, "the half million or more separate self help organizations embody an extraordinary variety of types, purposes, structural and ideological features, tap a wide variety of motives, and appeal to a vast range of numbers (p. 135)." In 1996, approximately 10 million Americans participated in self-help groups (Kessler, Mickelson, & Zhao, 1997). It is estimated that upwards of 25 million Americans have belonged to a self-help group at some point in their lives (Kessler et al., 1997). It is also estimated that there are more than 800 self-help groups nation wide addressing most social problems and health issues (McGinnis & Foege, 1993; White & Madara, 1995). With a specific focus on anonymous and step groups, an unpublished list names 258 groups that use the step program and/or the name "Anonymous." In that these figures are nearly 10 years old, it is likely that these numbers may well be higher.

Effective Mechanisms of Self-Help Groups

Self-help groups offer varying sources of help for people. A universally accepted definition of self-help groups is unattainable and a commonly accepted definition of self-help is necessarily loose. As Katz (1981) observed, "the half million or more separate self help organizations embody an extraordinary variety of types, purposes, structural and ideological features, tap a wide variety of motives, and appeal to a vast range of numbers

(p. 135)." At their basic level, self-help groups refer to people with a common or similar problem in living that come together to share and learn from each other (Humphreys & Rappaport, 1994; Jacobs & Goodman, 1989; Maton, Leventhal, Madara, & Julien, 1989; Phillips, 1990).

There are several defining features of a self-help group. The emphasis in self-help groups is on reciprocal assistance and the interdependence of someone accepting self-responsibility and maintaining independence, while helping others and receiving help from others (Borkman, 1999). There is a consumer oriented emphasis within self-help groups on an "inside" understanding of the presenting problem. This experiential knowledge is shared between and with the people experiencing the common problem (Borkman, 1976; 1990). Consistent with a consumer oriented focus, indigenous leadership is another defining component of many self help groups (Riessman & Carroll, 1995; Schubert & Borkman, 1991). In addition, participation and contributions are voluntary and professional involvement in group activities is rare (Kurtz, 1997). With regard to how self-help groups are implemented, there tends to be an intentional process that includes regular procedures, routines, and prescriptions for addressing people's problems and issues of everyday life (Chinman, et al., 2002; Levine & Perkins, 1987; Levy, 2000). Through these processes, new information, perspectives, training, skills and exposure to successful role models are attained, while allowing for vicarious learning, modeling and an enhancement of problem-solving skills. (Chinman, 2002; Gartner & Reissman, 1982; Kaufmann, Freund & Wilson, 1989; Kurtz, 1990; Kurtz & Powell, 1987; Levy, 1976; Rootes & Annes, 1992; Stewart, 1990).

Riessman's work (1965) highlighted the process of self-help participants helping themselves and others, and that those who help are helped the most. From his work, the term "helper-therapy" is used to describe this mechanism of self help. Maton (1988) highlighted the value of being involved in the provision of help and support which is characteristic of self-help groups. Self-help groups often provide members with relationships and social support that help them combat their feelings of social isolation, loneliness, and alienation (Maton, 1988; Roberts et al., 1999; Salem et al., 2000).

Powell (1975) conceptualized self-help groups as referent groups and went on to identify six change mechanisms of self-help groups including providing role models who have overcome their problems, but who have also been in the position of the groups' members. Salem et al. (2000), in examining consumer perspectives of referent and expert power, found that there was a significant correlation between a consumer's rating of a group's helpfulness with their rating of referent and expert power thus lending support to multiple forms of social influence that can be evidenced in self-help settings.

Leiberman (1979) conducted comparative analyses across numerous self-help and professionally led groups and his work indicated that there are a variety of helping processes that are perceived to be beneficial to members including group cohesiveness, the impartation of information and the installation of hope. Self-help also seems to provide individuals with schizophrenia an opportunity to engage in activities that they value and participate in roles that may not have been otherwise available to them (Levine, 1988).

In addition to effective mechanisms, there have been a few empirical studies that address the issue of self-help effectiveness (Kessler et al., 1997; Rawlings & Horner, 1988). Much of the research on self-help group effectiveness has addressed behavior control problems such as drug/alcohol addictions (Humphreys, 1997).

Some studies examine the effectiveness of self-help by looking at patient reported outcomes and experiences in self-help groups. In a review of research on self-help effectiveness, Humphreys (1997) argues that this research is of uneven quality, but he concludes that self-help group members tend to be satisfied with the support they receive and further, they feel that the groups are effective. Self-help groups that have demonstrated positive outcomes have been in the areas of substance abuse (Humphreys & Moos, 1996), bereavement (Lund & Caserta , 1993), care giving (McCallion & Toseland, 1995), diabetes (Gilden, Hendryx, Clar, Casia, & Singh, 1992), and depression (Kurtz, 1988). Although, a meta-analysis of 21 controlled studies of Alcoholics Anonymous (AA) suggests that AA at best does no better than alternatives, and in some cases may do significantly worse (Kownacki & Standish, 1999).

Other studies examine the effectiveness of self-help by looking at the member reported benefits of self-help groups. In a review of research on self-help groups, Kyrouz and Humphreys (1999) found them to be beneficial to their members for a variety of problems. Four studies were conducted with self-help groups for parents of children with disabilities or chronic nonprogressive conditions. Two of these studies were questionnaire based (Iscoe & Bordelon, 1984; Rawlins & Horner, 1988), and two were qualitative (Bennett et al., 1996; Law et al., 1999). These studies indicated that the group members found the self-help groups to be beneficial and the qualitative studies indicated that participants value the groups as a source of information, a support or emotional outlet, and a means of developing ideas and actions (King et al., 2000). A study by Solomon et al (2001) also looked at the reported benefits of a self-help group by parents of children with disabilities. This study indicated that parents found self-help groups helpful and they were satisfied with the support that they received. In addition, sociopolitical, interpersonal and intraindividual change processes were identified as helpful amongst participants.

How families of persons with mental illness perceived the benefits of helpfulness of a self-help group was studied by Manulyn et al (1999). Their work indicated that parent participants' degree of perceived benefit was related to the helpfulness of the group and their length of participation. Another mechanism, the degree of compatibility between a person's personal and treatment belief system, was predictive of greater involvement in a 12-step group after substance abuse treatment discharge (Mankowski et al., 2001). Segal and Silverman (2002) examined factors that may influence positive outcomes for people who participate in self-help groups. They recognized that self-help groups generally promote a strengths-based approach that focuses on the promotion of greater control over one's life situation, independent social functioning and assisted social functioning. Their research revealed that an ingredient that appeared to promote positive outcomes for self-help group participants was the provision of opportunities for them to meaningfully participate in decisions about their own care.

The effective mechanisms of self-help groups (e.g., experiential knowledge, indigenous leadership, voluntary participation, lack of professional involvement, helper-therapy, social support) are different from the mechanisms generally understood to accompany traditional services. One of the differences between self-help and traditional service is that self-help groups achieve personal change by relying on it's member-constituted group whereas traditional services effect change through a professional (Kurtz, 1997).

When looking at the internal processes between self-help and traditional services, Lieberman (1990) identifies five dimensions with which to compare the two systems: 1) a view of the group as a “social microcosm”; 2) the group’s technological complexity/simplicity; 3) the psychological distance between helper and helpee; 4) the specificity-generality of helping methods; and, 5) the degree of differentiation among members. Within each of these dimensions, self-help groups and traditional services, such as a psychotherapy group, operate with different mechanisms.

There are three other dimensions through which a differentiation between self-help and traditional services can be made. The first dimension is that self-help groups tend to have open boundaries that permit the admittance of anyone who qualifies for membership whereby professionally led groups do not (Kurtz, 1997). The second dimension is that there are generally fees associated with professional service, whereas self-help groups may ask for small donations, but rarely charge a fee (Kurtz, 1997). Finally, with the exception of their own national federation, self-help groups generally do not depend on the support of an outside organizations whereas professional services are generally offered within social agencies and mental health facilities (Kurtz, 1997).

Empirical Literature of How People Utilize Both Self-Help and Traditional Services

Irrespective of effective or different mechanisms between self-help and traditional services, there is a small empirical literature that speaks to how consumers utilize both systems of care. Some attention has been given in the literature to professional and system-level support for a collaborative approach between traditional service providers and self-help. At this level, collaboration means systems of care working to create a ‘network’ of and support for programs and services, including self-help, that are deemed valuable or of assistance to people in need. This approach to collaboration implies a top-down approach to service delivery and focuses on how the systems can work together. This is different, however, from consumer-driven service utilization. Under a consumer-driven approach, 'packages' of services are created by consumers based on the programs and services available to them and on their unique needs and circumstances. This consumer-driven approach emanates from the mental health consumer movement that emphasized consumer self-help, empowerment, and advocacy (Chamberlin, 1990).

There is some professional literature that speaks to a consumer-driven approach to utilization of professional treatment and self-help (Jacobs & Goodman, 1989; Kurtz, 1990; Lotery & Jacobs, 1994; Murray, 1996; Reissman & Carroll, 1995; Stewart et al, 1994). This consumer-driven approach would support a package of service whereby people could build a treatment plan that addresses their unique situation and places value on the individual contributions of different options. This, too, would attract people who might not otherwise avail themselves of mental health services but, at the same time, capture those who simultaneously and/or sequentially utilize professional treatment (Salzer et al., 2001). A first person account by Bassman (2001) notes that "many forms of self-help are supportive of and secondary to "expert" professional opinions" (p. 24).

Results from Humphreys et al (1999) study of the combined effects of treatment and self-help groups suggest that there are compatibilities between self-help and the treatment programs traditionally serving substance abusing patients and that learning how these informal and formal treatment systems can function synergistically will promote individual recovery from substance abuse problems. Despite the reasoning behind utilizing one, or both, systems: economics (self-help is typically free); dissatisfaction with conventional treatment; and/or the pressures of welfare reform and managed care, Norcross (2000) encourages the awareness of the attributes of self-help and their integration into professional treatment so as to meaningfully advance self-help.

In her book, Temes (2002) details what she refers to as 'The Collaborative Cure' whereby a person with schizophrenia develops their own 'team' to assist in their recovery. The efforts of the team members are collaborative, and members, beyond the person themselves, represent the person's family, psychiatrist, psycho pharmacologist, pharmacist, social worker, peer, friend, and psychotherapist, each of whom recognize the contributions of the other members and shares the solitary goal of supporting the recovery of the person with schizophrenia.

The extent to which this collaborative approach is supported may be mitigated by Ben-Ari's research with professional involvement (2002) where whether or not self-help groups were likely to support collaboration was related to the kind of self-help group being considered. Health-oriented groups were more likely to stress collaboration, twelve-step groups less likely, and alternative lifestyle groups falling somewhere in between.

Resistance to systemic collaboration between health care and self-help has been documented (Reissman, 2000). However, Salzer et al. (2001) believe that the professional community needs to develop ways for non-professional and self-help services to be supported as a valuable and contributing part of the public health delivery system. To achieve this goal, they consider it crucial that professionals become aware of the valuable contributions of the self-help community and how they can be incorporated into a collaborative relationship with professionals. Successful efforts in this regard can go a long way to minimize professional resistance. It is encouraging that some of the professionally written literature is imploring its professional community to better understand and coordinate potential linkages between self-help and professional treatment community (Chinman et al., 2002; Reissman & Banks, 2001).

It is important to be clear that self-help and traditional services do not need to be collaborative for a consumer to use and benefit from both systems. Without systems of care participating in an intentional collaborative effort, consumers are often in a position of being able to 'pick and choose' what programs or services they are interested in or feel will best address their unique situation. An examination of the role that each may or may not play in a person's recovery, especially from a consumer perspective, and a self-help group's view of the role of traditional services, will further illuminate this point.

Moos, et al. (2001), examined substance abusing and psychiatric disordered patients who utilized both formal and informal care systems. These patients participated in both outpatient mental health care and self-help groups. Patients who had regular outpatient mental health care and who attended self-help group meetings had better substance abuse and social functioning outcomes than others less involved in both formal and informal care.

Literature addressing the relationship between self-help and professional care, or utilization of both, is becoming more and more present in the literature. This literature tends to emphasize the differences between professional care and self-help. It focuses primarily on professional involvement in self-help groups, the appropriateness of their involvement, their roles, and their impact. There is also a small literature on professional attitudes about self-help and referral patterns of patients to self-help groups. This literature focuses on the roles and views of professionals. This literature fails to address self-help member's utilization of traditional services, especially with regard to first-person accounts of their experiences within and between these systems of care.

Consumer Reports of How People Utilize Self-Help and Traditional Services

The traditional treatment system has failed some people. This is captured in first person accounts of people's experiences with the mental health system where they portray "the system" as non-supportive, dependency creating and hopeless. Consumers describe their experiences with negative overtures speaking to the depersonalizing, traumatizing, infantilizing, silencing, degrading, harmful, hopeless and discouraging nature of their experiences (Bassman, 2000; Bassman, 2001; Chamberlin, 1995; Deegan, 1990; Frese and Davis, 1997; Lynch, 2000; Tenny, 2000; Walsh, 1999). Bassman (2000; 2001) rejected the medically oriented diagnosis of mental illness that often carries a burdensome stigma. He argued that people's dissatisfaction with the mental health system has less to do with their own denial of their need for help and has more to do with their objection to what is accepted as helpful.

We know that some people have turned to self-help as an alternative to and in rejection of the traditional treatment system. In her efforts with the mental patients' liberation movement which started in the early 1970s, Chamberlin (1990) identifies one of the movement's main goals as developing self-help alternatives to medically-based psychiatric treatment and that it stood in opposition to the medical model and in support of self-reliance and self-determination. She points out that the key issues to many consumers are forced treatment and the vulnerability, loss of control, lack of participation in decision-making and powerlessness that consumers of traditional mental health services experience (Chamberlin, 1995). To Bassman (2001), "The value of self-help begins with the free and noncoercive choice exercised by participants (p. 24)."

Deegan, (1997), speaks about the life-enhancing hope that self-help groups offer and Tenney (2000) speaks of the value of sharing one's experience with someone who has experienced the same thing. Highlighting the uniqueness of each person's situation was something of import to Tenney (2000) who, in reference to inadequate traditional care, offered the insight that "....one of the problems of being human is that we see the world not as it is, but as we are. We need to listen to each other and share our truths" (p. 1442). Lynch (2000) further values the support that she engendered from her peers that have gone on to achieve personal/professional goals while at the same time being willing to share their hope, strengths and stories.

We also know that many consumers want and need things from the traditional treatment system. These include such things as medication, individual and group therapy, and evaluations. Frese's (2000) account of his mental illness supported accepting and understanding his disorder and recognizing the essential role that medication played in his treatment and recovery.

Personal reports suggest that self-help can help consumers define how services can help them. This is suggested by Marsh et al. (1997) in their attempt to implore professional understanding and support by stating: "We are people first, not illnesses. Treat us such. Work with us. Help us to become as independent, self-actualized, and as healthy as we can be (p. 365)." In their accounts, Frese (2000), Bassman (2000), and Lynch (2000) speak to the role of professional involvement, albeit on a different dimension than that previously delivered. They want professionals to join them in their recoveries. They want to be treated with dignity, and they want to transcend the professional despair and hopelessness. Lynch (2000) writes, “In my journey toward health, the most helpful experiences were with professionals who saw me as a person first, who adapted their treatment according to my need (p. 1431).”

Consumers also highlight their need for choice and partnership in their recovery programs. Bassman (1997) who states, “Choice is fundamental to growth and recovery. Without choice, motivation decreases, personal responsibility is abdicated, and hope is diminished (p. 239).” Other consumers cite professional interest in consumer-professional partnership, but recognize the difficulties located therein when there is a large and distinct power differential between consumers and professionals (Chamberlin, 1995). “When we look for therapy or help, we are looking for active collaborative relationship where power inequities are minimized (Bassman, 2001; p. 23).” Believing that choice and partnership are critical to a recovery program, Lynch (2000) described positive experiences with professionals who offered such things as flexibility, patience, and availability; affirming of her many strengths; assisting in developing a strong sense of self; and helping her risk giving up her identity as a “career mental patient” (p. 431). Not only is flexibility the essence of a successful approach to treatment for those with mental illness (Warner, 1996), but these first-person accounts give voice to an approach to mental health treatment that promotes collaboration.

The Influence of a Community Narrative on Service Utilization

One of the things that influences consumer utilization of services is the context, or narrative, of a particular self-help group. The perspective among self-help consumers between the role of self-help and traditional mental health services can be understood through a narrative framework. Simply explained, a narrative framework is one that understands life to be experienced as a story and these stories "order experience, give coherence and meaning to events and provide a sense of history and of the future" (Rappaport, 1993, p. 240). The narrative framework differentiates between a community narrative (a level of analysis that captures a community) and personal stories (an individual level of analysis). A community narrative is a level of analysis that captures a given community. Personal stories are the individual level of analyses that give a voice to the lived experience of consumers while, at the same time, contributing to and gleaning from the community narrative advanced by a self-help group. There is a dynamic interconnectedness between personal narratives and community narratives such that a community narrative can change, over time, as a result of contributions from the members' personal life stories while, at the same time, members' personal narratives can be changed as a result of the groups' narrative (Rappaport, 1993). As a community for living (Rappaport, 1993), a self-help group develops a narrative, or story, that reflects the group's goals, beliefs and philosophy, and in this case, a position regarding the role of traditional services. As members of a self-help group, a consumer is exposed to this ideology and, based on their experience, begin to incorporate the interconnectedness between their own personal story and the community narrative. How a self-help group views the role of traditional service delivery is likely to influence a consumer's view and utilization of those services.

How Outcomes of Self-Help Groups are Different from Traditional Mental Health Interventions

There have been only a handful of studies that have compared the outcomes of those involved in self-help and those using traditional services (Morgenstern et al., 1997; Ouimette et al., 1997; Project MATCH Research Group, 1997; Seligman, 1995). In research conducted by Yanos et al. (2001), working with patients diagnosed with serious mental illness, the relationship was examined between patients participating in consumer-run services (including self-help) and their recovery of social functioning. Again, the self-help or traditional services approach was endorsed and the findings indicated that patients involved in consumer-run services had better social functioning than those involved exclusively in traditional mental health services. Though generally demonstrating that self-help is as effective as traditional treatment, these studies perpetuate the dichotomy that people participate in one of the treatment regimes or the other, but not both. Further, these studies focused on outcomes, not necessarily effective mechanisms that may have existed in either system.

Conclusion

This study was conducted because the theoretical, empirical, and consumer literature has tended to focus on how self-help and traditional services are different and separate 'systems' of care. We know that there are mechanisms of self-help that provide necessary support and information to its members. These mechanisms include an emphasis on expertise that people gain through their experiences, voluntary participation, indigenous leadership, intentional processes, social support, and role modeling. The literature has been limited in its focus by not securing a self-help member's perspective. Beyond the insights we can gain from personal testimonies, we really know little about what types of support people use, how they use different types of support and, how they describe the role that each is playing in their lives. Further, we know that a self-help member's personal story of their lived experience is likely to be influenced by the group's community narrative. We also know that self-help groups vary in their positions and organizational philosophy regarding traditional services which may influence if, and how, people in self-help groups build a recovery program that incorporates traditional services. Considering what work has been done, little empirical work has explored this from the perspective of the consumer but, rather, has been advanced from a professional perspective. What remains unknown is the combination of what services self-help members actually use, what the community narrative of their group is, how members describe any differences or similarities between the roles of traditional services and their self-help group, and how the group's community narrative fits with their personal narrative regarding utilization of traditional services.

Chapter 3

METHODS

Overview

The methods employed in this study provided an avenue through which to address the following research questions to enhance our understanding of how those involved Schizophrenics Anonymous (SA), a self-help group for people with schizophrenia, describe the role of self-help and traditional services play in their lives, as well as how they might eave these sources of treatment and support to promote their movement toward recovery: 1) What is the SA community narrative regarding the utilization of traditional services? 2) What is the pattern of traditional service use among SA members? 3) How do SA members describe the similarities, differences, and interactions between the role of traditional services and SA in their recovery? 4) How does the SA community narrative fit with the member's personal narratives and the utilization of traditional services?

Study Design

This study was part of a larger evaluative study of Schizophrenics Anonymous examining member engagement and change. Qualitative interview data were collected from 45 SA members from 12 different SA groups in Michigan. These interviews took between 45 minutes and six hours to complete. In the interviews, participants were asked to tell the story of their experience in SA and the story of their mental illness. They were asked about the support and assistance that they have received from SA, traditional services, and friends and family members. Although data was collected regarding these various sources of help and support, the larger study did not include an analysis of consumer perspectives of Schizophrenics Anonymous as compared to traditional services.

As a result, this dissertation research included a secondary data analysis that utilized interview data that had already been collected. The interviews were taped. They were then transcribed and all identifying information was removed from the transcripts. These transcripts were analyzed in the study.

Theoretical Framework

In this study, understanding the perceptual differences among consumers concerning SA and traditional mental health services was explored through a narrative framework. Through a narrative framework, the personal stories of people involved with SA were examined and the relative degree of fit between their personal stories and the SA community narrative were revealed as it relates to the role of SA and traditional treatment services. Within this framework, the potential exists to bridge the gap in our understanding of the role of SA as an alternative source of treatment and support for people moving toward recovery, a role involving coexistent, concomitant or concurrent sources of treatment and support.

A narrative approach was used in this study because it validated the perceptions of the participants as captured through first-person accounts of their actual experience (Davidson, 1992; Evered & Louis, 1981). This allowed the consumer perspectives to be understood within the context of their lives with schizophrenia, the professional context of traditional mental health services, and the social context of a self-help group. Within-case analyses were conducted to explore how individuals view the relationship between traditional services and self-help in their own lives. In addition, the content of the printed literature and materials of SA were analyzed in order to articulate SA's community narrative. Participants' personal stories were compared to the SA community narrative to examine the extent to which a member's personal narrative and use of traditional services fits with the SA community narrative.

This examination of Schizophrenics Anonymous has provided an understanding of it as a self-help group whereby membership is viewed as a form of community, and, in this instance, a community that encourages the involvement of the traditional treatment community, as contrasted with "traditional" conceptions of mutual-aid groups as alternative treatment options.

An interpretive framework was also incorporated into this study. An interpretive framework places priority on revealing first-person subjective experiences in an attempt to reveal the meaning of a phenomenon or experience situated within its social context (Holstein & Gubrium, 1995; Schwandt, 1994). An interpretive approach is guided by a desire to understand, in a person's own terms, their intended meaning by building a bridge between the text and the researcher's own experience and context, while acknowledging that the values, biases and assumptions of the researcher are an inescapable and undeniable aspect of the process of interpretation (Tappan, 1997).

The study used a narrative approach and an interpretive framework in order to understand how people with schizophrenia experience and describe the similarities, differences, and/or interactions between Schizophrenics Anonymous and traditional services. Again, this approach was indicated because it lead to understanding through its emphasis on first-hand descriptions of lived experiences. It also allowed meaning and description to emerge from participants instead of being dictated by researchers or others who are outsiders to the experience (Davidson et al., 1997). Finally, this approach allowed consumer perspectives to be understood within the context of the lives of people with schizophrenia, the context of traditional care, and the social context of a self-help group.

By allowing consumers to describe their perspectives, they were viewed as the experts in this process and not acted upon as passive objects of investigation, which undermines their perceptions (Davidson et al., 1997; Estroff, 1989). An interpretive framework and a narrative approach were indicated for this study because the assumptions and goals of these approaches were compatible with the purposes of this study.

Use of Qualitative Methods

Qualitative methods were used for this study for two principal reasons. First, the data for this study was part of an original data set where the research design and analysis was qualitative. Because of this, utilization of qualitative methodology for this secondary data analysis was appropriate for this research.

Second, qualitative methodology was indicated for this study because it is the methodology of choice when little is known about a phenomenon, or when the research questions relate to understanding or describing a particular phenomenon. As well, a qualitative approach is consistent with the goals of rich description, understanding and meaning that will emerge through the interpretive approach utilized in this study. Qualitative methodology allows investigators to study a particular phenomenon in depth and detail, from an emic, or insider's perspective.

The depth and detail of the descriptive data collected through qualitative methods enhances understanding through the use of first hand accounts of the actual experience (Patton, 1990). The informants' perspective of this phenomenon extends beyond their account of events and actions. This perspective is not to be assessed in terms of its truth or falsity but rather, as part of the reality that the investigators are trying to understand (Bogdan & Bilken, 1992; Maxwell, 1996). The open-ended responses to qualitative inquiry are broader, lengthier and more detailed than responses to quantitative inquiry. However, responses to open-ended questions enable the investigator to "understand and capture points of view of other people without predetermining those points of view through prior selection on questionnaire categories (Patton, 1990, p. 24)." First hand accounts of consumer perspectives disclose the "depth of emotion, the ways that they have organized their world, their thoughts about what is happening and their basic perceptions (Patton, 1990, p. 24)."

There are proponents of the utilization of qualitative methodologies in research involving schizophrenia (e.g., Davidson & Strauss, 1995; Davidson et al., 1997; Hatfield & Lefley, 1993) and self-help research in general (Bogdan & Bilken, 1992; Humphreys & Rappaport, 1994; Maxwell, 1996; Merriam, 1988) because these methodologies are better positioned to explore processes than quantitative modes of inquiry. In this study, the use of qualitative methodology was suggested so as to better understand the similarities, differences, and interactions between self-help and traditional care in the lives of people with Schizophrenia and how they define and engage these different sources of treatment and support in their movement toward recovery (Davidson & Strauss, 1995; Davidson et al., 1997).

Therefore, to address the research questions of this study, self-help and traditional services as sources of treatment and support in the lives of people with Schizophrenia were explored through the qualitative, open-ended interviews that were collected to elicit people's story of their experiences with these systems.

Setting Description

Schizophrenics Anonymous (SA) is a self-help organization for people with schizophrenia or related disorders. Founded in the metropolitan Detroit area in 1985, it is organized and managed by persons with the illness. SA was patterned after the format and ideology of Alcoholics Anonymous (AA) and incorporates the features of weekly meetings, steps for recovery, philosophy and mutual support between meetings (P., John, 1997). There are now more than 140 groups meeting throughout twenty other states, Canada, Mexico, Venezuela and Brazil (National Schizophrenia Foundation, 2002). The SA statement of purpose is:

5. To help restore dignity and sense of purpose for persons who are working for recovery from schizophrenia or related disorders.
6. To offer fellowship, positive support, and companionship in order to achieve good mental health.
7. To improve our own attitudes about our lives and our illness.
8. To provide members with the latest information regarding schizophrenia.
9. To encourage members to take positive steps toward recovery from the illness.

(Schizophrenics Anonymous, 2002)

The organization's mission statement outlines their six-step program of recovery that helps form the foundation of the SA community narrative. The six steps of recovery (Mental Health Association in Michigan, 1994; 1997) provide tools for members to work on recovery and they are:

1. I surrender. I admit I need help. I can't do it alone.
2. I choose. I choose to be well. I take full responsibility for my choices and realize that the choices I make directly influence the quality of my days.
3. I believe. I now come to believe that I have great inner resources and I will

try to use these resources to help myself and others.

4. I forgive. I forgive myself for all the mistakes I have made. I also forgive and release everyone who has injured or harmed me in any way.

5. I understand. I now realize that erroneous, self-defeating thinking contributes to my problems, unhappiness, failures, and fears. I am ready to have my belief system altered so my life can be transformed.

6. I decide. I make a decision to turn my life over to the care of God, as I understand Him, surrendering my will and false beliefs. I ask to be changed in depth.

Like Alcoholics Anonymous and other self-help groups, SA has a program of recovery that intends to help its members rise above their illness. SA does this by applying six recovery steps and members are encouraged to share their experiences, feelings and hopes in a confidential and nonjudgmental environment. There are no dues or fees to attend SA meetings and anyone who wishes to recover from a schizophrenia-related illness is invited. As a departure from other step groups, there is no expectation that SA members will apply the six recovery steps sequentially or that they will even be addressed or used at all by some groups (Walsh, 1994).

Another difference is that, except in the broad sense of spirituality, religious discussions are prohibited. While SA members speak to their individual spirituality as it pertains to finding meaning or a higher purpose in their lives, they may not promote a specific religion or religious identity. SA has also been described as providing a home for individuals with schizophrenia and a setting that fosters peer support and acceptance (John P., 1997). This may be an invaluable benefit of participating in SA for those individuals who find themselves socially isolated and experience, first-hand, the stigma that often comes with a mental illness.

Also, the SA group philosophy (the community narrative) focuses on cooperation with mental health professionals. For some members, SA performs as an adjunct to treatment, instead of an alternative or replacement for traditional services. In this vein, SA gives permission for its members to weave a recovery program that can include both SA and traditional treatment services. The implications of this phenomenon for this study are the possibility of finding and giving voice to some of these interwoven approaches.

SA groups generally meet weekly at a predetermined time and location. SA meetings are lead by a SA leader who, in most cases, is a member of SA who has schizophrenia and who assumes the primary responsibility for leading the group. In some groups, there is also a co-leader. There is a recommended format for running SA groups but, within this, there is flexibility in how the format is implemented, which can result in a lot of variation between groups (National Schizophrenia Foundation, 2002). Groups can vary considerably with regard to the number of people attending, the experience of the leader, the group's utilization of the program and literature, and the particular social context or group setting (i.e., churches, community mental health centers, or a local Big Boy restaurant) of a group.

Project Description and Procedures

This study was situated within a larger evaluation study of Schizophrenics Anonymous. The larger evaluation did not include exploring perspectives on the similarities, differences, or interactions between self-help and traditional care as its main purpose. Thus, this study was a secondary data analysis utilizing interview data that had already been collected. To this end, the specifics of access and entry to the organization, consent and confidentiality procedures, measurement development, and data collection and management had already been developed, implemented and approved by the Michigan

State University Committee on Research Involving Human Subjects (UCRIHS). However, for the purposes of this study, a separate UCRIHS application was submitted and approved based on these same procedures (see Appendix A).

Sample

The participants in the larger evaluation study were selected on dimensions that the research team felt may influence the participant's experiences of the SA group (Berg, 1995; Miles & Huberman, 1994). Although the selection criteria did not take into account the purpose of the proposed study, the rationale for using each criterion to select participants can be linked to consumers' utilization of self-help.

The first criterion had participants selected according to how long they had been involved in their SA group at the time of data collection. This was based on the assumption that those who have been involved in the group longer will have more knowledge of the group's values and philosophy, which promotes the utilization and value of both self-help and traditional services. Based on the assumption that different roles within the group or organization promote different competencies and opportunities, the second selection criterion selected participants according to the different roles that they occupy within their particular SA group or within the larger SA organization (i.e., leader or member). The role that a person holds within their group or the larger SA organization may reflect their adoption of the SA community narrative that validates the role of both self-help and traditional service by individuals with mental illness. Finally, participants were selected according to their group membership based on the assumption that groups vary and that beliefs regarding self-help and traditional treatment services may be related to a particular group's use of the SA literature and program, and the unique social context and sharing of stories that occurs within a specific group.

Participants in the larger evaluation study were selected on the following criteria: (a) length of participation (1=involved with SA 2-6 months, 2=involved with SA for more than six months up to two years; 3=involved with SA for more than two years); (b) their role within the group or organization (member, group leader, or an organizational leader defined as an individual who is involved in the SA organization in addition to, or instead of running a group); and (c) the Schizophrenics Anonymous group membership (12 groups are represented in the final sample). Interviews were conducted with all group and organizational leaders. One SA group member was randomly selected from each of the three "length of participation" categories in each of the 12 groups because of the large number of possible participants who were members. Consistent with Miles & Huberman (1994), this allowed for the selection of only three members from each SA group which maintained the credibility of the sample and ensured that each "length of participation" category was adequately represented in the final sample. The selection process resulted in all organizational leaders and group leaders, of active SA groups in Michigan (N=17) and a random selection of members based on the criteria discussed above (N=28), being selected for participation. Please see Table 1 (Weaver Randall, 2003), pp.39-40, for a description of the final sample.

To introduce the study and ask for participation, contact was made with all SA group leaders in Michigan. A letter was sent to them explaining the study and asking the leaders to call the Mental Health Association in Michigan if they did not want a member of the research team to contact them. There were 26 active SA groups in Michigan at the time the interview took place. Fourteen groups were eliminated due to problems with attendance, driving distance, declining to participate, untypical SA group structure, and groups inaccessible because of their location in inpatient hospital or prison settings; thus a total of 12 groups were selected to participate in the study. Please see Table 2 (Weaver Randall, 2000), p. 41, for the description of groups included in the final sample. Of the remaining 12 SA groups, the leaders were phoned, invited to participate, and informed about the overall purpose of the study. If they felt their group would be interested in participating, they were asked to get permission from the group members for one of the research team members to visit the group to discuss the study. Once permission was secured, a member of the research team visited the group to explain the study and had members fill out a "Consent to Contact Form" to those interested in participating. To participate in the interview at a place of their choosing, they were told that they would receive ten dollars. The "Consent to Contact Form" provided information on how to get in touch with the member, as well as information about their role and involvement with the SA organization (see Appendix B).

Procedures

As previously indicated, this study was done in the context of a larger evaluation study which did not have as its explicit purpose to understand the role of self-help and traditional services in the treatment of schizophrenia. However, within the interviews for the larger study, participants' stories about their experiences and feelings about SA and traditional services emerged embedded in their personal narratives. Following established practice to make sure that themes of self-help and traditional services occurred across cases (e.g., Kearney, et al., 1994), a count of cases that included these themes was conducted.

A preliminary analysis of the data was undertaken to document how participants' stories of their involvement in SA and traditional treatment services emerged in the interviews. A count was conducted on the number of members that reported on both SA and traditional treatment service experiences. This preliminary analysis yielded 36 interviews where specific examples of views about both SA and traditional treatment were identified. Thus, even though the larger evaluation study did not specifically address the role of SA and traditional treatment services, there was evidence that members' experiences with both approaches were an identifiable component of their stories.

The study included two activities that were initiated within the context of the larger study: (a) analysis of semi-structured in-depth interviews with members and leaders of Schizophrenics Anonymous; and (b) analysis of Schizophrenics Anonymous' organizational materials. Because the goal of this study was to provide a description and understanding of the role of SA and traditional treatment services from the member's perspective, the primary focus of this study rested on the semi-structured interview. Through an exploration of SA's organizational materials, the SA community narrative emerged. In addition, an understanding of the SA community narrative enhanced our understanding of consumer perspectives on SA and traditional treatment services throughout the analysis and interpretation of the interview data.

Consent

Depending on a participant's role within the organization, each participant signed one of three different consent forms (see Appendix B). Prior to beginning the interview but after the participant had a chance to read it and the interviewer reviewed the important elements of anonymity, confidentiality, voluntary participation, and risks of participation, participants signed this formal consent. Before the interview began, each participant was reminded that they could refuse to answer specific questions or to discontinue their participation in the study at any point during the interview. For reasons unknown to the interviewer, one participant chose to discontinue participation after completing half of their interview.

Semi-structured, in-depth interviews

Each of the interviews was conducted with an emphasis placed on allowing the participants to tell their story within the established semi-structured format. This semi-structured approach was utilized to ensure that certain aspects of their experiences were covered that were important for the larger evaluation study. There were four sections of the interview protocol (see Appendix C). These sections were: (a) the participant's story about their involvement in Schizophrenics Anonymous; (b) the participant's story of their mental illness; (c) interpersonal relationships and social support; and (d) demographic information and mental health service utilization. The open-ended questions started each section with the exception of section (d) which included mostly close-ended demographic questions. For each question, there was a list of predetermined probes that were used if the participant's story did not address certain aspects of their experience. This being said, the interviewers were in no way restricted to the probes and interviewers were allowed to utilize their own probes based on the content and flow of a particular interview.

At the beginning of the interview, participants were asked to tell the story of their involvement with SA. Specific follow-up questions asked if they were not brought up in the participant's story. As it relates to the study at hand, the following question (and prompts) were reflected in the Interview Protocol (see Appendix C):

13. Now, I would like you to describe SA for me. For example, if you were telling a potential member about SA what would you tell them?

____ Why should someone join?
____ Philosophy/important beliefs of SA.
____ Are there similarities and/or differences between SA and traditional mental health services?

In addition, the next question asked the participant to tell the story of their mental illness which, again, was followed by a series of more specific questions if they did not emerge from the participant's story.

All of the interviews were conducted in a setting of the participant's choice. These settings included individuals' homes, restaurants, mental health agencies or other community setting (i.e., a library). The interviews were conducted by two Psychology graduate students who had been involved with the larger evaluation study for at least one year at the time of the interviews. All of the interviews were audio taped which allowed the interviewers to pursue meaning by asking the participants for follow-up information, asking for examples of what they were describing, or by asking additional questions (Fontana & Frey, 1994) in an attempt to ensure that the interviewer and participant shared a common understanding of the phenomenon. The interviewers took notes on the content of the interviews and also recorded questions that emerged during the interview. As participants addressed specific questions or probes, the interviewer checked them off on the interview protocol to verify that those dimensions had been covered and would not need further attention.

There was variation in the length of the interviews, ranging from 45 minutes to six hours. Longer interviews were often conducted in more than one session which depended on the participant's preference. On more than one occasion, two to three sessions were needed to complete an interview. Each interview was transcribed verbatim by a professional transcriptionist and was checked for accuracy by listening to the entire interview tape and comparing the transcribed text with the spoken words. To maintain the anonymity and confidentiality of the participants, all identifying information was removed from the transcribed interview.

Exploration of written materials

SA's first program materials and literature were developed in 1987 and continue to be revised and expanded by Schizophrenics Anonymous members and leaders. Most recently, changes and revisions have been authored under the auspices of the National Schizophrenia Foundation which places an emphasis on consumer-focus and consumer-involvement in all its activities. The printed documents included in this study were: *Schizophrenics Anonymous: A Self-Help Support Group* (the Blue Book); the *SA Forum*; *Schizophrenia Update*; and *Group Leader Circular*. A video was also included titled, *Joanne Verbanic Speaks on Schizophrenia and Schizophrenics Anonymous (S.A.),* that featured the founder of SA talking about her personal struggle with schizophrenia and its impact on her desire to start a self-help group for other people with schizophrenia. Combined, these materials described the organization's purpose, goals and beliefs and provided a description of the structure and format used to conduct SA groups. Please refer to Appendix D for a complete list of materials included. These particular documents were selected because they are utilized quite frequently by SA group leaders in the conduct of their individual meetings. For each of the printed documents, all relevant copies were secured to cover the time period two years prior to the interviews, essentially covering 1995 through 1997. Because these documents undergo periodic revision and expansion, it was determined that those documents that were being utilized two years prior to and up until the respective interviews would best reflect the perspective of Schizophrenics Anonymous at the time of the interview. This study explored these documents relative to how the Schizophrenics Anonymous organization formally described its community narrative regarding the role that self-help and traditional services play in participants' lives and how they build a recovery program to meet their individual recovery needs.

Summary of Table 1

-72% (69/96) of the SA members of active community groups in Michigan volunteered to participate.

-Overall response rate of 92% (46/49) which equals a 89% (17/19) response rate for SA members and a 93% (28/30) response rate for SA members.

*At the time the interviews were conducted, there were no members attending this group.

**The first member randomly selected for participation was unable to complete the interview because of psychiatric problems that resulted in hospitalization, so another member from the same category was selected. This accounts for the one member who did not participate in the study and the 28/30 or 93% response rate.

***This group was being followed longitudinally (interviews were conducted at three time points) and therefore all current members of the group were interviewed (N=6).

****At the time the interviews were conducted, this group did not have a leader.

‡ Interviews were conducted with all members of this group because at the time the interviews took place, the research team thought the group would be followed longitudinally. However, because of limited resources this did not occur.

† This group had very low attendance and was struggling. After consenting to participate in the study, the two co-leaders, the only active members of the group, decided not to participate. This accounts for the two leaders who did not participate in the study and for the 17/19 or 89% response rate for leaders.

Table 1. Description of Derivation of Final Sample

Group ID	Leader's Estimate of The Number of Current Group Members	Total Number of Members Who Volunteered	Volunteer Rate (column 3 divided by column 2)	Number of members who volunteered to participate broken down by length of participation category.			Number of Members who participated in the interviews broken down by length of participation category.			Number of Leaders Interviewed	Total Number of Members and Leaders Interviewed
				2 - 6 months	6 months to 2 years	2 years or more	2 – 6 months	6 months to 2 years	2 years or more		
00	4	4	100%	0	0	4	0	0	0	4(more than 2 yrs)	4
02	10	7	70%	2	2	3	1	1	1	1 (more than 2 yrs)	4
03*	3	0	0%	0	0	0	0	0	0	2 (more than 2 yrs)	2
04	15	13	87%	4	6	3	1	1	1**	1(more than 2 yrs)	4
05	6	4	67%	0	2	2	0	1	1	1(more than 2 yrs)	3
10	12	10	83%	5	1	4	1	1	1	1(2-6 months)	4
11***	6	5	83%	3	2	0	3	2	0	1(more than 2 yrs)	6
13	4	3	60%	0	1	2	0	1	1	1(more than 2 yrs)	3
14	6	6	100%	5	1	0	1	1	0	1(6 months – 2 yrs)	3
15*	1	0	0%	0	0	0	0	0	0	2(more than 2 yrs)	2
16	12	6	50%	1	4	1	0	1	1	0****	2
17†	1	0	0%	0	0	0	0	0	0	0†	0
38‡	6	7	86%	5	1	1	4	1	0	1(2-6 months)	6
40	10	4	40%	4	0	0	1	0	0	1(more than 2 yrs)	2
Total	96	69	72%	29	20	20	12	10	6	17	45

Source: Weaver Randall, K. (2000), *Understanding Recovery From Schizophrenia in a Mutual-Help Setting.* Unpublished Masters Thesis, Michigan State University, E. Lansing, Michigan, p. 340

Table 2. Start Date and Setting of Groups Included in Sample

Group ID	Start Date	Setting
00		Organizational Leaders Not Currently Associated with a Group
02	6/15/91	Drop-In Center
03	2/15/96	Church
04	3/15/94	Drop-In Center
05	3/15/88	Church
10	10/15/93	Community Mental Health Center
11	10/3/96	Clubhouse
13	10/2/90	Community Mental Health Center
14	7/15/96	Clubhouse
15	6/15/93	Church
16	11/15/96	Clubhouse
38	5/15/97	Drop-In Center
40	10/15/95	Church

Source: Weaver Randall, K. (2000), *Understanding Recovery From Schizophrenia in a Mutual-Help Setting.* Unpublished Masters Thesis, Michigan State University, E. Lansing, Michigan, p. 342

Interpretation and Analysis

The purpose of the activities in the stages of analysis and interpretation was to explore and understand the qualitative data that had been collected (Miles & Huberman, 1994). This was accomplished through an analysis of the interviews where specific examples of experiences and perceptions with SA and traditional treatment services were identified, and the SA literature. A thematic content analysis was used as the primary analysis tool to explore and understand the data. The analysis involved the following steps in the order presented: (a) reduction of the empirical materials; (b) setting level analysis; (c) analysis of traditional service utilization; (d) cross-case analysis; and, (e) within-case analysis.

Data Reduction

The process of data reduction involved the condensing of the interview transcripts and organizational materials into a manageable and meaningful format. Consistent with Miles & Huberman (1993), this process entailed condensing and transforming the data in a manner that provided context and focus to relevant data. In addition, it organized the data in a way that afforded an opportunity to draw and verify conclusions.

Analysis Plan

Multiple methods were employed in this project. The specific methods are linked to each research question and are as follows:

Setting Level Analysis

A setting level analysis was conducted on SA. An important piece of qualitative work is the provision of an understanding of the context. This is portrayed through rich description. A description of the setting at the organizational level was utilized to understand how SA might contribute to a member's description and understanding of their program of recovery. The organizational beliefs of SA, its community narrative, specifically around the role of itself and traditional services was examined through the organization's materials. This is important when trying to understand how a self-help group might influence consumer understandings and experiences of the role of traditional services in their recovery from and coping with mental illness.

A simple random sampling process was utilized with the SA literature previously identified. This sampling procedure was intended to produce a representative sample from each set of documents available during the specified time frames. The documents selected were coded by a naive outsider and this immersed researcher specifically in terms of the organization's community narrative regarding the role of traditional services. The coding categories were grounded in the data from which it emerged (Denzin, 1978; Glaser & Strauss, 1967). An interactive process was engaged between the coders whereby their independent coding categories were presented and reviewed. Areas of consensus and agreement in coding categories were noted and differences discussed. A constant comparative method as described by Lincoln & Guba (1985) was used to arrive at themes and patterns. As the coding categories were developed, an iterative process was used to toggle back and forth between the SA literature and the coding categories. A third independent reader reviewed the resulting categories to make sure that the claims and assertions were not derived from a misreading of the data and that they were documented adequately (Berg, 1995). The literature was then re-coded a final time using the final themes and patterns. The results of the content analysis have been displayed in a descriptive matrix (Table 3, p. 47-48) as described by Miles and Huberman (1994).

Descriptive Statistics

Descriptive statistics were used to describe the pattern of traditional service use among SA members. Data for this question were obtained from the fourth section of the interview where demographic and mental health service utilization was collected. The majority of the questions in this section involved one or two word responses or provided multiple response options for the participant to choose from. Specifically, the data was in response to questions that asked about consumer interaction with traditional services (i.e., living situation, hospitalization, medications, outpatient/day treatment participation, individual/group therapy). The data on respondents using traditional services are presented in Table 4 (p. 49).

Cross-Case Analysis

A cross-case analysis was employed to explore the themes of similarities, differences, and interactions between self-help and traditional services across individual cases (Miles & Huberman, 1994). This allowed for the identification of themes regarding service utilization across cases, allowed for the coding of cases using these themes, and led to making cross-case comparisons to see whether cases fell into groups, based on shared patterns of service utilization. All interview transcripts were read and data that emerged regarding self-help and traditional service utilization was identified. This data was used to create an emergent coding frame. A constant comparative method as described by Lincoln & Guba (1985) was used to arrive at themes and patterns. As the coding categories were developed, an iterative process was used to move back and forth between the interview transcripts and the coding categories. Each time a theme was revised or a new theme added, coding was started at the beginning of the first document.

This was done until the themes were discrete and consistent in meaning. Resulting themes were reviewed by an independent reader to ensure that coding themes and patterns were not derived from a misreading of the data and that they had been documented adequately. When inconsistencies in patterns emerged, they were discussed relative to their impact on the validation of the overall themes and patterns (Berg, 1995).

Within-Case Analysis

With the knowledge of the themes and patterns across cases, a within-case analysis was conducted. A within-case analysis was utilized to capture and maintain the coherence of an individual's story (Mishler, 1986). A within-case analysis facilitated an examination of how sequences of events or experiences within individual lives influenced their descriptions or experiences. Identification of the patterns or relationships between an individual's background and experiences (their service utilization story), and their perception and description of their stories of the role of self-help and traditional services in their movement toward recovery, were the goals of the within-case analysis in this study.

Case summaries provide an opportunity for an integrated and holistic view of an individual that may not have emerged in a cross-case analysis, and they will give voice to the consumer's personal narrative, particularly with regard to service utilization. Case summaries were written for the interviews that contain enough detail and description of the role of SA and traditional services to create a meaningful summary. Case summaries were not written for the interviews that did not contain service utilization information. Two particular questions on the interview protocol (see Appendix C) ask the participants to tell their story of involvement with SA and to tell the story of their mental illness, from which experiences with traditional services emerged. Beyond this, the entire interview was reviewed for service utilization, perceptions, and experiences that emerged in other parts of the interview. Case summaries were then compared to identify any similarities, differences, or interaction between the role of traditional services and SA. Case summaries are important for this study because they reveal consumers' personal narratives regarding the similarities, differences, and interactions between self-help and traditional services and were reviewed by an independent outside source.

The results of the setting level analysis were compared to the personal narratives revealed in the interview transcripts (case summaries and service utilization data) with specific regard to the role and utilization of traditional services by members of this self-help group. The relative degree of fit between the personal narratives and the community narrative was examined and discussed. As expected, there were varying levels of 'fit'. These varying levels of 'fit' are examined and discussed with regard to the consumer's length of involvement in SA, their role within the organization, and other co-variants that emerged from the analysis.

Table 3. Thematic Coding of Organizational Literature by Document and Year of Publication

DOCUMENT	**EXPLICIT SUPPORT** SA is a Supplement to Traditional Services	**EXPLICIT SUPPORT** SA Encourages Use of Traditional Services	**IMPLICIT SUPPORT** SA is a Piece of the Puzzle	**IMPLICIT SUPPORT** SA Normalizes Member Experiences	**SA PROVIDES EDUCATION**	**MEMBER STORIES**
Blue Book						
1994	X	X	X	X	X	X
1997	X	X	X	X	X	X
Group Leader Circular						
1995	X	X	X		X	X
1996		X	X			
1997		X	X		X	
SA Forum						
1995		X	X			
1996		X	X		X	
1997	X	X				X

DOCUMENT	**EXPLICIT SUPPORT** SA is a Supplement to Traditional Services	**EXPLICIT SUPPORT** SA Encourages Use of Traditional Services	**IMPLICIT SUPPORT** SA is a Piece of the Puzzle	**IMPLICIT SUPPORT** SA Normalizes Member Experiences	**SA PROVIDES EDUCATION**	**MEMBER STORIES**
Schizophrenia Update						
1995					X	
1996					X	
1997					X	
SA Video	X	X		X	X	

Note: The SA **Blue Book** is a publication circulated by SA that reflects the organization's background, information about schizophrenia, steps for recovery, information about starting an SA group, SA's guiding principles and personal stories of SA members. The **Group Leader Circular** is a monthly publication written and circulated by SA to each of its group leaders as a vehicle to generate discussion or provide organizational information. The **SA Forum** is a quarterly newsletter circulated by SA that reflects information on research, upcoming conferences, and historical information on SA. Fourth, the Schizophrenia Update is another monthly newsletter, circulated by SA to leaders of SA. The **Schizophrenia Update** predominantly focuses on providing education regarding the latest research in the areas of mental health, treatment, and medication that stands to impact people with schizophrenia. Finally, the **SA Video, *Joanne Verbanic Speaks on Schizophrenia and Schizophrenics Anonymous***, is a 28 minute video in which the SA Founder, Joanne Verbanic, describes her personal story of being diagnosed with schizophrenia, her recovery efforts, and how her experiences led her into becoming the founder of Schizophrenics Anonymous.

Table 4. Number and Percentage of Respondents Reporting Use of Traditional Services at the Time of the Interview (N=45)

Characteristic	%	n
Psychiatric Medication	100%	45
Living Arrangements:		
Independent	62.2%	28
Family/Friends	15.6%	7
Supervised Apt	11.1%	5
Adult Foster Care	6.7%	3
Group Home	2.2%	1
Homeless Shelter	2.2%	1
Outpatient/Day Treatment	80%	36
Medication Management	57.8%	25
Individual/Group Therapy	46.7%	21
Drop-In Center/Clubhouse	37.8%	17
Case Management	31.1%	14
Day Programming	24.4%	11

Conclusion

Combined, multiple levels of analysis were employed to examine the data that emerged within 45 qualitative interviews of members of Schizophrenics Anonymous. This was conducted with a particular emphasis on understanding the organization's community narrative around the role of self-help and traditional services, members service utilization patterns, as well as their descriptions of the roles that the two systems play in their recovery efforts, and the relative degree of fit between the community narrative and a members personal narrative. An approach that included a content analysis, service utilization analysis, cross-case analysis, and within-case analysis was implemented and the results are the basis of the subsequent chapter.

Chapter 4

RESULTS

Overview

First, demographic information is presented on all study participants. Second, the results of the first research question will be presented by presenting the results and discussion of the Schizophrenics Anonymous (SA) community narrative. This will include presenting the personal narrative of the SA founder and discussing the role it played in framing the organization's community narrative. Third, to address the second research question, frequency distributions regarding the utilization of traditional services will be presented. Fourth, the third research question will be addressed by presenting the results of the cross-case and within-case analyses. Fifth, the fourth research question will be addressed by comparing the community narrative revealed in the first research question with the personal narratives revealed in the third research question and discussing the results contained therein.

In all cases, the names of the participants have been replaced by pseudonyms and other identifying information has been removed to protect the identity of the participant. All verbatim quotes have been referenced by an interview identification number. This number appears in parentheses after the verbatim text.

Description of Participants

The demographic characteristics of all the participants have been summarized in Table 5, (pp. 53-54). The majority of the participants (58%, n=26) were women and White (85%, n=38). The participants had an average age of 42, with a range of 22 to 74 years old (SD=10.96). Thirteen (29%) participants had completed a college degree, 18

(40%) participants had completed high school. Most participants were not working (64%, n=29), did not have children (73%, n=33), and had never been married (71%, n=32). The majority of the study participants were supported primarily by Social Security Disability (67%, n=30). Sixty-two percent (n=28) were able to live independently in their own apartment or house. All of the participants in this study had experienced mental illness and subsequent treatment. The majority (58%, n=26) of the participants reported a diagnosis of schizophrenia, all reported taking medication for psychiatric reasons and had been hospitalized an average of eight times for psychiatric reasons.

The demographic characteristics of the participants in this study are consistent, in general, with people who participate in self-help groups in the United States. According to Kessler et al (1997), woman have been more likely than men to participate in self-help groups, married people have lower rates of participation, and blacks are only half as likely as whites to participate in self-help groups overall. The authors offer caution, however, that the results could be deceptive because "they confound the demographic correlates of having problems with the demographic correlates of using self-help groups to manage these problems" (p. 33).

Table 5. Summary of Demographic Characteristics of Participants (N=45)

Characteristic	Category	%	n
Gender	Female	57.8%	26
	Male	42.2%	19
Age	Mean=42	Range 22-74	
Ethnicity	White	85%	38
	African American	9%	4
	Hispanic	4%	2
	Other	2%	1
	TOTAL	100%	45
Diagnosis	Schizophrenia	58%	26
	Schizo-affective Disorder	16%	7
	Manic-Depression	11%	5
	Other	9%	7
	TOTAL	100%	45
Education	Some High School	13%	6
	HS Graduate	40%	18
	Some College	18%	8
	College Degree	29%	13
	TOTAL	100%	45
Income Source[1]	Earned Income	29%	13
	SS/SSI	29%	13
	SSDI	67%	30
	Welfare Benefits	4%	2
	Family Member	27%	12

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[1] Some respondents reported multiple sources of support

Traditional Services[2]	Individual/Group Therapy	47%	21
	Medication Mgmt	58%	25
	Case Management	31%	14
	Drop-In/Clubhouse	38%	17
	Outpatient/Day Tx	80%	36
Living Arrangements	Independent	62%	28
	Family/Friends	16%	7
	Supervised Apt	11%	5
	Adult Foster Care	7%	3
	Group Home	2%	1
	Homeless Shelter	2%	1
Religion	Yes	72%	33
	No	28%	12

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[2] Some respondents reported utilization of more than one traditional service

Results of the SA Community Narrative Analysis

Research Question #1: What is the SA community narrative regarding utilization of traditional services?

One of the factors that may influence how self-help group participants utilize traditional services is the group's ideology about the problem and its solution (Antze, 1976). Self-help groups can be conceptualized as communities for living (Rappaport, 1993). As a community, a self-help group develops a community narrative, or story, that reflects the group's goals, beliefs, and philosophy.

One of the components of a mental-health self-help group's community narrative is its view of the role of traditional services in recovery from mental illness. For the purpose of this study, traditional services are defined as those services that require professional involvement. These include such services as hospitalizations, prescription of medication, individual or group therapy, and case or medication management services. Whether or not a self-help group supports the utilization of traditional service delivery is likely to impact a consumer's view and use of those services or may attract people who share that view.

Impact of Founding Member's Personal Narrative on Development of Community Narrative

It is important to look at how a community narrative first develops. The development of a groups' community narrative will generally take on the ideological position of its original founder(s). For example, Alcoholics Anonymous (AA), the long standing self-help group for people recovering from alcohol abuse, was founded by Bill W. and Dr. Bob who were struggling with their own personal recoveries. It was their experiences with alcoholism and recovery that shaped the essence and perspective upon which the AA organization was built.

SA is no different. Joanne Verbanic is the founder of SA It is through her experiences, and with the support of her psychiatrist and the Mental Health Association in Michigan, that Joanne founded SA. She was one of the interviewees in this study. However, in light of her role in the development of the organization, her interview was analyzed separately with regard to her experiences with traditional services and how these experiences contributed to the development of the SA community narrative. It is important to highlight that SA is a self-help group and, as such, upholds a self-help doctrine regarding the anonymity of its members. However, since the organization's inception, Joanne has been clear about distinguishing between her efforts to advance a self-help group for people with schizophrenia and her personal and public efforts to erase the stigma associated with a diagnosis of schizophrenia. As excerpted from a SA video, *Joanne Verbanic Speaks on Schizophrenia and Schizophrenics Anonymous (n.d.),* "Everything said at SA meetings is confidential. SA members should remain anonymous except those who wish to work on special issues. I'm not anonymous. I'm purposely going public with my name to help erase the stigma because I'm working on an issue." Consistent with this, for the purposes of this study, Joanne Verbanic has given express written permission for the utilization of her full name.[1]

In the interview, there is extensive documentation of not only her own struggle with schizophrenia and recovery, but also a first-hand account of her efforts to establish the self-help group. It is clear that the founder had an extraordinary relationship with her psychiatrist with whom she communicates on a regular basis, particularly as she struggled with the demands of coping with a mental illness, going public with her illness in an

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[1] The letter is on file with Dr. Debby Salem, Michigan State University

attempt to erase the stigma associated with it, maintaining a full time job, and starting up and leading a self-help organization. Her descriptions of the similarities, differences and interactions between SA and traditional services are intricately interwoven into her belief system which have developed as a result of her experiences. Then, as now, she believes that SA is a supplement to traditional services, quickly to acknowledge that SA and traditional services have different, yet important roles, in people's lives.

> "Not group therapy, definitely not group therapy. I think it's very dangerous and I tell them in SA to talk about feelings. You know, you may express the fact that you're angry or you can talk about your anger situation and I'd say you're angry. I think you should talk with your therapist about that. And the reason I say that is suicide. There's a fine line there and you don't want get into these feelings. We're not professionals. The professionals need to deal with the feelings. With an exception. You know what I'm talking about. The deep feelings that somebody's suicidal and has little self esteem and that, we would give them their time at the table and have empathy, but refer them to professionals. I always say we don't get into like therapy. Well, group therapy, you get into feelings. We don't do that. This is self-help. Talk about daily living and coping skills and exercise. We get into stress management. Sometimes we have speakers for stress management. And things like that. But I think it's very important that we don't get into these deep insight therapy feelings...I had my psychiatrist, God, and SA. And that was my whole life...I want SA to be informative and to educate the people as much as they can about the illness...the new medications and stuff like that. I think it's real important. You can't expect somebody to take responsibility for their illness if they don't know about their illness [230100]."

To her, SA provides the support that consumers often need to navigate their recovery. This support is communicated largely through the shared experiences of other group members, all of whom have been diagnosed with schizophrenia (or schizophrenia-related illnesses), each with unique experiences from which to provide support and advice to other group members.

The fact that she believes that SA is a supplement to traditional services is likely to be instrumental in shaping the community narrative of SA in general and, of particular interest to this study, in the role of SA and traditional services in people's recovery efforts.

Extending this, it is reasonable to hypothesize that a self-help group's support for the utilization of traditional service delivery is likely, over time, to impact a consumer's view and use of those services or may attract people who share that view.

A content analysis was conducted to explore SA's community narrative regarding the role of SA and traditional service in recovery from schizophrenia. The SA materials described the organization's purpose, goals and beliefs and provided a description of the structure and format used to conduct SA groups. There were five sources of information utilized in this analysis. First, the SA Blue Book is a publication circulated by SA that reflects the organization's background, information about schizophrenia, steps for recovery, information about starting an SA group, SA's guiding principles and personal stories of SA members. The Blue Book is the foundation of SA and SA group meetings, something which members are exposed to at each meeting. Second, the Group Leader Circular is a monthly publication written and circulated by SA to each of its group leaders. The group leaders often use this a tool for their own leadership development and often utilize it in the conduct of their respective meetings as a vehicle to generate discussion or provide organizational information. Third, the SA Forum is a quarterly newsletter, circulated by SA, sent to internal and external supporters of SA. The SA Forum generally reflects information on research, upcoming conferences, historical information on SA and ongoing reminders of SA founding principles and guidelines. Fourth, the Schizophrenia Update is another monthly newsletter, circulated by SA to leaders of SA. The Schizophrenia Update predominantly focuses on providing education regarding the latest research in the areas of mental health, treatment, and medication that stands to impact people with schizophrenia. Finally, the video, Joanne Verbanic Speaks on Schizophrenia and Schizophrenics Anonymous, is a 28 minute video in which the SA Founder, Joanne Verbanic, describes her personal story of being diagnosed with schizophrenia, her recovery efforts, and how her experiences led her into becoming the founder of Schizophrenics Anonymous. This video is widely disseminated to people interested in starting up SA groups and is often viewed at SA meetings, particularly when the group is new or there are new members who could benefit from the foundational premise upon which the organization was built. Please refer to Appendix D for a complete list of materials that were included.

The analysis of these documents revealed that the SA community narrative supports and encourages members' utilization of traditional services in four different ways. First, SA supports it's members utilization of traditional services by explicitly encouraging members to seek traditional services. It does this by explicitly identifying SA as being supplemental to traditional services and by explicitly encouraging the utilization of traditional services. Second, use of traditional services was implicitly supported and identified as a piece of a member's recovery and SA often portrayed a member's utilization of traditional services as a normal and accepted part of their recovery efforts. Third, they provide information to the membership on how to manage their recovery better by educating them about traditional services (e.g, medications, hospitalization, community programs, etc). Finally, the literature provides anecdotal stories of members who have used traditional services in their recovery efforts.

The coding of the SA literature was an interactive and a constant comparative process conducted by a naive outsider and this immersed researcher. A third independent reader reviewed the resulting categories to make sure that the claims and assertions were not derived from a misreading of the data and that they had been documented adequately (Berg, 1995). Consistent with display techniques described by Miles and Huberman (1994), the results of this content analysis have been displayed using a descriptive matrix (see Table 3, pp. 47-48). Below, I provide two sources of support for each code: (1) an account of the documents in which the code emerged and (2) several of the most illustrative examples of each code. All of the examples in support of each category can be found in Appendix E.

Explicit Statements in Support of the Use of Traditional Services

SA's support for utilization of traditional services was explicitly reflected in their organizational materials. In these sections, the SA literature either explicitly identified SA as being supplemental to traditional services, or it explicitly encouraged the utilization of traditional services. This explicit support was captured in each of the organization's documents with the exception of the Schizophrenia Update.

SA as a supplement to traditional services.

> "S.A. is intended to be supplemental to professional help (Blue Book '94, pp. 3-4; Blue Book '97 p. 3)."
>
> "...we want to make available our application of this adjunct recovery program to as many people with schizophrenia who want it (Group Leader Circular, Jan 95)."
>
> "MSU Study Results Encouraging........... Members view the helping roles of SA and professionals differently. While they view SA helping in many domains, members tend to view professionals as the best equipped to help them with medication and symptom management. Fellow SA members, on the other hand, were viewed as best equipped to help when they are feeling lonely or want to talk to someone who understand what it is like to have schizophrenia. This finding is consistent with SA's goal to provide support in conjunction with professional services (SA Forum, Fall '97)."
>
> "Schizophrenics Anonymous is only supplemental to professional help. We believe in recovery, medications and professional help. Everyone in the group has professional help in addition to SA (SA Video)."

SA encourages members to utilize traditional services.

> "To choose to be well may involve cooperating with a psychiatrist or a psychotherapist, listening to what they say, and adhering to their advice. Another choice may be recognizing the need to take the medication that helps so many schizophrenic patients (Blue Book '94, pp. 7-8; Blue Book '97, p. 6)."

> "Generally, SA has a three-part formula with regards to a group leader helping a member. It goes like this: 1) Strongly refer the member to a mental health professional, particularly the attending psychiatrist or the professional associates, 2) Do what you can do as an SA leader to provide the member with caring fellowship and support, and 3) Continue to refer the member to a mental health professional (Group Leader Circular, Mar 95)"

> "We really choose to be well but we don't know how to be well sometimes and that's where professional help comes in. We don't know what steps to do to stay well (SA Video)."

Implicit Statements in Support of the Use of Traditional Services

SA's support for utilization of traditional services was also implicitly reflected in their organizational materials in a variety of ways. In one way, the SA literature referred to SA as a piece of a member's recovery. In another way, the SA literature often portrayed a member's utilization of traditional services (e.g., medication, hospitalizations) as a normal and accepted part of their recovery efforts. This implicit support was captured in each of the organization's documents with the exception of the Schizophrenia Update.

SA as a piece of the puzzle.

In these sections, support for the use of traditional services was not as explicit. Support was implicated by referring to SA as only a piece of a member's recovery puzzle. There were also accounts in the literature where a member's utilization of traditional services was viewed as a normal part of the recovery process. These were captured in the Blue Book, the Group Leader Circular, and the SA Forum, and, they were documented in the SA video. This category was not revealed in the Schizophrenia Update.

> "Mission Statement: The mission of Schizophrenics Anonymous is to add the element of self-help support to the recovery process of people suffering from schizophrenia. (Blue Book'94, p.3; SA Forum, Fall '95; SA Forum, W '96, p.5)."
>
> "...the program [SA] doesn't pretend to have all the answers, but the steps do address the difficulties of the afflicted and the problems associated with the illness (Blue Book'94, p. 6, Blue Book '97, p. 5)."
>
> "....However, we all agree on the major point of S.A., a two-part expression of its mission: First, Schizophrenics Anonymous seeks to apply the concept of self-help group recovery for people with Schizophrenia; and second, we want to make available our application of this adjunct recovery program to as many people with schizophrenia who want it (Group Leader Circular, Jan 95)."

SA normalizing member's usage of traditional services.

The SA literature also normalized member's utilization of traditional services. This was found predominately in the Blue Book and was supported in the SA video. Through this normalization process, the organization acknowledged the existence of traditional services in the lives of its members and went further by giving permission and support for their inclusion.

> "To choose to be well may also require the patient to acknowledge that, at some point during his or her period of recovery, there may be a setback and rehospitalization could be necessary...(Blue Book '94, pp. 7-8; Blue Book '97, p.6)."
>
> "For some members, recovering may mean the ability to hold a demanding job; for others, it may mean the acquisition of grounds privileges at a state hospital. If each person in these circumstances is doing the best that he or she can then they are equal in our eyes. (Blue Book '94, p. 10; Blue Book '97, p. 8)."
>
> "Aspects of Recovery: What is recovery from schizophrenia?......More broadly, it might include living independently, forming meaningful relationships, being financially self-supporting, and not having to be rehospitalized for psychiatric reasons......Still others are doing their best by residing on a locked ward at a state-run hospital, taking medication, eating, and behaving the best they can (Blue Book '94, p. 12; Blue Book '97, p.10)."
>
> "S.A.'s Attitudes Towards Setbacks and Stigma: .....An example of a major setback would be a person experiencing a psychotic episode which resulted in rehospitalization....Hospitalization is for many a common setback. However,

> Schizophrenics Anonymous does not consider returning to the hospital, either voluntarily or otherwise, to be a personal failure or weakness. We believe it shows a realistic understanding of the limits imposed by our illness. The decision to return voluntarily to the hospital shows that we take full responsibility for our choices and that we choose to be well. At SA we feel that setbacks are a normal, expected part of our usually chronic illness. We view them as a temporary intensification of symptoms which will often pass. (Blue Book '94, p. 14; Blue Book '97, p. 11)."

> "We in Schizophrenics Anonymous believe that choosing to stay well means taking the medication. Sometimes it means re-hospitalization. We don't look at re-hospitalization as a failure. We look at it as a temporary learning experience. With each hospitalization that I had, I gained a little more. I learned a little more. I grew a little more and I got stronger until I'm at the point of recovery I am today (SA Video)."

SA Educating Members About Traditional Services

The SA literature revealed the organization's commitment to educating members about traditional services. The fact that SA is providing its members with information and education about traditional services portrays its support for, and understanding of, the role for traditional services and this, in turn, is likely to influence an individual member's service use. This category was captured within each of the SA documents, and the Schizophrenia Update (34 publications) was exclusively dedicated to providing education to SA members.

> "What is Schizophrenics Anonymous?.......To provide members with the latest information regarding schizophrenia...in addition, members share information regarding developments in schizophrenia research (Blue Book '94, p. 4; Blue Book '97, p.4)."

> "We're subscribing to the best journals and newsletter in order to gather quality information for you: *American Journal of Psychiatry, Hospital and Community Psychiatry, Schizophrenia Bulletin, Harvard Mental Health Newsletter, The Menninger Letter, Psychiatry Drug Alerts*, and numerous others. Please think of ways to share this information with the members of your group and we'll make some suggestions on how to do this inexpensively in future months (Group Leader Circular, Feb '95).

> "Update on New Antipsychotic Medication.....Zyprexa....What does all this mean

> to SA members? We can be hopeful that these new approved drugs will provide additional symptom relief (and side-effect relief) for those out of the hospital already; and for those in the hospital a new range of hope may emerge (as I the possibility that the negative symptoms may lessen). We can all have come consolation that the scientists are aggressively seeking new pharmaceutical treatments for our mental pain (SA Forum, F '96, p.3)."

> "–News on New Medications. There are more indications that the eagerly awaited experimental medications for schizophrenia will gain FDA approval soon. The *Detroit Free Press* in its November 11, 1997 issue said that we are on the verge of federal approval for Serlect (generic name "sertindole") and Seroquel (quetiapine). At this writing in late November we are uncertain what date FDA approval will come, though arrival of the medications in pharmacies should come soon after such approval. An interesting point in the Detroit newspaper is that a third new antipsychotic medication is in line for FDA approval. This medication is called Zeldox, with the generic name Ziprasidone. New information on these medications will be printed here as events happen...(Schizophrenia Update, December 1997).

Personal Stories of Using Traditional Services for Recovery

The SA literature gives examples of members using traditional services which is reflected through anecdotal stories about members utilizing both SA and traditional services in their personal stories of recovery. This was captured within the Blue Book, the Group Leader Circular and the SA Forum. The fact that the organization's literature contained SA members' stories about the role of traditional services points, again, to the fact that it supports and encourages members' utilization of traditional services and wishes to convey this support through their literature.

> "Paul's Story: The [SA] group has helped me psychologically to fight my symptoms (voices), and the medicine does the rest (Blue Book '94, p. 24; Blue Book '97, p.19)."

> "Laura's Story: But with the help of the group and my therapy, I managed to stay out of the hospital (Blue Book '94, p. 29; Blue Book '97, p.22)."

> "This month David M., a long-time member of SA, will be observing the tenth anniversary since his last psychiatric hospitalization. In November 1985 David was in the hospital for a month, and has not been admitted since. He has undifferentiated schizophrenia, has been in treatment since 1960, with numerous

> hospitalizations and a history of self-destructive behavior. David reports that while in the state hospital in 1985 the attending psychiatrist said, "David, I wish that you would take care of yourself really well." David said that for the first time he decided to cooperate fully with the professionals at the hospital. Below are seven things that David says he did to stay out of the hospital (and to feel better).....2) I cooperated with treatment. I stop fighting the medication and became a believer in psychiatric treatment. I discussed my problems with my psychiatrist and prepared for each visit with notes and a list of questions......7) I joined Schizophrenics Anonymous. At SA I learned to accept my illness, and learned that despite this illness, I can engage in many growth-oriented activities. I also enjoyed all the fellowship (Group Leader Circular, Nov 95)."

> "From the Founder.........Although I was able to accept my vision loss, I began to experience a depression. Along with a short stay in day-hospital, I relied on my therapist and the six steps of SA to help get me through it all. SA provided me the right perspective and hope for 'recovery' to adjust to this major life trauma (SA Forum, Fall '97)."

In summary, when combined, these documents contribute to the community narrative for SA, specifically as it relates to the utilization of traditional services. The SA literature reveals that its community narrative both supports and encourages members to utilize traditional services. This support was encouraged both explicitly and implicitly in the literature. Support was also transmitted by educating members about traditional services. Finally, the literature provided anecdotal evidence of members' utilization of both SA and traditional services. A negative case analysis was performed, looking for evidence of alternative ideologies regarding service use. There was no evidence in this content analysis to support a community narrative that spoke of SA as being an alternative to, or something to be used in the place of, traditional services. As an organization, SA imparts a message that values the role of both self-help and traditional services in a member's recovery, that it is a supplement to traditional services, and helps members become better educated about traditional services. Being exposed to this consistent message over time is likely to impact a member's own perspective and utilization of traditional services, and the clarity and consistency of the message is likely to discourage potential members who hold negative views of the value of traditional services.

Results of the Service Utilization Analysis

An analysis of the service utilization patterns of the members of SA was conducted. This analysis revealed that all of the participants (100%) were taking psychiatric medication and the vast majority of members (91%) reported having been hospitalized in the past for psychiatric reasons, with the mean number of hospitalizations being 7.8 within a range of 1 to 50 hospitalizations. At the time of the interview, besides taking medication, twenty percent of the members reported not utilizing any other traditional mental health services. The remaining 80% reported participating in some form of outpatient or day treatment programming (i.e., individual/group therapy, case management), and/or attended a drop-in center or clubhouse. Please refer to Table 4 (p. 49) for member service utilization patterns. As a group, these members interface with the traditional service delivery system in at least one way, and in some cases, multiple ways. These patterns of service utilization are consistent with what we know about the SA community narrative that both supports and encourages members to utilize traditional services, particularly to take medication. The support that members experience for involvement with traditional mental health services within the SA group structure is likely to impact their subsequent utilization of traditional services and the development of their personal narrative.

Results of Cross-Case Analysis

One way to begin to examine how members of SA described the differences, similarities, and interactions between the roles of traditional services and SA in their recovery is through a cross-case analysis. In this study, SA members and leaders were asked to share their stories of mental illness, SA, and recovery. Across these interviews, data emerged that spoke to how self-help participants actually experience the differences, similarities, and interactions between self-help and traditional services and how they use them in their personal recovery. This data provides an understanding about how self-help group participants describe the extent and type of utilization of traditional services and further, how they describe the differences and similarities between them. By analyzing their stories of support and assistance, we will also have a better understanding of the extent to which self-help group participants draw upon multiple sources of support, and how participants might weave different sources of support into a recovery program.

The data that emerged across cases in response to this question can be summarized in the following ways: 1) Most members saw self-help and traditional services as different from each other, serving different needs; 2) Some members saw similarities even though they tended to be superficial and not well articulated; and, 3) Many members talked about how SA and traditional services interact in their lives to promote recovery. Please refer to Table 6 (p. 69) for the thematic coding of the cross-case analysis. It is important to note that not all interviews addressed all three dimensions. In fact, only a small portion of the members addressed all three dimensions. A larger portion of the members addressed one dimension (almost exclusively differences), leading some to acknowledge that the two systems address different areas of their recovery. Seven members were unable to articulate any similarities, differences, or interactions between SA and traditional services. An examination of these interviews revealed that these members tended to be newer to the organization (6 months or less) and, the majority of them did not share their diagnosis, did not know their diagnosis, or had not been diagnosed with schizophrenia or a schizophrenia-related illness.

Table 6. Meta-Themes and Sub-Themes of Similarities, Differences and Interactions between SA and Traditional Services

Dimension	Meta-Theme	Sub-Theme	n	%
Similarities	Structure is Similar Between SA and Traditional Services		3	6.8%
	Process is Similar Between SA and Traditional Services		12	27.3%
Differences	Knowledge Base is Different		13	29.5%
	Setting Characteristics are Different		35	79.5%
		Structure is Different	26	59%
		Process is Different	29	65.9%
	SA Members Acknowledge Different Areas of Responsibility for SA and Traditional Services		12	27.3%
Interactions	SA Provides Information About Traditional Services		7	15.9%
	SA Provides Information About Medication		15	34.1%
	SA Encourages Members to Communicate with Traditional Service Providers		7	15.9%
	SA Members Recognize the Need for Both SA and Traditional Services		12	27.3%

Differences

Theoretical, empirical, and consumer literature has tended to focus on how self-help and traditional services are different and that they are separate 'systems' of care. This attention to differences emerged in the data. Most members were able to articulate at least one area where they perceived a difference between SA and traditional service. Three meta-themes emerged within this dimension: (1) the knowledge base is different between SA and traditional services; (2) the settings characteristics are different between SA and traditional services; and, (3) SA and traditional services address different aspects of their recovery. These categories are not necessarily exclusive, meaning, some members spoke to only one area, while others spoke to more than one.

Knowledge Base is Different

The first meta-theme, the knowledge base being different, contained two themes: (a) professional education and training is different; and, (b) professionals were unable to understand or empathize. Within this, some members identified professional education and training as a strength,

> "The psychiatrists are good. They're gonna know a heck of a lot more about the medical side of the illness than we're ever gonna know. They know more about the illness...they know more about the recent advances, the things that are gonna happen...Therapists are gonna know a lot about, say about your personal therapy and they're gonna know about cognitive therapy and they're gonna know more about methods of, scientific methods of theories of psychotherapy [210100]."

while others members perceived professional education and training as a limitation.

> "And when there's more than two, people who have been there... not, not to say anything negative about professionals but they know from books and internships and stuff, residencies and everything. But they maybe haven't felt in their, for weeks, months, years on end of pain. You know, they haven't felt the stigma and then these folks [SA] have [070105]."

> "And I think the thing that strikes me most is that social workers have been trained

> in mental health but not in mental illness. They don't know how to deal with mental illness. They just assume that they know what people ought to be like because they know what mental health is. But they are not familiar with all the side lines of mental illness [410140]."

Members also believed that professionals were unable to empathize or understand schizophrenia, especially with regard to symptoms and the impact of living with schizophrenia.

> "He [professional] doesn't know what the voices are telling you. Cause he hasn't had any talk to him...they can't have empathy. Been there haven't really done that, you know. People at Schizophrenics Anonymous have [010211]."

> "Because I can relate to these people. They [SA] can relate to me and my psychiatrist and my therapist cannot. You know, no matter how much I try to make them understand, they will never know what it's really like...just like if I had my arms and legs chopped off and I had to see a therapist about it, I would rather see a therapist that was in the same position than I was than someone who was not because they wouldn't understand and that's how I feel, I want someone who understands [100110]."

Setting Characteristics are Different

The second meta-theme that emerged is that the setting characteristics are different. This category captured the vast majority of data across all interviews and across the three dimensions. Within this, two predominate themes emerged: the SA structure is different from the structure of traditional services; and, the SA process is different from that of traditional services.

SA structure is different.

That the SA structure is different from the structure of traditional services was identified by every member who identified any differences and was expressed in many ways. There were five sub-codes within this theme: (1) SA is consumer led; (2) SA format is more casual; (3) control of process; (4) cost; and, (5) SA is more available. Citations within each sub-code are not necessarily exclusive, meaning, some members spoke to only one sub-code, while others spoke to more than one of these. Many members spoke to the fact that SA is consumer (non-professional) led.

> "It's peer led. You know, there's no professional there...and it was run by a peer person and there's other peer people there [120103]."
>
> "Because it's not, it's not therapy as such. It's a self support group. It's run by the members of the group and they are supported by the structured format of the meetings and the literature and the principles and the goals of SA [410140]."

Some members also addressed the fact that the SA format is more casual.

> "I like the easy-going-ness of meetings, you know. You don't feel threatened or I didn't feel threatened at all. You know, like if it was, just this guy with a PhD like they do sometimes in hospitals, you know [110103]."
>
> "It's [therapy] much more intense. It's much more, you know, it's like five days a week. It's much more time to spend. It's [SA] much more casual, relaxed. The meetings, maybe there should be a meeting a day but there are like different things going on [440238]."

That SA members have control of the process within SA (which they lack within traditional services) is another theme that emerged within member interviews.

> "We can relate to one another and express what we did if we want. And if you don't want to say nothing, you can pass. It's your option [290202]."
>
> "Some traditional stuff, it's not, it's uncomfortable, I guess you'd call it...because everything's kind of this is how it goes and that's the way it goes, you know...And sometimes with the traditional stuff, you just say that and that's the end of it [450238]."

The fact that SA does not cost anything (and traditional services do) was also articulated by members.

> "If you'd like to join us, it doesn't cost anything [120103]."
>
> "Talk about it and other people will give them advice on how to deal with it. So it's like free counseling. That's what it's like, it's like free counseling [220202]."

And finally, within the theme of structural differences between SA and traditional services, some members indicated that SA is more available.

> "And I only see the doctor every six weeks so I need that weekly support. Sometimes I need it more than once a week, when I start feeling sad. So I need that weekly support that I get from hearing the group members' stories and their problems and fears [190213]."

> "It helps, it helps to have a place to go during the week because things come up, and I can't just call the doctor all the time or see her. I was seeing her once a week but sometimes in the middle of the week, you know, you need some support [280115]."

SA process is different.

The process is different between SA and traditional services and was the second theme that emerged in how members described how the setting characteristics are different between SA and traditional services. There were five sub-codes that emerged within this theme: (1) SA fosters shared experience; (2) SA is supportive; (3) SA fosters helper-therapy; (4) there is a level of closeness between members within SA; and (5) an ability to talk about their illness. Citations within each sub-code are not necessarily exclusive, meaning, some members spoke to only one sub-code, while others spoke to more than one of these. The majority of members identified that SA fosters a feeling of shared experience.

> "Because she [SA leader] also has a mental illness and she was very warm and a loving person. You know, I felt relaxed. Not just like a professional. See, she was like a peer, had been there, and that is the difference probably ...There's not just one type of schizophrenia anyway. You know, or clinical severe depression, because schizophrenics also share a lot of the same symptoms with one another so we can identify. And we've all gone to see doctors. We've all gone to Community Mental Health or have seen private psychiatrist or therapists. We've all had hospitalization and been on medication, so we all identify with one another...Then, you know, we would hash it all out. You know, you wouldn't feel alone. Like I would think is it just me that they're doing this to and they said no.......And helping to solve your problems and you didn't feel so isolated or alone, you know? ......I learned from other people that I'm not alone [120103]."

> "You're not alone...Well, we take medication. We all take medication. We don't work. We know how to deal with day to day not knowing we're going to have a job. And we're all on some type of public assistance, dealing with Medicaid and all

> this stuff. We're all seeing our doctors.... But this group, we were all having similar experiences. It was just nice that there was a place you could go to. And everybody kinda understood you and what you were going through [280115]."

As well, some members indicated that SA is more supportive than traditional services.

> "I'll call somebody from my meeting. I'll call them and talk to them and that always makes me feel better. Because even when I was able to call my therapist before, she was this old lady that was my therapist and really wasn't like a friend. But with the program I have people to call that are friends. Maybe they don't have all of the answers in the world but they are there for me if I need them and I know that they understand because they went through the same thing [100110]."

> "And it was run by a peer person and there's other peer people there. And they gave a lot of support to me which I needed, I needed all the support I could get. It was a very difficult time in my life. So I got a lot of support and love...you know, as little or as much as you like about yourself at that particular time of the day or week or month, what you're going through. And then we offer support and help, you know, as much as we can because we're not professionals [120103]."

SA also fosters helper-therapy (helping others is a form of therapy for the helper) which was not available to them in professional relationships.

> "I'm able to give them [SA members] advice, they're [SA members] able to give me advice [070105]."

> "I found it [SA] very helpful to me. And I found I could help others there, too [280115]."

> "I think I helped a lot of people. I know I've helped a lot of people. And a lot of people have helped me in return [350100]."

Some members highlighted that there's a distinguishable level of closeness between members within SA that does not exist with a traditional service provider.

> "They're [members of SA] a lot closer to me. The people here can get a lot closer than the doctor does, and the therapist or the treatment specialists or whatever [140211]."

> "Oh, yeah. We are more of a fellowship, people in our groups, if groups are working well, we become friends. We don't become friends with therapist [210100]."

Other SA members revealed that they are able to talk about their illness in SA which does not happen for them within the traditional services system.

> "Well, Schizophrenics Anonymous is where you can bring out your feelings better. But if you're with a mental health worker, all you talk about is you instead of schizophrenia...Like mental health helps people out, like giving them medication and stuff. But in a Schizophrenics Anonymous group, you get to talk about your problems and plus have people support you. At mental health all you got is your mental health worker and you talk to her or him and they don't, you know, really know... they know what you want to do but they kind of shy away [260214]."

> "Well, a lot of times, I don't know about others, well, yes, some of us, we're hesitant to say things to our doctors or workers. Because sometimes they tend to wanta... oh, you're going to the hospital, you're going to day care, you know. You don't really need that right then, you know...You just wanta discuss things and some things may be about family, you know...Maybe there's some empathy or more understanding of what you're going through [with SA]. Like I always say you never know until you go through it yourself. And a lot of people have a big distrust of doctors [280115]."

Finally, members identified that SA, as opposed to traditional services, was more able to help them in their recovery.

> "They [SA] seem to help me a lot more than anything else. Seems to be the best kind of therapy for me [140211]."

> "It was a smaller group, much smaller group, much smaller. And I found it was helping me much more....I found it very helpful to me [280115]."

SA addresses different aspects of recovery.

The third meta-theme to emerge under the dimension of differences is that some members were able to acknowledge and articulate that SA and traditional services address different areas of their recovery.

> "So it's not group therapy. If you want group therapy, you have to go to a clinic or a psychiatrist. Well, a psychiatrist gives you medication and talks about your symptoms. Therapists help you deal with emotional parts of it. And SA helps you, helps you talk about your problems [130115]."

> "My therapist, I would talk more about the family. I'd like to save the kind of personal, personal time and help with personal problems with the group and when

> it comes to family, I share that with the therapist because I don't want to tie up the time here [290202]."

> " [SA] Group is different from my social worker and case manager, in that, group is what can I say it is a somatizing experience. The body of our concerns seems to be there. The peak of my physical experience seems to be my social worker. The peak of my emotional experience seems to be my case worker. And they understand these things [480216]."

In conclusion, the dimension of differences between SA and traditional services captured a significant amount of attention in member interviews. Three meta-themes emerged: the knowledge base is different; the setting characteristics are different; and, members acknowledge different areas of responsibility for SA and traditional services. Please refer to Appendix F for a complete compilation of the citations from members regarding the differences between SA and traditional services.

Similarities

Of the three dimensions, the dimension of similarities was not articulated very clearly or frequently in the interview data. Very few SA members were able to articulate similarities between SA and traditional services. All of the interviews that identified similarities also addressed one or both of the other dimensions (differences and interactions) in their interview. Two themes emerged that identified similarities: structure and process. Though limited in depth and breadth, these members were able to draw some parallels between the two system.

Some members addressed similarities in the structure between SA and traditional services, albeit in very limited and specific ways.

> "They're similar in the way that we have a group and sometimes, and sometime not [0202011]."

> "Well, they do have steps. Most of them all share steps of some sort [120103]."

The process between SA and traditional services was identified as being similar by some members. Members felt that both systems provide opportunities for members to share and both systems provide support. Members identified sharing as a similarity in process between SA and traditional services.

> "...they're allowed to say what they feel. In other words, if they get their turn, if they don't get their turn, they won't say anything. And I guess the outpatient program I was going to was like a group, too, also. And we'd all sit around and say, and discuss, you know, well, I'm sit with this and I feel this way and I wanta do something about it [020211]."

> "I guess it's not a whole lot different from a group therapy session...everybody has their say and you get feedback and things like that [250210]."

Other members identified both systems providing support as a similarity in process between SA and traditional services.

> "It's all a support system for people [060104]."

> "Oh, I think it's probably very similar to other mental health establishments...well, it's in the method of their giving their affirmations and their comments during the meeting that I would imagine other mental health places offer the same type of thing [310210]."

Please refer to Appendix G for a complete compilation of the citations from members regarding the similarities between SA and traditional services.

Interactions

In examining how members view SA and traditional services as similar or different, data emerged revealed how members described any interaction that they believed to exist between SA and traditional services. Many members were able to articulate at least one area where they perceived an interaction between SA and traditional service. As with the similarities and differences dimensions, with one exception, these members addressed at least one of the other dimensions (similarities or differences) within their interview. These members were able to describe four ways (meta-themes) in which SA and traditional services interact: (1) SA provides information about traditional services; (2) SA provides information about medication; (3) SA encourages members to communicate with traditional services providers; and, (4) members recognize the need for both SA and traditional services. Citations within these categories are not necessarily exclusive, meaning, some members spoke to only one area, while others spoke to more than one.

SA Provides Information About Traditional Services

The first way that SA and traditional services were identified as interacting involves SA members saying that SA provides information about traditional services. Within this, some members mentioned getting information about interfacing with traditional services as well as information about available services.

> "Because they've had resources with certain agencies.....because they've had experience with agencies that have helped them with a certain problem [010211]."

> "How we handle Medicaid problems, medication problems. How we deal with our families. The way they deal with us, you know. Of course, the doctors, how we deal with them [280115]."

Other members indicated that information about available traditional services is provided to them in the SA group.

> "I guess I learn about different treatments constantly and I'm able to listen to different members' problems and I've learned a lot of information that I withdraw as needed, so I know I have tons, you know, recognizing different side effects and things like that, and that's from the experience [080102]."

> "Or I've got this problem with medication. I didn't know how to deal with it. Or when you go to the therapist and the doctor, you only get so much information and you only get so much time. But I think it's, one thing that really disturbed me, one thing that really kept me going with wanting to be in SA was I wanted to learn more about the different types of programs that were out there. Just in case I ever had a relapse. So I would know where to go. And more importantly, I wanted to learn, what was I gonna say? [350100]."

SA Provides Information About Medication

The second meta-theme that emerged within the interactions dimension is that SA provides an avenue through which to share information about medication. Within this, members mentioned the SA emphasis on medication compliance.

> "Because it [SA] keeps yo out of the hospital because they let you know that medication is very important....To always take my medication until my doctor wants to reduce or take me off it. By doing that, I'll stay out of the hospital...I believe the medication can be addictive but it might give me the common sense I need to keep me from doing what I did...Because it keeps you out of the hospital because they let you know that medication is very important [240210]."

> "In fact, the first step is I surrender, I admit I need help. I cannot do it alone. So we have to admit that we have the illness or a related illness and we need the help of other people. And I also explain that in SA we rely on professional help. And if the doctor wants it, we comply with taking medication. To keep our illness in remission [410140]."

Other members spoke to learning about different types of medication in SA.

> "Of course, we do get newsletters which have information about new medications and things. More about the illness, you know. What to expect down the road, that type of thing. As we grow older, do medications do to us and how the illness progresses and things like that [280115]."

> "I've gotten a lot of information from mental health association. I'm not as in the dark as I used to be...the varying ranges of symptoms and the ranges of medications and what people do to help themselves [200100]."

And finally, members indicated that they had a chance to participate in general discussions about medication and the side effects from taking medication.

> "We can even discuss medicines. We can discuss medicines even. And we can exchange ideas on medicine. I think it's fabulous...I really never accepted it. I always passed it off as medical until I came here...I was seeing all these doctors and getting all this medicine, I had no idea what was going on , why I was getting medicine or anything. And now I understand more and I'm open minded. And I like to help other people in a similar situation [290202]."

> "Medications come up also. We'll compare, oh, hey, you ought to be taking more of this or try this new thing, it's great. Well, he'll [leader] tell us go to this bookstore and get this information. He tells us who's in charge of the mental health

in the area and about hospitals, who to call about hospitals [340205]."

SA Encourages Members to Communicate with Traditional Service Providers

The third meta-theme within the interaction dimension that emerged from the data is that SA helps and encourages its members to communicate more effectively with traditional service providers.

> "One night, there was one man having a lot of problems with side effects. He was rocking and he was new to us too. And he was rocking and rocking and the whole group, the [SA] group, a couple of the guys jumped in and told him what he could say to the doctor, that he should tell his doctor, because there were things available to help him...I think we [SA] send people out more empowered to deal with their doctors and deal with their therapists and less intimidated by the diagnosis...ask questions and doubt. If you have a doubt, you're allowed to say so. They believe in medication but they don't, I interpreted it as we believe in medication but we also believe in...we encourage people to have frank discussions about the side effects...they [SA] don't just say it's wonderful, keep taking your medicine, and don't open your mouth and ask any questions, you know? So engage your doctor in frank discussions is encouraged by SA [080102]."

> "But the group encourage, when you have symptoms, the group will encourage to talk, to tell your doctor because a lot of us are afraid to tell our doctors. Like if you become suicidal, or we don't want to live, or we are having a severe side effect and we're afraid to tell our doctor, the group will encourage the person...Of course, a doctor gives the medicine and that's very important. Like I said, if the symptoms are strong or you have symptoms, we encourage them to tell the doctor. And we explain why [290202]."

Members Recognize Need for Both SA and Traditional Services

And finally, some SA members were able to articulate the need for both SA and traditional services in their recovery efforts.

> "It's the best of both worlds...well, one thing that an SA leader should never forget is that SA is an adjunct. You know, we have our limits. The treatment comes from the doctor but if you don't, I mean, you can be on the right medication, but if you've been sick your whole life and you don't know how to socialize. Coming to a group, I mean, you might be symptom free but we can give you pointers...we're like a supplement to their treatment but at the same time, we can offer a unique perspective because we've all been where they are at or have been. They can get unique advice from the inside which you won't be able to get from [the professionals]...we're a supplement to seeing your doctor or your other

> professionals [070105]."
>
> "And I don't think SA should ever try to do it all, I think it just should stay where it's at now...and, one thing that I learned from the doctors is that if you have side effects over two to three days, you should tell your doctor. I like to relay that story to my group, you know? And I like to think that they're both for each other, they're trying to make you a normal person, both of them working together. You know, you got your medication and you've got your health but you know, that's not gonna do it all for you. Just like going to SA is not gonna do it all for you. You need both. And I'm a firm believer in that [110103]."
>
> "But the keys I found out worked out was seeing my therapist, seeing my doctor to get my medication and coming to these meetings...If you listen to your therapist, listen to your doctor and come to group, this meeting, with all three of them combined, it really, I have forgot my past. I'm more focused on my present and future now. This gives me hope [300202]."

Please refer to Appendix H for a complete compilation of the citations from members regarding the interactions between SA and traditional services.

Within-Case Analysis

A within-case analysis was conducted to identify the patterns or relationships between an individual's background and experiences, their perceptions, and the description of their stories regarding the role of self-help and traditional services in their movement toward recovery. Case summaries have been written that identify the member's age, ethnicity, role within the organization (member or leader), length of participation in SA, number of hospitalizations and date of late hospitalization, living arrangements, source(s) of financial support, diagnosis, agreement (or not) with the diagnosis, sources of traditional support being utilized and their verbatim testimony regarding the similarities, differences, and interactions between SA and traditional services.

The case summaries were then sorted and examined, looking for patterns in the narratives. What emerged from the data is three types of stories: Some members had no story around the role of SA and traditional services in their recovery; some members had stories that clearly articulated the differences between these two systems of care; and, the third type of stories that emerged acknowledged differences between the systems, but also recognized that they needed both SA and traditional services in their recovery efforts. The summaries were grouped in this way because these were the clear distinctions that emerged within the data. While there was evidence of other dimensions in the data, they did not emerge in a consistent or clear way that would have contributed to our understanding of member stories. Please refer to Appendix I for all of the within-case summaries used in this analysis.

Personal narratives with no reference to SA and traditional services.

There were some members whose personal narrative did not include their perceptions or experiences on the role of SA and traditional services. When looking within each of these summaries, a couple of noteworthy points emerged. First, the majority of these members had been involved in SA for less than six months. This group did not represent a cadre of members who had been immersed in the SA ideology and culture but, rather, members who were generally new to the organization. Being relatively new to the organization, their exposure to the narrative has been limited and, in some ways, it's not surprising that these members didn't articulate a similar story.

All of these members were taking psychiatric medication. In addition, in all but one case, these members were also utilizing other forms of traditional mental health services. For many, this included living a group home, adult foster care, or a supervised apartment. They were also likely to be involved in individual or group therapy, day programming, and attended a drop-in center or clubhouse. These members were deeply embedded in the traditional mental health system, possibly sorting out what works for them, and what doesn't. The reality of multiple levels of involvement with the traditional service delivery system and one's relative newness to the self-help group is likely to have diminished their ability to see and articulate the similarities, differences and interactions between these systems of care. It is reasonable to assume that, over time, members will begin to develop their own personal narrative, and assess the relative degree of fit between their narrative and the narrative of SA, which may impact their membership in the organization and, of particular interest to this study, influence their utilization of traditional services.

Personal narratives that identified differences between SA and traditional services

Many members had personal narratives that focused primarily on differences between the two systems. Although some also identified ways in which the two systems of care were similar and/or how they interacted, the ways in which they were able to describe the similarities lacked depth and breadth, and their descriptions of the interactions emphasized how SA provides information about medications. The descriptions these members provided articulated many of the dimensions of difference that have been previously identified in professionally driven research and in consumer's personal stories. The differences include that SA is consumer led, members have control of the process, it promotes the exchange of shared experiences, is supportive, and fosters the concept of 'helper-therapy'. Members also identified some differences between these two systems that have not been previously identified in the literature. One of these dimensions is the ability to talk about their illness in SA, where members articulated that this is something they were unable to do within a traditional mental health service system. Being able to talk about such things as recovery, common problems, symptoms, and the side-effects of medications were noted as being possible in SA that were not otherwise afforded within the traditional mental health service system. Another dimension is that SA is more available to its members than traditional services tend to be, including the fact that it is more accessible, it is open to anyone, and it more flexible.

It is important to note that this group of people represents more than half of the interviews. This is a substantial number of people who articulated in a meaningful ways how these two systems of care are predominately different. When looking at these case summaries, clearly differentiated patterns or relationships did not emerge that would explain, a member's given perspective. A review of these summaries relative to such things as length of participation, roles within the organization, and utilization of traditional services revealed that this is a very heterogeneous group. Because there were a broad and disparate range of personal narratives represented in this group, their case summaries are not included here. The one dimension on which there existed commonality was that they were all taking psychiatric medication. This is and of itself is important. Here we have a large number of members of a self-help organization, where the organization encourages the utilization of traditional services, taking psychiatric medication. While this is a self-report item, and we have no way of really knowing if they are taking their medications, it is noteworthy that they all said that they were taking psychiatric medication.

It is not clear what factors or dimensions are at play in the construction of these members' stories. These members could be at a critical developmental juncture in their recovery programs. They are members of a self-help group that values the role of traditional services, they utilize traditional services in at least one way, and they recognize that SA is different in what it is able to contribute to their respective recovery 'package'.

As they begin to recognize the recovery package that best addresses their situation, which includes their personal narrative on the role of self-help and traditional services, their narrative may more closely align itself with the SA community narrative. A person whose personal narrative is more closely aligned with the narrative of SA is likely to begin to express it and continue to stay involved, perhaps even begin to consider leadership within the organization. A person whose personal narrative is not closely aligned with the SA narrative is not likely to feel as supported in their recovery and may not feel as supported in their recovery efforts.

Personal narratives that reflected a need for both SA and traditional services

There were case summaries that reflected a member's understanding of the differences between SA and traditional services. In addition, however, these members recognized and articulated that they needed both systems in their respective recovery programs. The personal narratives of these members articulated in multiple and distinct ways that these two systems of care are different yet they also recognized the need for both SA and traditional services in their lives. These members saw SA as supplemental to traditional services, that they needed something more than what traditional service was able to provide, and they likened it to being the best of both worlds. This is a very different story than that articulated in the previous interviews. It seems as though these members have clearly articulated that while these systems of care are different, they each address different aspects of their recovery and, in fact, they need both in order to continue moving forward in their recovery.

> 08 is a 42-year old Caucasian woman who is a leader of SA and has been attending SA for more than two years. She has been hospitalized two times, with her last hospitalization being in May of 1996 (one year). She lives independently and is supported through her earnings. She has been diagnosed with schizophrenia,

> agrees with the diagnosis, and takes psychotic medication. Beyond taking psychiatric medication, she does not participate in formal programming within the mental health system. 08 was one of the members who was able to articulate similarities, differences, and interactions between the two systems of care and she recognized the need for both SA and traditional services in her recovery efforts [080102].
>
> 28 is a 51-year old Caucasian woman who is a leader of SA and has been attending SA for more than two years. She has been hospitalized eight times, with the last hospitalization being in June of 1995 (two years). She lives independently and receives support through Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, she does not participate in any outpatient or day treatment services. She was able to articulate both differences and interactions between SA and traditional services, expressed that they address different areas of recovery, and that she needed both in her own personal recovery efforts [200115].
>
> 33 is a 35-year old Caucasian woman who is a member of SA and has been attending for more than two years. She has been hospitalized ten times, with the last hospitalization being in November of 1988 (nine years). She lives independently and supports herself through her earnings and Social Security Disability. She has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. She participates in therapy and receives case management services. She is one of the members who identified similarities, differences, and interactions between SA and traditional services, identifying that each system addresses different aspects of recovery and that she needs both in her own personal recovery efforts [330205].

This is a much smaller group of people than was captured in the previous group. When the case summaries for members whose personal narratives reflected a need for both SA and traditional services were examined more closely, a more homogeneous group emerged. While they each were utilizing varying levels of traditional services, each of these members, except one, had been involved with the organization for more than two years. Even that one member had been involved with SA for over15 months. These members also either lived independently, or with family, as opposed to more formalized living arrangements through the mental health system. They were also, except for one, leaders of a SA group. The member of SA who was not a leader was able to provide substantial and meaningful examples of the similarities, differences and/or interactions between these two systems, and acknowledged that she needed both in her recovery efforts. She was a member of a group whose leader subscribed to a similar perspective and demonstrated a comparable ability to articulate this story. This is the same member who had not been involved with SA for more than two years, but it is likely that her leader's strong articulation of the similarities, differences, and interactions accelerated her exposure to this narrative.

Clearly, there is a group of people who have a personal narrative that identifies that SA and traditional services are different, but of importance, take a necessary next step to acknowledge that they need both systems of care in their recovery programs. These members seem to have adopted the SA narrative as their own personal narrative and they tended to be leaders of groups or, in one instance, a member of a group with a strongly articulated narrative that valued the role of both SA and traditional services.

In summary, the results of the within-case analysis converged with the data that emerged through the content and cross-case analyses. There was very little attention or emphasis on similarities between SA and traditional services, most members were able to articulate differences between the two systems of care, and others recognized the need for both systems of care in their recovery efforts. This study provides preliminary support for the suggestion that the longer someone is involved with this organization, the more likely they will subscribe to or adopt the SA community narrative as their own. Extending this, recognizing that not every group is right for every person, members who's personal narrative does not evolve in a meaningful way so as to align themselves with the SA community narrative may, in fact, drop out of the group. These two perspectives are in concordance with the literature regarding the dynamic interconnectedness between personal narratives and community narratives (Rappaport, 1993). While these perspectives were beyond the scope of this study, the data suggests that further work in these regard is warranted.

Relative Degree of Fit Between Personal Narratives and the SA Community Narrative

For the study at hand, the content analysis revealed that the SA community narrative regarding the role of traditional services is one that supports and encourages its members to utilize traditional services. Data emerged within the cross-case analysis to converge with many of the themes from the content analysis which, in some instances, was corroborated by member's personal stories. This data is presented below.

The SA community narrative explicitly supported member utilization of traditional services. This explicit support was identified in their literature where the organization recognized SA as supplemental to traditional services,

> "S.A. is intended to be supplemental to professional help (Blue Book '94, pp. 3-4; Blue Book '97 p. 3)."

and by encouraging members to utilize traditional services,

> "Generally, SA has a three-part formula with regards to a group leader helping a member. It goes like this: 1) Strongly refer the member to a mental health professional, particularly the attending psychiatrist or the professional associates, 2) Do what you can do as an SA leader to provide the member with caring fellowship and support, and 3) Continue to refer the member to a mental health professional (Group Leader Circular, Mar 95)."

The cross-case analysis revealed convergent data on these two dimensions. With regard to SA being a supplement to traditional services, a member can be quoted as saying,

> "...we're like a supplement to their treatment but at the same time, we can offer a unique perspective because we've all been where they are at or have been...we're a

> supplement to seeing your doctor or your other professionals [070105]."

and another member speaks to how SA encourages members to utilize traditional services.

> "Well, I think that you can go to SA but you should always still be seeing a doctor for medication. And if you've really got it bad at that time in your life, you may need more healing and you may want to go to a person that you can talk to like a psychiatrist or somebody you can talk to who knows about the illness [330205]."

The SA community narrative also provided evidence of their implicit support for the utilization of traditional services by recognizing that SA is only one piece of a member's recovery,

> "Mission Statement: The mission of Schizophrenics Anonymous is to add the element of self-help support to the recovery process of people suffering from schizophrenia. (Blue Book'94, p.3; SA Forum, Fall '95; SA Forum, W '96, p.5)."

and, the literature often normalized a member's utilization of traditional services by acknowledging the existence of traditional services in the lives of its members and, in essence, giving permission and support for their inclusion in members' recovery packages.

> "S.A.'s Attitudes Towards Setbacks and Stigma: ...Hospitalization is for many a common setback. However, Schizophrenics Anonymous does not consider returning to the hospital, either voluntarily or otherwise, to be a personal failure or weakness. We believe it shows a realistic understanding of the limits imposed by our illness. The decision to return voluntarily to the hospital shows that we take full responsibility for our choices and that we choose to be well. At SA we feel that setbacks are a normal, expected part of our usually chronic illness. We view them as a temporary intensification of symptoms which will often pass. (Blue Book '94, p. 14; Blue Book '97, p. 11)."

The cross-case analysis revealed evidence of this implicit support as well. Regarding the theme that SA is only a piece of a member's recovery, one member made the following statement,

> "So it's not group therapy. If you want group therapy, you have to go to a clinic or a psychiatrist. Well, a psychiatrist gives you medication and talks about your symptoms. Therapists help you deal with emotional parts of it. And SA helps you, helps you talk about your problems [130115]."

while another member addressed the 'permission' given to members to utilize traditional services,

> "Learned from being in SA. The illness isn't totally catastrophic. You can get better. With support, with support. As an adjunct to your doctors, you know...well, we take medication. We all take medication. We don't work. We know how to deal with day to day not knowing we're going to have a job. And we're all on some type of public assistance, dealing with Medicaid and all this stuff. We're all seeing our doctors [280115]."

The SA organizational literature contained information about psychiatric medication and research on schizophrenia which are ways that the organization represents their commitment to educating members about traditional services. In multiple ways and across all organizational documents, the literature portrayed support for, and understanding of, the role for traditional services by educating its members about them.

> "We're subscribing to the best journals and newsletter in order to gather quality information for you: *American Journal of Psychiatry, Hospital and Community Psychiatry, Schizophrenia Bulletin, Harvard Mental Health Newsletter, The Menninger Letter, Psychiatry Drug Alerts*, and numerous others. Please think of ways to share this information with the members of your group and we'll make some suggestions on how to do this inexpensively in future months (Group Leader Circular, Feb '95).

This was corroborated by a member's account within the cross-case analysis,

> "Because they've had resources with certain agencies....because they've had experience with agencies that have helped them with a certain problem....and some have been in therapy longer. Have known about their illness for longer than I've known about mine. So they, they're able to help because of their experiences in that way [010211]."

Finally, the SA literature provided anecdotal support for members who successfully wove both systems of care into their recovery efforts,

> "Paul's Story: The [SA] group has helped me psychologically to fight my symptoms (voices), and the medicine does the rest (Blue Book '94, p. 24; Blue Book '97, p.19)."

and some members were able to articulate this same theme in their stories,

> "But the keys I found out worked out was seeing my therapist, seeing my doctor to get my medication and coming to these meetings...If you listen to your therapist, listen to your doctor and come to group, this meeting, with all three of them combined, it really, I have forgot my past. I'm more focused on my present and future now. This gives me hope [300202]."

The foregoing represents a considerable degree of convergence between the community narrative of SA and the data that emerged throughout these interviews. To a greater or lesser degree within members' personal stories, there is evidence of convergence as well.

We know from the within-case analysis that some members essentially had no personal narrative, or story, on the role of SA or traditional services in their recovery efforts. These members tended to be involved in multiple levels of traditional service delivery and had been with SA, and under the influence of its community narrative, for a shorter period of time (less than two years). Other members had a personal narrative that conformed to the community narrative with regard to recognizing the differences between the systems of care. These members were able to articulate SA is similar to, different from, and, in some instances, interacts with the traditional service system. Their perspectives tended to focus on how SA and traditional services were different and they viewed SA and traditional services as separate systems of care. However, there were some members whose personal narrative tended to conform more closely with the SA community narrative regarding the role of traditional services. Beyond being able to articulate the ways in which these systems of care are the same, different, or interact, these members recognized the need for both SA and traditional services in their recovery efforts. This latter group of members had been involved with SA longer, and they were either leaders of SA or a member of a group whose leader subscribed to and articulated a narrative along these same lines.

In summary, the content analysis revealed multiple ways in which SA, as an organization, supports its members utilizing traditional services. When the cross-case analysis was factored into the analysis, there was considerable convergence between the themes that emerged in the content analysis and the themes that emerged in the cross-case analysis. We know that, depending on the member, the relative degree of fit between a member's personal narrative and the SA community narrative varied. Even within this, the degree of buying into the SA narrative varied, where some members were able to clearly articulate the differences, and therefore beginning to converge with the SA community narrative, while another group of members not only identified the differences between the two systems of care, but even went so far as to talk about how they needed both SA and traditional services in their recovery. It is this latter set of personal narratives that achieved a parallel convergence with the SA community narrative.

Meeting the Criteria of Trustworthiness

With qualitative methodology, trustworthiness and authenticity replace traditional positivist criteria of internal and external validity (Lincoln and Guba, 1985; 1989). Within qualitative work, the four traditional criteria to judge the rigor of an inquiry (internal validity, external validity, reliability and objectivity) have been replaced by credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985; 1989).

Credibility is reflected in the degree to which thematic constructions and data interpretations match the participants' realities and the realities represented in the research conclusions (Lincoln and Guba, 1985; 1989), and there are several ways to achieve this. One way to achieve credibility is through prolonged engagement. This author has attended numerous different SA groups, group leader training conferences and has been involved with the organizational meetings, trainings, interviewing and analysis of a SA evaluation project within the Michigan forensic system for more than three years. Credibility was also promoted by engaging a disinterested peer to discuss the findings, tentative analyses and conclusions which facilitated my understanding of my role in the data analysis and drawing of conclusions. Another technique that was used to ensure credibility was the inclusion of negative case analysis. As previously described in reference to the SA community narrative, a negative case analysis was performed, looking for evidence of alternative ideologies regarding service use. There was no evidence in the content analysis to support a community narrative that spoke of SA as being an alternative to, or something to be used in the place of, traditional services.

According to Lincoln and Guba (1985; 1989), "member checks" are also an important technique for establishing credibility. A member check was carried out with three members of the organization in authenticating the interpretations of the data. Two of the members had been involved with SA for over five years, and the other had been involved for about two years. Each of them had held a leadership position within an SA group at one time, or were currently a group leader. The interpretations and findings of the cross-case and within-case analyses of this study were presented. Overall, there was a high degree of convergence on the interpretations and findings of this study, particularly along the dimensions of members' being able to share their stories and experiences, and the importance of medication. However, there were two issues that emerged from the member check process that were not captured in this study.

First, according to one of the members, SA performed a very important socialization experience. She told the story about how she knew that her behaviors were socially inappropriate. She expressed this in terms of communicating and interacting in a social situation. She indicated that attending SA was important because it taught her how to act and react in social situations. Because of her involvement in SA, she was able to share her experiences and learn from other members about social expectations and norms. She is much more comfortable, confident, and self-assured in social situations and credits this to SA.

Second, a member talked about the fact that schizophrenia does not seem to be popular, or a priority, amongst mental health professionals. When asked to expand, she felt that mental health professionals were fearful of people with schizophrenia, that professionals viewed people diagnosed with schizophrenia as being in dire situations, and that professionals were not familiar with the disease. She perceived professionals as unwilling to be trained in treating schizophrenia because it is such a debilitating illness and these same professionals were much quicker to tend to illnesses such as manic-depression and depression, implying that these illnesses were more treatable. These perceptions contributed to the stigma that the members felt accompanied a diagnosis of schizophrenia.

Overall, this member check process confirmed the credibility of the interpretations and findings of this study which is the most important technique to use in establishing credibility (Lincoln and Guba, 1989).

The second criterion with which to assess trustworthiness is transferability (Lincoln and Guba, 1985;1989). Transferability, which parallels external validity, is the extent to which conclusions drawn from this study are only transferred to other appropriate contexts. Transferability is facilitated by the participants being afforded an opportunity to provide, in their own words, a description of their particular social and individual contexts as well as the self-help setting within which this study was situated. The object in establishing transferability is to clearly establish the hypotheses for the present study, provide an extensive and careful description of the time, place, context and culture in which the hypotheses were salient. To transfer the findings of this study would require similar social, individual and setting contexts of the cases included in this study.

The third criterion with which to assess trustworthiness is dependability, which parallels reliability (Lincoln and Guba, 1985;1989). These were achieved by: 1) maintaining an extensive record of all the empirical data; 2) maintaining an extensive record of the data analysis techniques; and 3) maintaining a detailed record of all decisions of the author employed for the proposed study. So as to validate the appropriateness of the process, an independent auditor was secured to examine the data sources, the data analysis, and the interpretation processes.

Confirmability is the final criterion to assess trustworthiness and it is conceptualized as parallel to the conventional criterion of objectivity (Lincoln and Guba, 1985;1989). The goal with confirmability is to assure that the data, interpretations and outcomes have emerged separate from the researcher, meaning from the data, and are not evaluator constructed data. This means that the data have to be tracked to their sources and that the logic is both implicit and explicit in the narratives of the case studies. Confirmability has been achieved by maintaining and making available both the materials used for the study at hand and the processes used to analyze them.

Chapter 5

DISCUSSION, LIMITATIONS AND IMPLICATIONS

Overview

Over the past two decades, there has been increasing use of self-help groups by people with serious mental illness (Chinman et al., 2002). The findings from this study provide consumer perspectives on how self-help and traditional care are similar and different, and on how consumers integrate these sources of support to promote their recovery. The group's community narrative is discussed, and the findings suggest that in the group studied, the community narrative appears to influence members beliefs and behaviors. Study limitations and implications for social work practice, theory, research and policy are suggested.

Discussion

The findings of this study build upon the existing empirical literature and published consumer anecdotal reports that reflect how many mental health consumers utilize both traditional services and self-help, either simultaneously or sequentially, in their efforts to cope with their mental illness. The professional literature speaks to a consumer-driven approach to the utilization of professional treatment and self-help (Jacobs & Goodman, 1989; Kurtz, 1990; Lotery & Jacobs, 1994; Murray, 1996; Reissman & Carroll, 1995; Stewart et al., 1994). A consumer-driven approach supports the development of packages of services whereby people could build treatment plans that address their unique situations, and this approach places value on the individual contribution of different options. Within the published consumer literature, Bassman (2001) notes that 'many forms of self-help are supportive of and secondary to "expert" professional opinions" (p.

24). While there is growing empirical and consumer literature on the role of self-help and traditional services, the emphasis tends to be on the differences between the two systems of care. The present study took a different perspective.

The findings of this study advance existing literature by revealing, from a consumer perspective, how members utilize self-help and traditional services in their efforts to cope with their illness, how they view the similarities and differences between self-help and traditional services, and how they describe the contributions of these systems in their movement toward recovery.

Most of the literature about self-help, to date, has been written by professionals who have focused on how self-help groups have developed to provide a system of support for their members. The professional perspective is one that is steeped in the value of educational training and research, with a traditional emphasis on the medical model approach to diagnosis and treatment (Rappaport, 1993). This conception is not consistent with the self-help ethos that often rejects members' views of themselves as recipients of services, but rather adopts a new ideology and a transformation of identity, or sense of self.

In contrast, the findings of this study are grounded in consumer perspectives' of their experiences with these systems of care. It is important to add consumer perspectives to the understanding of self-help and service utilization for several reasons. First, these findings add perspective from consumers who utilize these systems and whose perspective is experiential, two dimensions largely absent in the current literature. In addition, this consumer perspective is consistent with the social work practice principles of self-determination and individualization. Recent policy and programmatic shifts in the delivery of mental health care, whereby consumers are being encouraged to become more active and involved in their care, require that we understand how consumers view their treatment and support experience. As such, their views of the services they are utilizing are important to capture. The absence of this consumer-centered approach to understanding self-help as a system of support has been a serious omission in the existing literature.

Consumer Perspectives on the Differences Between Schizophrenics Anonymous (SA) and Traditional Services

Previous literature has emphasized the differences between self-help and traditional services. The present study validates many of the key differences between self-help and traditional services that have been previously advanced, empirically and conceptually, by professionals or in anecdotal consumer reports. The findings presented here, from an empirical consumer perspective, validate our understanding of the differences between self-help and traditional services including: the ability to share experiences (Borkman, 1976, 1990); the promotion of the 'helper-therapy' process (Reissman, 1965); as well as the identification the effective mechanisms of self-help groups such as experiential knowledge (Borkman, 1976; 1990); indigenous leadership (Reissman & Carroll, 1995; Schubert & Borkman, 1991), voluntary participation (Kurtz, 1997), lack of professional involvement (Kurtz, 1997), and social support (Maton, 1988; Roberts et al., 1999; Salem et al., 2000).

In addition to these previously discussed characteristics, members identified two important differences between self-help and traditional services that have not previously been addressed in the literature. The first of these is being able to talk about their illness in SA in a way that they cannot talk in more traditional therapeutic settings. The sense of closeness and safety to talk about their illness, particularly with a group of people with the same illness, is valued by consumers. Being able to talk about their illness provides consumers with the support that they need to make sense of their illness, their treatment, and their recovery. Members report that this opportunity is frequently not available in traditional settings.

The second difference centers around the relaxed nature of the SA meetings. Previous literature reported that SA is more available and accessible to members (Kurtz, 1997), which is a structural dimension. The findings of this study support this. However, what emerged as unique within the findings of this study is that members often spoke about how SA is more relaxed and the meetings have an easy-going nature to them. SA is not only more available and accessible to members, but members also expressed an appreciation for the fact that it was a less structured experience, more relaxed and easy-going. In this regard, it was more welcoming to members. With this in mind, members recognized that SA provides something unique and different from the other support that they have been receiving in traditional settings.

Consumer Descriptions of the Interaction between SA and Traditional Services

Previous literature has tended to emphasize the differences between self-help and traditional services (Leiberman, 1979; Levine, 1988; Maton, 1988; Powell, 1975; Reissman, 1965; Roberts et al., 1999; Salem et al., 2000). It also focused on professional involvement in self-help groups (Ben-Ari, 2002; Cherniss & Cherniss, 1987; Leiberman, 1979), and professional attitudes and referral patterns of patients to self-help groups (Humphreys, 1999; Powell, et al., 2000) . While this literature has advanced our understanding the differences between these systems of care, it has failed to address how self-help members incorporate the utilization of traditional services in their recovery efforts, especially with regard to first-person accounts of their experiences within and between these systems of care.

Although the findings of this study clearly articulate differences between self-help and traditional services, an important advance is that participants describe the use of self-help in conjunction with other sources of support in their recovery efforts. The findings of this study demonstrate how participants talk about both of these systems as being important to them, and they describe the ways in which the systems interact in their recovery. SA is described as providing information about traditional services, providing information about medication, and encouraging members to communicate with traditional service providers. The findings suggest that SA helps members to utilize traditional services more effectively by giving them information and strategies for dealing with traditional service organizations.

In speaking to the ways in which they use self-help in conjunction with traditional services, some members recognized the need for both SA and traditional services in their lives and were able to articulate this in their personal stories. These members described how they drew upon the strengths of each system, based on their individual circumstances, and integrated them in such a way as to describe their recovery as fuller, more complete. This is consistent with McGuire (1988) who argued that people find many different ways to create 'packages' of services that draw upon multiple sources of help, self-help and traditional services among them. Taken together, these findings contribute to our understanding of how some mental health self-help group members utilize self-help and traditional services in their efforts to cope with their illness, how they view the similarities and differences between self-help and traditional services, and how they describe the

contributions of both systems in their movement toward recovery.

In summary, the findings of this study also highlight that these two systems, traditional care and self-help, are different by way of the support that they offer and the manner in which they offer their support. This is important to our understanding of how consumers see self-help groups as similar to, or different and unique from, traditional care, as well as how they integrate self-help with traditional care. While most previous research looked from the perspective of professional treatment providers and their systems, this research adds the consumer perspective to our understanding by describing their use of these systems.

Again, it is important to emphasize that one of the major findings of this study is that members talk about both of these systems as being important to them and describe the ways in which the systems interact in their recovery. This expands previous professional literature that recognized compatibility between self-help and traditional services serving substance abusing patients (Humphreys, 1999). Through the findings of the present study, member descriptions of the differences were highlighted. In addition, many members reported that their participation in this self-help group encouraged their utilization of traditional services, and that their participation in SA assisted them with the integration of traditional services. For these members, not only did SA, in its difference from traditional services, add a dimension of support previously missing, it also assisted them in utilizing traditional systems and encouraged their utilization in a more effective way.

At this juncture, it is important to reiterate the fact that self-help and traditional services are distinct systems of care, each with its unique strengths and relative limitations. Indeed, the consumer perspectives represented in the findings of this study acknowledge that these are different systems of care and that consumers can benefit from both. As social workers, it is important to recognize and respect how consumers are describing their experiences as well as to recognize that self-help groups are in a position to provide a level of support that consumers may not have previously experienced. However, it is equally important to recognize that for many consumers, their participation in self-help groups may encourage them to interact with the traditional service delivery system, particularly to take medication, and may make them more effective consumers (Hodges, et al., 2003). This finding enhances our knowledge and understanding of the unique role that self-help groups and traditional services can jointly play in consumers' lives.

The Role of Community Narratives

The findings of this study suggest that community narratives may indeed influence the personal narratives and behaviors of setting participants. When examining the founding member's personal narrative, the resulting community narrative, and members' personal stories, there are consistent messages about how SA is supplemental to traditional services; the value of traditional services, particularly medication; and that members are encouraged to utilize traditional services. Although causality cannot be determined based on the design of this study, there is support in the findings to suggest that members' length of time in the organization may contribute to the convergence of their personal stories with the community narrative. This is consistent with the narrative theory that has been previously advanced (Rappaport, 1993) that posits that community narratives influence personal stories. The SA community narrative is communicated clearly and consistently within the organization, and for some members who remain involved with the organization over time it is articulated in their personal narratives. While the degree to which members articulated the need for both SA and traditional services varied, the fact that they were all taking psychiatric medication speaks to the potential for reciprocal influence between the SA community narrative and patterns of traditional service utilization. However, these findings are derived from the present research, which is one of the first studies that actually looked at community narratives and personal narratives with an eye towards convergence. What is still not clear and therefore requires further study is the nature of the causal relationship between members' personal narratives and the community narrative of a group.

In summary, this study has shown that in members' descriptions of SA and traditional services, many of the previously identified differences advanced by professional and published consumers reports between the two systems converged with member perceptions and experiences. However, member descriptions also went on to reveal that they integrate both self-help and traditional services in their efforts toward recovery. The findings of this study also suggest that community narratives may influence the personal narratives and behaviors of setting participants. This influence is communicated clearly and consistently within the organization, and the suggestion that exposure to this narrative over time may influence a member's personal narrative, beliefs, and behavior is advanced.

Thus, this study provides an understanding of how a particular self-help group, SA, views the role of traditional services and the importance of a community narrative. However, it is clear from existing resources that all self-help groups do not have this same narrative. Quite the opposite is the case. Some self-help groups might adopt a much more critical approach, discouraging members from utilizing traditional services. Others could be neutral on the role of traditional services. While all settings have narratives, social workers need to be conscious of self-help groups within their communities and have an understanding of what messages these groups are communicating to their members. This will enable them to be more informed in making appropriate referrals and linkages for their clients.

Limitations and Boundaries

The purpose of this study was to describe and understand consumers' perspectives on the role of SA and traditional services, and to understand the role of the SA community narrative in shaping that understanding. As such, this study did not attempt to examine what SA and traditional services mean to all people with schizophrenia. The participants in this study chose to participate in SA, a voluntary self-help group that values the role of traditional services in members' recovery from schizophrenia. Therefore, it would be inappropriate to generalize these findings to other people with schizophrenia, especially those who may not be participating in SA, or may be participating involuntarily, such as those committed to psychiatric institutions or in mandatory treatment programs. The other inappropriate generalization of these findings would be to people who are members of other self-help groups.

Beyond this, although there is preliminary support for the influence of community narratives on the personal narratives and subsequent actions of its members, it is important to recognize that the direction of causality cannot be inferred. It is possible that members who do not agree with the community narrative are not joining or are dropping out of SA. The findings that members' length of time in the group is related to their personal stories, or narratives, suggests that the community narrative may influence the personal narratives over time. Nonetheless, the design of the study, its primary focus, and data analysis efforts were intended to understand more completely the phenomena of community narratives and the potential that may exist for these narratives to influence their members. In order to establish a causal relationship between a community narrative and a personal narrative, longitudinal studies are necessary.

In addition, this study was based on a secondary data analysis which did not have understanding the role of SA and traditional services in the lives of people with schizophrenia as its primary focus. A study with this as its primary focus may have elicited more in-depth understanding of the phenomena. However, one of the primary foci of the larger evaluative study was to understand consumer experiences with SA. Therefore, although not its primary purpose, member experiences with SA were relevant and meaningful.

Finally, my own biases must be taken into account because they helped shape the decisions that I made when designing and executing this study, including how I choose to understand the data that emerged. Although precautions were taken as prescribed in the section on authenticity and trustworthiness, it is reasonable to assume that someone else might have chosen to do this study in a different manner. However, the precautions that I employed to safeguard the conclusions of this study give me confidence that the results presented here could have been reached by other investigators. These results can be of assistance to individuals with schizophrenia as well as to professionals and programs that interface with consumers diagnosed with schizophrenia.

Implications

Implications for Social Work Practice

As professionals, social workers are often involved in referring or linking clients to treatment options, including self-help groups. Social workers may be providing services to someone who already has an established connection to a self-help group. The findings of this study provide consideration for the implications for social work practice. These implications are consistent with Kurtz (1997) who considers being knowledgeable about self-help organizations the first obligation of practitioners. This knowledge can be increased, specifically, with the following implications:

1) Social workers need to recognize that self-help and traditional services are different systems of care, each possessing consumer identified strengths and limitations.

2) Social workers need to recognize that some people can, and do, use self-help in conjunction with traditional services and consider both to be important ingredients in successful recovery efforts.

3) Social workers need to be aware of the importance that self-help groups can play in a client's life and tend to this during assessment and when developing and monitoring a client's treatment plan.

4) Social workers need to be aware that community narratives of self-help groups vary; because of this, they are encouraged to become familiar with the self-help groups within their communities and with the narratives that they impart to their members.

5) Social workers should be cognizant of the level of influence that a self-help

group may have on clients' treatment compliance, particularly as it relates to medication.

6) Social workers should be careful about the messages that they are sending regarding the role and utilization of self-help groups (mental health or otherwise) in peoples' lives and/or the interaction between self-help and traditional services.

7) Social workers are encouraged to explore the role of self-help groups in clients' lives. Current and emergent literature will challenge our traditional conceptions of the role and influence of self-help groups in clients' lives.

8) Providing information and education to a client about self-help groups encourages self-determination and recognizes the inherent dignity of each client.

Theoretical Implications

Within social work education, human behavior in the social environment courses provide both foundational (baccalaureate) and advanced (master's) knowledge and skills to understand human systems and corresponding environmental contexts. Social work is dedicated to a holistic approach to service delivery and often delivers services with a multi-disciplinary perspective.

The findings of this study provide theoretical support for the role and value of both self-help and traditional services in clients' lives. In addition, this study begins to document the range of ways that self-help groups view traditional services. The findings of this study provide theoretical support for the role and value of community narratives. These findings support work previously advanced by Rappaport (1993), who advanced the notion that self-help groups are communities for living and, as such, develop a narrative, or story, that reflects the group's goals, beliefs and philosophy. As members of a self-help group, consumer are exposed to this ideology and, based on their experience, begin to incorporate the interconnectedness between their own personal story and the community narrative. An examination of the role of the self-help group over time in the life of a person with schizophrenia could further enhance our understanding of this system of care. The study's findings also converge with a policy and programmatic shift in the delivery of mental health care whereby consumers are being encouraged to become more active and involved in their care. This more empowerment oriented approach allows for a self-help group to contribute a level of support that may not have been previously experienced by a consumer, while at the same time assisting them in managing multiple support systems and utilizing them more effectively. This perspective is likely to shape and influence the service delivery system for mental health consumers. Finally, in that self-help groups are, in fact, groups, they experience stages development. The impact of a group's developmental stage on clients, and on clients at different stages of recovery, would provide even further refinement to our understanding of the role of self-help groups.

Implications for Further Research

Research on self-help groups has progressed over the past 20 years (Kurtz, 1997). This research has covered such areas as quasi-experimental outcome evaluations, observations of group processes and ideologies, and descriptions of community self-help organizations (Leiberman and Borman, 1979). Other research has focused on professional relationships with self-help groups and the helping processes within self-help groups (Kurtz, 1990a). More recent studies assessed worldviews and ideologies (Kennedy & Humphreys, 1995), international and multicultural phenomena (Lavoie, Borkman, &

Gidron, 1995), and factors that contribute to self-help group affiliation and participation (Luke, Roberts, & Rappaport, 1993; Kurtz et al., 1995; Powell et al., 1995). As previously indicated, most previous literature has emphasized the differences between self-help and traditional services.

The findings from this study, however, suggest that not only are consumers recognizing significant ways in which these two systems are different, they are also describing how these systems interact in their lives. In addition, the findings from this study suggest that community narratives matter to people within that given community, and that these narratives tend to influence members' thoughts, beliefs and actions over time. However, many questions remain unanswered. Further research could include examination of the following issues:

1) a study of other self-help community narratives regarding the role of traditional services and how they are communicated;

2) the stage of a self-help groups' development and its impact on a clearly articulated community narrative;

3) the effect of a self-help group's developmental stage on the members' personal narratives and their utilization of traditional services;

4) the effect of a community narrative on a personal narrative over time; and,

5) an examination of the group processes that facilitate the adoption of a community narrative.

Two research endeavors are of particular interest. What was suggested but not answered in the findings of this study is whether community narratives are changing people or whether people are selecting groups based on their narratives. Only a multidimensional study can address this question. In addition, further study across self-help groups, of what they believe and how this gets communicated, would increase our understanding of the range and variety of narratives that exist.

Implications for Policy

The findings presented above recognize that within mental health, consumers are integrating self-help support into their recovery plans. Beyond this, in general, many people access self-help at one point or another, to address a need or problem in their lives. These findings recognize both the importance of self-help in people's lives and the fact that self-help can interact with traditional service delivery. Contributing to the literature on community narratives advanced by Rappaport (1993), the findings made clear that one of the things that may influence member utilization of traditional services is the particular group's community narrative.

The challenges to social work include developing program and policy language that recognizes and encourages the incorporation of self-help groups, while simultaneously respecting the different role that self-help and traditional services play in a consumer's life and not usurping the ideological premises upon which each were built. This is indeed a difficult balance to maintain, but nonetheless worthy of consideration.

Within this is the recognition that, as an adjunctive service delivery system, the role of a self-help group in a person's recovery should be more clearly communicated to the traditional service delivery providers. This is particularly relevant when, as was found in this setting, a self-help group supports its members in utilizing traditional services and encourages compliance with traditional services (i.e., medication). Incorporating this consumer perspective in the education and training of medical and mental health professionals is a logical next step. The objective would be to increase their knowledge of the multiple service systems accessed by consumers and how they view these sources of support as necessary ingredients to their ongoing recovery efforts. Ultimately, the hope is that these professionals will convey this new knowledge on to their patients.

Conclusion

This study has brought the consumer perspective to our understanding of the similarities and differences between self-help and traditional services. There are three major findings. First, consumers' reports converge with previously identified differences between self-help and traditional services advanced by professional literature and published consumer reports. Second, descriptions from members of SA revealed that they integrate both self-help and traditional services in their efforts toward recovery. Finally, the findings suggest that community narratives influence the personal narratives, beliefs, and behaviors of self-help group participants.

Looking forward, this study suggests questions that the field may want to examine in regard to other population groups, such as those dealing with substance abuse and gambling addiction. Such studies would help to reveal the consumer perspective of these impacted individuals, a voice frequently missing in the literature. This future research agenda reflects the greater role for self-help and other client driven services in members' recovery anticipated in the coming years. As our understanding of the role of self-help and traditional services in members' lives increases, so too will our ability to assist clients by better understanding the role of self-help in their lives, being cognizant of the messages we impart about self-help, being familiar with the community narratives of self-help groups within our communities, and making appropriate referrals to self-help groups for our clients.

APPENDICES

APPENDIX A

APPENDIX A

April 30, 2003
TO: Deborah SALEM
Department of Psychology
PSYCH Research Building

RE: **IRB # 02-388** CATEGORY: 1-4 EXEMPT
RENEWAL APPROVAL DATE: March 19, 2004
EXPIRATION DATE: February 19, 2005

TITLE: CONSUMER PERSPECTIVES OF THE PERCEIVED SIMILARITIES/DIFFERENCES .BETWEEN SCHIZOPHRENICS ANONYMOUS AND TRADITIONAL MENTAL HEALTH SERVICES

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete and I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the **UCRIHS APPROVED THIS PROJECT'S RENEWAL**.

RENEWALS: UCRIHS approval is valid until the expiration date listed above. Projects continuing beyond this date must be renewed with the renewal form. A maximum of four such expedited renewals are possible. Investigators wishing to continue a project beyond that time need to submit a 5-year renewal application for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If ttiis is done at the time of renewal, please include a revision form with the renewal. To revise an approved protocol at any other time during the year, send your written request with an attached revision cover sheet to the UCRIHS Chair, requesting revised approval and referencing the project's IRB# and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements thatare applicable.

PROBLEMS/CHANGES: Should either of the following arise during the course of the work, notify promptly: 1) problems (unexpected side effects, complaints, etc.) involving human subjects 2) changes in the research environment or new information indicating greater risk to the human than existed when the protocol was previously reviewed and approved.

If we can be of further assistance, please contact us at 517 355-2180 or via email: ucrihs@MSU.EDU

Sincerely,

Ashir Kumar, M.D.
UCRIHS Chair

APPENDIX B

APPENDIX B

Schizophrenics Anonymous Study Consent to Contact

Dear SA Member:

As part of our effort to understand the experience of participating in Schizophrenics Anonymous we are interested in conducting interviews with SA members. These interviews will be arranged with a member of the Michigan State University (MSU) research team and will involve questions regarding your living situation, employment and social activities, history of mental illness and treatments received, life satisfaction, and participation in SA. These interviews will be approximately 1 ½ to 2 hours in length and will be audiotaped. Those who participate will be reimbursed $10 for their time.

Unfortunately, due to limited time and resources, we will not be able to interview all members of SA. Instead, we will randomly select a group of SA members to interview. If you would be willing to participate in an interview, please complete the information requested below.

Voluntary Participation Your participation in this study is voluntary. You may choose not to fill out this form. There are no penalties to you or your group if you choose not to participate. You may also choose to withdraw from our study at anytime without penalty.

Confidential Participation The MSU research team will use data collection and data reporting procedures that will ensure that your participation in the study will be kept confidential. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any research reports. Instead, ID #'s will be used. All information about SA members (including this form) will be stored in locked facilities at MSU.

By completing this form and returning it to a member of the MSU research team, you indicate your voluntary agreement to participate in an interview. If you have any further questions about this study, please call Dr. Deborah Salem or Dr. Thomas Reischl at Michigan State University at (517) 353-5015.

Name ____ Gender ________________

Phone # ___________________________________Age _______________________

Best time to reach ________________ SA Group __________________

Date of 1st SA meeting __________________

Signature ________________________________Date _______________________

Schizophrenics Anonymous Study Consent Form

Established SA Group Leaders

Purpose of the Study

Some of the primary questions of this study are: "How does SA develop new group leaders?" and "How does SA engage new members?" To address these questions, the research team at Michigan State University (MSU) will be collecting information from a variety of sources. The sources include interviews and observations with employees of the Mental Health Association in Michigan (MHAM) and with organizational leaders from Schizophrenics Anonymous (SA) and with SA group leaders in regions where SA groups have already been established and with SA group leaders in regions where new SA groups are being established.

Procedures

Interviews with New SA Group Leaders in Established SA Regions. New SA leaders will be invited to participate in one 60-90 minute interview during their first year as a group leader. These interviews will focus on progress and problems with starting and maintaining the SA groups and the impact of the weekly meetings on group members. These interviews will also cover the leaders' living situation and psychiatric service use. These interviews will be audiotaped. At the completion of this interview, the group leader will receive $10.

Interviews with Experienced SA Group Leaders in Established SA Regions. Experienced SA leaders will be invited to participate in one 60-90 minute interview. These interviews will focus on progress and problems with starting and maintaining the SA groups and the impact of the weekly meetings on group members. These interviews will also cover the leaders' living situation and psychiatric service use. These interviews will be audiotaped. At the completion of this interview, the group leader will receive $10.

Voluntary Participation

Your participation in this study is voluntary. You may choose to not participate in any part of this study. You may choose to not participate in this study at all. There are no penalties to you or your organization should you choose not to participate in any or all of the data collection activities described on this consent form. During an interview, if you wish to stop for any reason, the interview will end.

Confidential Participation

The research team at Michigan State University will use data collection and data reporting procedures that will protect the confidentiality of your participation in this study. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any research reports. Instead, ID codes will be recorded on all interview forms and only pseudonyms or identified roles (e.g., group leader) will be used for reporting the results of this study.

Potential Risks and Benefits

There are very few risks from participating in this study. Interviews will require your time, but these procedures can be done at your convenience. The observations of organizational events require no extra time. The interviews will be of reasonable length--

no more than 90 minutes. Interviews will end early if the participant becomes tired or wishes to end the interview for any reason.

Since identifying information such as the person's gender, age, and the group leader role may be recorded and reported, there is a chance that you could be identified in the research reports. There is little risk that you could be personally identified by anyone outside the MHAM or SA organizations. The risk of personal identification, however, is reduced because the research team will only use ID numbers, pseudonyms, or role designations in data records and in reports. And all data records will be stored in locked facilities at MSU.

The potential benefits to participating in this study include having an opportunity to reflect on one's participation in the organizational expansion efforts of Schizophrenics Anonymous. Participation in the study will also help ensure that your experience related to SA's expansion will be more accurately recorded and interpreted. The agencies involved in this study could also benefit from helping the MSU research team because the reports on expansion efforts of SA could help guide future expansion efforts.

Consent to Participate

By providing your name, address, telephone number, and signature below, you show (a) your complete understanding of the information in this consent form and (b) your voluntary consent to participate in the research activities described in this consent form.

Print Your Name: ______________________ Telephone #: __________________

Print Your Address: _______________________
____

Your Signature: _______________________ Date: ___________

Witness Signature: _______________________ Date: ___________

Schizophrenics Anonymous Study Consent Form

New SA Group Leaders

Purpose of the Study

Some of the primary questions of this study are: "How does SA develop new group leaders?" and "How does SA engage new members?" To address these questions, the research team at Michigan State University (MSU) will be collecting information from a variety of sources. The sources include interviews and observations with employees of the Mental Health Association in Michigan (MHAM) and with organizational leaders from Schizophrenics Anonymous (SA) and with SA group leaders.

Procedures

Telephone Interviews with New SA Group Leaders. Members of the MSU research team will conduct weekly telephone interviews with SA group leaders involved in the SA expansion effort in Central Michigan. The weekly telephone interview will focus on recording attendance at the most recent SA meeting(s) and other issues related to the maintenance of the SA group.

Face-to-Face Interviews with New SA Group Leaders. Roughly 3-4 weeks after a new group leader begins leading a new SA group, they will be invited to participate in a 60-90 minute interview. New group leaders will also be invited to participate in similar follow-up interviews roughly 6 months and 12 months after a new group begins. These interviews will focus on progress and problems with starting and maintaining the SA groups and the impact of the weekly meetings on group members. These interviews will also cover the leaders' living situation and psychiatric service use. These interviews will be audiotaped. At the completion of each interview, you will receive $10 for your assistance.

Voluntary Participation

Your participation in this study is voluntary. You may choose to not participate in any part of this study. You may choose to not participate in this study at all. There are no penalties to you or your organization should you choose not to participate in any or all of the data collection activities described on this consent form. During an interview, if you wish to stop for any reason, the interview will end.

Confidential Participation

The research team at Michigan State University will use data collection and data reporting procedures that will protect the confidentiality of your participation in this study. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any research reports. Instead, ID codes will be recorded on all interview forms and only pseudonyms or identified roles (e.g., group leader) will be used for reporting the results of this study.

Potential Risks and Benefits

There are very few risks from participating in this study. Interviews will require your time, but these procedures can be done at your convenience. The observations of organizational events require no extra time. The interviews will be of reasonable length--

no more than 90 minutes. Interviews will end early if the participant becomes tired or wishes to end the interview for any reason.

Since identifying information such as the person's gender, age, and the group leader role may be recorded and reported, there is a chance that you could be identified in the research reports. There is little risk that you could be personally identified by anyone outside the MHAM or SA organizations. The risk of personal identification, however, is reduced because the research team will only use ID numbers, pseudonyms, or role designations in data records and in reports. And all data records will be stored in locked facilities at MSU.

The potential benefits to participating in this study include having an opportunity to reflect on one's participation in the organizational expansion efforts of Schizophrenics Anonymous. Participation in the study will also help ensure that your experience related to SA's expansion will be more accurately recorded and interpreted. The agencies involved in this study could also benefit from helping the MSU research team because the reports on expansion efforts of SA could help guide future expansion efforts.

Consent to Participate

By providing your name, address, telephone number, and signature below, you show (a) your complete understanding of the information in this consent form and (b) your voluntary consent to participate in the research activities described in this consent form.

Print Your Name: ______________________ Telephone #: __________________

Print Your Address: ______________________

____

Your Signature: ______________________ Date: ___________

Witness Signature: ______________________ Date: ___________

New Member Interviews

Purpose of the Study

The research team at Michigan State University is conducting a study to learn about how participation is SA groups affects the group members. The research team is especially interested in learning about (a) why members become involved in the groups and (b) how participation is SA is related to changes in members' life situations and self-understanding.

Procedures

Each member will be invited to participate in three interviews. If the member agrees, the first interview will occur two or three weeks after the member joins the SA group. The second interview will occur six months after the first interview and the third interview will occur 12 months after the first interview. The research team would like the members in this study to participate in all three interviews even if they are no longer active members of SA at the time of the follow-up interviews.

Each interview will probably take about 60 to 90 minutes. The interviews include questions about the member's living situation, employment and community activities, experiences with psychiatric services, understandings of their mental illness, social activities, life satisfaction, and participation in SA. When the interview is finished, the participant will received a $10 reimbursement for their time.

Voluntary Participation

Your participation in this study is voluntary. You may choose to not participate in any part of this study. For example, you may choose not to answer any question in the interview. You may choose to not participate in this study at all. There are no penalties to you or to SA if you choose not to participate in this study. During an interview, if you wish to stop for any reason, the interview will end.

Confidential Participation

The research team at Michigan State University will use data collection and data reporting procedures that will protect the confidentiality of your participation in this study. Personal identities of the participants in this study will not be recorded on data records and will not be reported in any research reports. Instead, ID codes will be recorded on all interview forms and only pseudonyms or identified roles (e.g., group leader) will be used for reporting the results of this study.

Potential Risks and Benefits

There are very few risks from participating in this study. Interviews will require your time, but they can be done at your convenience. The interviews will be of reasonable length--no more than 90 minutes. Interviews will end early if the participant becomes tired or wishes to end the interview for any reason.

Since identifying information such as the person's gender, age, and the group role may be recorded and reported, there is a chance that you could be identified in the research reports. There is little risk, however, that you could be personally identified by anyone outside the SA organization. The risk of personal identification, however, is reduced because the research team will only use ID numbers, pseudonyms, or role designations in data records and in reports. And all data records will be stored in locked facilities at MSU.

The potential benefits to participating in this study include having an opportunity to reflect on one's participation in the Schizophrenics Anonymous groups. Participation in the study will also help ensure that your experience in the group will be more accurately recorded and interpreted.

Procedures for Contacting You

When the research team contacts you to arrange for the interviews, procedures will be used to protect the confidentiality of your involvement in SA. For example, any letters sent to you will not include reference to SA on the outside envelope and we will not mention SA if we need to leave messages for you.

To help the research team know the best way to contact you if you move or change your telephone number, it would be very helpful if you would provide names, addresses, and phone numbers of two people who would know how to contact you in the future:

Contact Person: ______________________
Address: ______________________
____
Telephone: ______________________

Consent to Participate

By providing your name, address, telephone number, and signature below, you show (a) your complete understanding of the information in this consent form and (b) your voluntary consent to participate in the research activities described in this consent form.

Print Your Name: ______________________ Telephone #: ____________________

Print Your Address: ______________________

Your Signature: ______________________ Date: ____________

Witness Signature: ______________________ Date: ____________

APPENDIX C

APPENDIX C

MEMBER INTERVIEW

1. Date_____________________
2. Member ID__________________
3. Interviewer ID________________
4. SA Group ID ________________

Before beginning interview:
a) Discuss confidentiality.
b) Go over and sign consent form.

Directions to interviewer:

Allow member to "tell their story", as they touch on the areas outlined in prompts, check each one. When they are done with their story, ask them any prompt questions which they have not yet discussed.

SA INVOLVEMENT

I would like to begin our interview with a discussion of your experiences in Schizophrenic's Anonymous. I am interested to hear your views about SA as an organization, as well as your own personal involvement in SA and how this has influenced you.

5. First, I would like to hear the story of your involvement in SA. I would appreciate it if you could go back to the beginning, when you first heard about SA and tell me the story of how you became involved.

    ___ Who told you about SA? Had you heard about SA before?
    ___ When did you attend your first meeting? Why did you think it would be helpful? How did you feel on your way to the meeting?
    ___ What were your first thoughts/impressions of SA? How did you feel at the meeting? Did you talk? What did you think of the leader? Did they greet you? After the meeting did you share the experience with anyone?
    ___ Basic chronological flow of involvement.
    ___ What was a typical meeting like? (Structure, what kinds of things would people talk about?)
    ___ Why do you think you have stayed involved?
    ___ Have you ever attended any other SA meetings?

6. Have you been involved in any SA activities outside of attending your group?
    ___ retreat
    ___ social events

7. What have you liked the most about your experience in SA? What about being in SA has been the most helpful to you? What would you say you have learned from being in SA?
    ___ support
    ___ friendship
    ___ information about schizophrenia
    ___ six steps
    ___ spiritual component

8. Have there been things about being a member that have been difficult or less satisfying?

9. *Referent Power*
Do you feel that you have a lot in common with other SA members or leaders? If yes, what are the most important things you have in common? How is this helpful in a self help group like SA?

10. *Experiential Knowledge*
a) In what ways are other SA members and leaders best able to help you? What types of things can they best help you with?
___ support
___ expertise/technical information

10. b) What types of things do you feel that they are least able to help you with? What types of things might you seek someone else's help with? Who else would you turn to?
___ support
___ expertise/technical information

11. Now, I would like you describe SA for me. For example, if you were telling a potential member about SA what would you tell them?

___ Why should someone join?
___ Philosophy/important beliefs of SA.
___ Are there similarities and/or differences between SA and traditional mental health services?

12. Has there been a person or experience you have had with traditional mental health services that has been helpful? Who? How? Why?

13. Is there anything else about your involvement in SA that you would like to mention?

PERSONAL STORY
Now, I am going to ask you some general questions about what living with a mental illness has been like for you.

14. First, could you tell me the story of when you first realized that you had a mental illness.

___ Identify things that have been most difficult (symptoms, interpersonally), summarize and ask how this has effected their life and how they have coped with it.
___ If they haven't mentioned SA ask if SA has helped them cope and how it has helped.

15. Would you say there are ways that your mental illness has impacted how people treat you or interfered with other things in your life? Would you tell me about that?

16. Are there ways that your mental illness has helped you grow as a person or learn

things about yourself? Would you tell me about that?

SOCIAL SUPPORT

Now I would like to find out about what your social life is like and who you consider to be your social supports.

17. Can you tell me who are the most important people in your life, what your relationships are like with them, and what sorts of things you do with them?

18. Overall, how happy or satisfied are you with your current social life and social supports?
    1. not at all satisfied
    2. a little satisfied
    3. somewhat satisfied
    4. mostly satisfied
    5. extremely satisfied

19. Can you tell me who helps you when you really need help or when you are upset about something? What type of help or assistance do they provide?

20. Overall, how happy or satisfied are you with your current relationships?
    1. not at all satisfied
    2. a little satisfied
    3. somewhat satisfied
    4. mostly satisfied
    5. extremely satisfied

Now that you have told me about your social life and your relationships with other people, I would like to know if there is anything that you wish was different about these things.

21. Is there anything that you would like to be different about your relationships or social life?
    ___more or less contact with other people
    ___relationships that you don't have now that you wish to have

DEMOGRAPHICS

Up to this point in the interview I have been asking you very open ended questions. Now I would like to continue by asking you some structured questions about yourself and your background.

22. Gender
    1. male
    2. female

23. How old are you? ______ years

24. Date of birth ____/____/____

25. What's the last grade that you completed in school?
    1. elementary school
    2. some high school
    3. high school graduate

4. some college
5. associates degree
6. bachelors degree
7. graduate degree (Please specify)_____________________

26. Do you think of yourself as belonging to any organized religion?
    1. no
    2. Catholic
    3. Jewish
    4. Protestant
    5. Other __________________

27. Are you or have you ever been married?
    1. never married
    2. currently married (Please specify how many times _____)
    3. legally separated
    4. divorced
    5. widowed

28. Do you have any children?
    1. no
    2. yes

If yes go to 29.
If no go to 30.

29. How many children?_________

30. Are your parents living?
    1. no
    2. one parent living (Please specify which one _________)
    3. both parents living

31. Ethnic background
    1. Asian
    2. African-American
    3. Hispanic
    4. Native American
    5. White
    6. Other_______________

COMMUNITY ADJUSTMENT

Now I'd like to ask you some questions about your current living situation.

32. a) Where are you currently living? What kind of living situation is it? (code below)

    b) <u>INDEPENDENT</u>:
    1. independent house or apartment
    2. with family or friends
    3. boarding house (pay for room in house, no staff)
    4. single room occupancy hotel (pay for room in hotel)
    <u>SUPERVISED</u>:

5. supervised apartments (independent apt., staff available)
6. group home (shared home, staff available)
7 adult foster care (with foster parents)
8. hospital (long hospitalization/no current residence)
9. homeless (on the streets)
10. homeless shelter or program
11. other (specify)

33. How long have you lived there? __________ months

34. Who do you live with? ________________________________
If roommate probe as to whether or not a romantic relationship?

35. Overall, how happy or satisfied are you with your current living situation? (Use card)
1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

Now I would like to ask you some questions about whether you are currently involved in any work, volunteer, or school situation.

36. First, are you currently working for pay?
1. no
2. yes

If yes go to 37.
If no go to 39.

37. a) What is your job? Describe in detail (duties, how long there) (code below)

b) Indicate type of employment:
1. competitive employment- paid job obtained on open market
2. transitional employment- paid job obtained through training program
3. sheltered employment- paid job, long term, controlled environment

38. How many hours per week do you work? ________________

39. Are you currently volunteering anywhere?
1. no
2. yes

If yes go to 40.
If no go to 41 if working for pay or 44 if not working for pay.

40. Where are you volunteering? Describe in detail (duties, how long there).

If not working for pay go to 40.
If working for pay go to 44.

41. a) Can you tell me why you aren't working for pay at this time? (code below)

b) Indicate reason person is not working
1. can't find a job
2. physically disabled
3. psychologically disabled
4. retired
5. homemaker
6. student
7. other (Please specify________________________________)

42. When did you last work? or, Have you ever worked?
Number of months since last job______

43. Are you currently looking for work?
1. no
2. yes

44. How do you support yourself financially?
Or, if currently working: Do you have any other sources of financial support outside of your earned income? (Circle all that apply)
1. earned income (savings)
2. social security benefits (SSA) or supplemental security income (SSI)
3. social security disability income (SSDI)
4. armed service related disability income
5. social welfare benefits (welfare, AFDC, food stamps)
6. retirement, investment, savings
7. rent supplements (HUD, public living programs)
8. family and spouse contribution
9. other (specify)

45. To what extent do your financial resources provide for your basic needs? Do you have enough money for the essentials (rent, food, clothing)? Overall, how satisfied are you with your financial situation? (Use card)
1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

46. Are you in school or some kind of training program?
1. no
2. yes

If yes go to 47. If no go to 50.

47. Are you in school/training program full time or part time?
1. full-time
2. part-time

48. Are you working towards a degree?
1. no
2. yes

49. Where are you attending school/training program and what are you taking?

50. Overall, how happy or satisfied are you with your work/volunteer/school/training program situation? (Use card)
1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

Now I would like to ask about some of your social activities and what you do with your time.

51. What (else) do you do doing during the day?
1. formal day programming within mental health system
2. drop in center or Clubhouse
3. hangs out (no structured activity)
4. other (specify)

52. Can you describe a typical day?

53. Are you involved in any regularly scheduled activities? What are they?
How often do you participate in them?

54. Have you attended any other self-help groups?
1. no
2. yes

If yes go to 55.
If no go to 56

55. What group? How often did you attend?

56. Do you attend religious services?
1. no
2. yes

57. Overall, how happy or satisfied are you with the way that you spend your time? (Use card)
1. not at all satisfied
2. a little satisfied
3. somewhat satisfied
4. mostly satisfied
5. extremely satisfied

PSYCHIATRIC HISTORY

Now I would like to ask you some questions about your mental health history.

58. Have you ever been hospitalized for psychiatric reasons?
0. no
1. yes

If yes go to 59.
If no go to 62.

59. How many times (in life)? ____________

60. a) Where was your first hospitalization?________________________________
b) When was your first hospitalization? ____/____/____

61. a) Where was your last hospitalization?_________________________________
b) When was your last hospitalization? ____/____/____

62. Are you taking any psychiatric medication?
1. no
2. yes

If yes go to 63.
If no go to 66.

	63. <u>Name</u>	64. <u>Dosage (mg/day)</u>	65. <u>Purpose</u>
a			
b			
c			
d			
e			
f			
g			

66. Do you know what your psychiatric diagnosis is?
____

67. Who diagnosed you?
____

68. Do you agree with that diagnosis?
1. no
2. yes

If yes go to 70.
If no go to 69.

69. Why not?

70. Are you currently involved in any outpatient or day treatment?
    1. no
    2. yes

If yes go to 71.
If no go to 75.

71. What type of treatment? Where do you go? Who do you see? (Circle all that apply)
    1. individual and/or group therapy (specify type of therapist)
    2. medication management
    3. day programming (voc. rehab., recreational activities, day hosp., etc.)
    4. case management
    5. other

72. How often do you see this person?
    1. daily
    2. 2-4 times a week
    3. once a week
    4. about once every 2 weeks
    5. about once a month
    6. less than once a month

73. <u>Treatment</u> 74. <u>Frequency code</u>

a____

b____

c____

75. Have you ever had a problem with drug or alcohol abuse?
    1. no
    2. yes

If yes go to 76.
If no go to 77.

76. Can you tell me about this?

77. Did you ever seek treatment for your drug/alcohol abuse?
    1. no
    2. yes

78. Overall, how happy or satisfied are you with your mental health treatment? (Use card)
    1. not at all satisfied
    2. a little satisfied
    3. somewhat satisfied

4. mostly satisfied
5. extremely satisfied

FUTURE

To wrap up the interview I would like to ask you a couple of questions about the future.

79. Could you tell me in general how you think things will go for you in the future?
    ___ Are you hopeful
    ___ Any short or long term goals

80. Is there anything that I didn't ask you that you think is important or that you would like to tell me about?

To end interview:
1. Remind member about confidentiality.
2. Provide payment and have leader sign payment voucher.

APPENDIX D

APPENDIX D

SA ORGANIZATIONAL LITERATURE, 1995-1997

ITEM	**DATE**
The Group Leader's Circular	January - December 1995
	January 1996
	February 1996
	March 1996
	April 1996
	May 1996
	June 1996
	July 1996
	August 1996
	September 1996
	December 1996
	January - December 1997
The SA Forum	Summer 1995
	Fall 1995
	Winter 1995
	Summer 1996
	Fall 1996
	Winter 1996
	Spring 1997
	Fall 1997
Schizophrenia Update	January - December 1995
	January 1996
	February 1996
	April 1996
	May 1996
	June 1996
	August 1996
	September 1996
	October 1996
	November 1996
	December 1996
	January - December 1997
The Blue Book	1994; 1997
Video:	Joanne Verbanic Speaks on Schizophrenia and Schizophrenics Anonymous (n.d.)

APPENDIX E

APPENDIX E

Content Analysis - SA Literature: Community Narrative: complete coding quotes

SA's Explicit Support for the Utilization of Traditional Services

SA as a supplement to traditional services

"Group Philosophy: S.A. is a recovery oriented group which has developed a six-step program as described in the next chapter. These suggested steps recommend a set of attitudes and actions that will enhance the chances of recovery from a schizophrenic illness. The group also emphasizes the importance of adhering to the advice of mental health professionals, especially psychiatrists and therapists. For instance, group members are encouraged to take anti-psychotic medications prescribed by their doctors and if hospitalization is required, members are encouraged to cooperate. Many members of the group have benefited (sic) from these therapeutic methods as well as from psychotherapy. When problems arise, such as side effect of medications, members are advised to make immediate contact with their doctors. S.A. is intended to be supplemental to professional help (Blue Book '94, pgs. 3-4; Blue Book '97 p. 3)."

"....However, we all agree on the major point of S.A., a two-part expression of its mission: First, Schizophrenics Anonymous seeks to apply the concept of self-help group recovery for people with Schizophrenia; and second, we want to make available our application of this adjunct recovery program to as many people with schizophrenia who want it (Group Leader Circular, Jan 95)."

"Each SA leader has different boundaries of ability to help others. Your mental health professional is a person who would have a good sense of what these boundaries are for you and could estimate what your level of giving within SA should be. Please ask your psychiatrist, your therapist, or other key professionals about your limits for giving. Particularly: "At what point is my work within SA hurting me?" And please follow your professional's advice (Group Leader Circular, Mar 95)"

"Greetings fellow group leaders and facilitators: Ever since Joanne V. founded SA in 1985, she has stated many times that SA is a supplement to the regular treatment our members receive from their psychiatrists and other mental health professionals (Group Leader Circular, Apr 95)."

"MSU Study Results Encouraging..."Members view the helping roles of SA and professionals differently. While they view SA helping in many domains, members tend to view professionals as the best equipped to help them with medication and symptom management. Fellow SA members, on the other hand, were viewed as best equipped to help when they are feeling lonely or want to talk to someone who understand what it is like to have schizophrenia. This finding is consistent with SA's goal to provide support in conjunction with professional services (SA Forum, Fall '97)."

"When I first started out with Schizophrenics Anonymous, I tried to introduce the twelve steps of AA and just change some of the wording and um…it wasn't working for the group. I don't believe you treat schizophrenia the same way you treat alcoholism because an alcoholic can quit drinking and he recovers from an illness. Where a schizophrenic lives with the delusions and the voices daily and has to learn how to cope with them and dismiss them. So I introduced the six step program to SA. It's the six steps that I need in my life to…along with medication and professional help. Schizophrenics Anonymous is only supplemental to professional help. We believe in recovery, medications and professional help. Everyone in the group has professional help in addition to SA (SA Video)."

SA encourages members to utilize traditional services

"To choose to be well may involve cooperating with a psychiatrist or a psychotherapist, listening to what they say, and adhering to their advice. Another choice may be recognizing the need to take the medication that helps so many schizophrenic patients (Blue Book '94, pgs. 7-8; Blue Book '97, p. 6)."

"The "desire to recover" from schizophrenia involves, among other things, adherence to a doctor's advice, taking medication, and following the S.A. steps (Blue Book '94, p. 17, Blue Book '97, p. 14)."

"Generally, SA has a three-part formula with regards to a group leader helping a member. It goes like this: 1) Strongly refer the member to a mental health professional, particularly the attending psychiatrist or the professional associates, 2) Do what you can do as an SA leader to provide the member with caring fellowship and support, and 3) Continue to refer the member to a mental health professional (Group Leader Circular, Mar 95)"

"One fundamental tenet of SA is that each member follow medical advice to the letter and take all medication as prescribed. Members are strongly encouraged to report side effects of medication, changes in symptoms and to ask questions about the treatment of their illness...we should encourage all members to develop an open rapport with their professionals...We should remind members that psychiatrists are trained and licensed and are focused on helping members further their recovery in an atmosphere of dignity and confidentiality. From time to time it is important to mention that our illness is a biochemical disorder involving brain chemistry - a physical problem that we should not be ashamed of. By taking our medication and being open with our psychiatrists, we can better help in controlling our symptoms and working toward our recovery (Group Leader Circular, Apr 95)."

"...being open to good advice from our mental health professional and other responsible persons will help us toward recovery, the Six Steps are bedrock of SA philosophy (Group Leader Circular, Aug 95)."

"We really choose to be well but we don't know how to be well sometimes and that's where professional help comes in. We don't know what steps to do to stay well (SA Video)."

SA's Implied Support for the Utilization of Traditional Services

SA as a piece of the puzzle

"Mission Statement: The mission of Schizophrenics Anonymous is to add the element of self-help support to the recovery process of people suffering from schizophrenia. We hope that this will contribute to the sense of well being of S.A. members and help them cope with the difficulties imposed by their illness (Blue Book'94, p.3; SA Forum, Fall '95; SA Forum, W '96, p.5)."

"Mission Statement: The mission of Schizophrenics Anonymous is to add the element of self-help group support to the recovery process of people suffering from schizophrenia. We hope that this will contribute to the sense of well being of

S.A. members and help them cope with the difficulties imposed by their illness (Blue Book '97, p. 12)."

"Steps for Recovery:....someone suffering from schizophrenia may wonder why he or she has hallucinations or strange ideas, or why he or she must be placed into a psychiatric hospital, or why he or she must take powerful anti-psychotic medications...the program doesn't pretend to have all the answers, but the steps do address the difficulties of the afflicted and the problems associated with the illness (Blue Book'94, p. 6, Blue Book '97, p. 5)."

"Steps for Recovery...Step One...Sometimes he or she discovers it [schizophrenia] from a doctor's diagnosis (Blue Book '94, p. 6, Blue Book '97, p. 5)."

"Schizophrenics Anonymous Welcome State To Newcomers...About ninety percent of people with schizophrenia improve with medical treatment and new scientific research offers hope for all those with the illness...have you talked to psychiatrists, been in mental hospitals, taken antipsychotic drugs, or had awful side effects from these drugs? So have we (Blue Book '94, p.32 ; Blue Book '97, p. 28)

"....However, we all agree on the major point of S.A., a two-part expression of its mission: First, Schizophrenics Anonymous seeks to apply the concept of self-help group recovery for people with Schizophrenia; and second, we want to make available our application of this adjunct recovery program to as many people with schizophrenia who want it (Group Leader Circular, Jan 95)."

"Have you observed that when a person attends an S.A. group for the first time they sometimes say, "I always thought I was the only person with Schizophrenia." It's understandable. The person with schizophrenia can spend years seeing a psychiatrist and other mental health professionals and never come in meaningful contact with other persons with the illness (Group Leader Circular, Mar 95)."

"The conference is being held in a very nice hotel this year and we will have access to the pool...Also, remember to bring all needed medications (Group Leader Circular, July 97)."

"Twenty-Five Things an SA Member Can Do To Help The SA Group:..11) Tell your psychiatrist or case-manager about SA (Group Leader Circular, Dec 97)."

"Thinking About the Program...Our Hope...Over the past five years our hopes for symptom relief and the lessening of misery have lifted as new medications have been introduced. Psychotic symptoms and depression are more readily relieved under these new medications and with fewer side-effects. More lifetime patients in mental hospitals are being released and those of us who have been out for a long time are feeling better. More new medications are on their way, bringing more hope (SA Forum, W '95)."

"More on the Columbus SA Group Study...Those most likely to benefit...The program seems more suitable to person with schizophrenia who have a...4) fairly conventional view about treatments for schizophrenia...(SA Forum, Fall '96, p.4).

<u>Normalization of member experiences</u>

"Steps for Recovery: Step Two: I choose to be well. I take full responsibility for my choices and realize that the choices I make directly influence the quality of my days...To choose to be well may involve cooperating with a psychiatrist or a psychotherapist, listening to what they say, and adhering to their advice. Another choice may be recognizing the need to take the medication that helps so many schizophrenic patients. To choose to be well may also require the patient to acknowledge that, at some point during his or her period of recovery, there may be a setback and rehospitalization could be necessary...The decision to be well may mean different things to different people. For instance, a schizophrenic patient in the back wards of a state psychiatric hospital may not be responsible for his or her illness. He or she may be so overwhelmed with symptoms (such as voices) that personal choice is limited. Yet, S.A. encourages such a patient to make the best of his or her circumstances, to make choices that would influence the quality of his or her days. This might involve avoiding behaviors that would lead to the patient being placed into seclusion in a locked room or to be placed into restraints. We would encourage behaviors that would lead to the granting of special passes to the patient, such as a grounds card, enabling the patient to get out of the ward and into the sunlight of the institution's grounds (Blue Book '94, pgs. 7-8; Blue Book '97, p.6)."

"Steps for Recovery: Step Five: I now realize that erroneous, self-defeating thinking contributes to my problems, failures, unhappiness and fears. I am ready to have my belief system altered so my life can be transformed....For some members, recovering may mean the ability to hold a demanding job; for others, it may mean the acquisition of grounds privileges at a state hospital. If each person in these circumstances is doing the best that he or she can then they are equal in our eyes. (Blue Book '94, p. 10; Blue Book '97, p. 8)."

"Aspects of Recovery: What is recovery from schizophrenia?..More broadly, it might include living independently, forming meaningful relationships, being financially self-supporting, and not having to be rehospitalized for psychiatric reasons...Still others are doing their best by residing on a locked ward at a state-run hospital, taking medication, eating, and behaving the best they can (Blue Book '94, p. 12; Blue Book '97, p.10)."

"S.A.'s Attitudes Towards Setbacks and Stigma:...An example of a major setback would be a person experiencing a psychotic episode which resulted in rehospitalization....Hospitalization is for many a common setback. However, Schizophrenics Anonymous does not consider returning to the hospital, either voluntarily or otherwise, to be a personal failure or weakness. We believe it shows a realistic understanding of the limits imposed by our illness. The decision to return voluntarily to the hospital shows that we take full responsibility for our choices and that we choose to be well. At SA we feel that setbacks are a normal, expected part of our usually chronic illness. We view them as a temporary intensification of symptoms which will often pass. While treatment can often control the symptoms, it may cause changes in us which nonschizophrenic persons sometimes view negatively. Examples would include apathy due to increased medication or apparent "laziness" which results from the necessity to cut back on stressful schedules (Blue Book '94, p. 14; Blue Book '97, p. 11)."

"Schizophrenics Anonymous Welcome Statement To Newcomers:...About ninety percent of people with schizophrenia improve with medical treatment and new scientific research offers hope for all those with the illness...Have you talked with psychiatrists, been in mental hospital, taken antipsychotic drugs, or had awful side effects from these drugs? So have we....We have these things in common. In a way, it's like a homecoming. You are welcome here (Blue Book '94, p. 32)."

"We in Schizophrenics Anonymous believe that choosing to stay well means taking the medication. Sometimes it means re-hospitalization. We don't look at re-hospitalization as a failure. We look at it as a temporary learning experience. With each hospitalization that I had, I gained a little more. I learned a little more. I grew a little more and I got stronger until I'm at the point of recovery I am today. To be well means to stay off substance abuse. Choosing to be well means doing the choices of your day of activity that can help towards your recovery whether it be exercise or nutrition or whatever it can be but we choose to be well. Most members of the group pick this step. We really choose to be well but we don't know how to be well sometimes and that's where professional help comes in. We don't know what steps to do to stay well (SA Video)."

SA Educating Members About Traditional Services

"What is Schizophrenics Anonymous?....To provide members with the latest information regarding schizophrenia (Blue Book '94, p. 3; Blue Book '97, p.3)."

"Structure of Meetings...In addition, members share information regarding developments in schizophrenia research (Blue Book '94, p. 4; Blue Book '97, p.4)."

"S.A.'s Attitudes Towards Setbacks and Stigma:...An example of a major setback would be a person experiencing a psychotic episode which resulted in rehospitalization....Hospitalization is for many a common setback. However, Schizophrenics Anonymous does not consider returning to the hospital, either voluntarily or otherwise, to be a personal failure or weakness. We believe it shows a realistic understanding of the limits imposed by our illness. The decision to return voluntarily to the hospital shows that we take full responsibility for our choices and that we choose to be well. At SA we feel that setbacks are a normal, expected part of our usually chronic illness. We view them as a temporary intensification of symptoms which will often pass. While treatment can often control the symptoms, it may cause changes in us which nonschizophrenic persons sometimes view negatively. Examples would include apathy due to increased medication or apparent "laziness" which results from the necessity to cut back on stressful schedules (Blue Book '94, p. 14; Blue Book '97, p. 11)."

"David's Story: My relationship to the Schizophrenics Anonymous group? It's two years, every Sunday, including game nights, Christmas parties and picnics....we have also had some excellent speakers, especially the doctor from Lafayette Clinic, who brought us up to date on the latest research...(Blue Book'94, p. 26; Blue Book '97, p. 20-21)."

"Tamara's Story...Our SA group has discussed many different issues, some of which are...medication, its benefits and its side effects (Blue Book '97, p. 23)."

"Kathy's Story...SA was (sic) place for me to learn about mental health (Blue Book '97, p. 25)."

"Schizophrenics Anonymous Welcome to Newcomers...About ninety percent of people with schizophrenia improve with medical treatment and new scientific research offers hope for all those with the illness (Blue Book '94, p. 32, Blue Book '97, p.28)."

"We're subscribing to the best journals and newsletter in order to gather quality information for you: *American Journal of Psychiatry, Hospital and Community*

Psychiatry, Schizophrenia Bulletin, Harvard Mental health Newsletter, The Menninger Letter, Psychiatry Drug Alerts, and numerous others. Please think of ways to share this information with the members of your group and we'll make some suggestions on how to do this inexpensively in future months (Group Leader Circular, Feb '95).

"Program: Speeches and Workshops for SA Convention/Conference: Medication Topics: New Medications: Antipsychotics and Anti-Depressants; Medications: Compliance Benefits, Impacts of Non-Compliance; Indigent Drug Programs –What's That? (Group Leader Circular, Aug 95)."

"We will hold our annual leadership 'Pow Wow' for all current leaders to discuss issues pertinent to our leadership roles, and we have confirmed a psychiatrist to answer questions about medications (Group Leader Circular, Apr/May 97)."

"SA Anniversary Conference Planned....The first will be an all-day conference on schizophrenia held at a university with guest speakers discussing diagnosis, treatment of symptoms and new medications (SA Forum, W 95, p. 4)."

"Research Study Published - - "Schizophrenics Anonymous: The Franklin County, Ohio Experience"...4. The actions and side effects of medications. "Almost all members use psychotropic medications, and in sharing this characteristic they are eager to learn from each other about the relative effectiveness and side effects of various medications. Side effects are major concerns to all persons attending SA"...9. Dealing with mental health professions. Sometimes there are disputes with mental health professionals. "These are not always serious, but members seek advice in how to address disagreements with professionals, whom they perceive as being in more powerful positions in the relationship (SA Forum, Schizophrenia Update 96)."

"Update on New Antipsychotic Medication...Zyprexa....What does all this mean to SA members? We can be hopeful that these new approved drugs will provide additional symptom relief (and side-effect relief) for those out of the hospital already; and for those in the hospital a new range of hope may emerge (as I the possibility that the negative symptoms may lessen). We can all have come consolation that the scientists are aggressively seeking new pharmaceutical treatments for our mental pain (SA Forum, F '96, p.3)."

"Univ. Of Mich. Study Released...the residents expressed positive attitudes toward them [SA meetings]...learned about the purpose of medications (SA Forum, W '96)."

"To provide members with the latest information regarding schizophrenia (SA Video)."

"<u>More on Medications</u>. It's entirely possible that in the next five years a very large segment of our S.A. membership will be prescribed newly developing medications that will help us feel better by way of more symptom relief and the reduction of disturbing medication side-effects. Aside from the new medications already making their mark–Clozaril, Risperdal, and Prozac (and its cousins Zoloft and Paxil)–there is a whole new generation of meds currently going through clinical trials. In all, there are about fifteen experimental antipsychotic meds (for schizophrenia) and about eight antidepressatns now being tested on human volunteers.... (Schizophrenia Update, January 1995)."

"Tardive Dyskinesia Dr. Jack M. Gorman, in his guide to psychiatric medications, describes tardive dyskinesia as an adverse side effect from continuous use or neuroleptics, or antipsychotic drugs. This side effect involves involuntary and purposeless movements of the face and other parts of the body, involuntary in that the patient often cannot control the movement. Examples of these movements include senseless chewing, lip smacking, and grimacing, as well as, sudden or writing movements of the hands, arms, and legs... (Schizophrenia Update, April 1995)."

"Update on Research for New Psychiatric Medications About a year ago we ran a couple of articles in this publication on new research medications for schizophrenia and depression. Since then three new antidepressants have been released: Effexor, Serzone, and Luvox. Over the coming decade numerous other medications now being tested will reach out medicine chests. Experts say these new medications will increase our symptoms relief and decrease the distrubing side-effects of the old medications....(Schizophrenia Update, October 1995)."

"News on Olanzapine (Zyprex) A couple of months ago we alerted you that the new experimental antipsychotic drug Olanzapine had passed its clinical trials and is currently under final review by the FDA. It is likely that Olanzapine, along with the new experimental antipsychotic Sertindole, will be at our pharmacies late this year or sometime next year....(Schizophrenia Update, April 1996)."

"FDA Approves Remeron for Depression/News on New Antipsychotics In June, the U.S. Food and Drug Administration approved the new antidepressant drug Remeron (mirtazapine). This new drug may now be marketed by its manufacturer, and it will no doubt be reaching the medicine chests of S.A. members who are experiencing depression....(Schizophrenia Update, September 1996)."

"The Diagnosis of Schiophrenia. Up until now, we haven't really published the official criteria that psychiatrists use in order to apply the diagnosis of "schizophrenia" for one of us. Such diagnostic criteria are found in the new DSM-IV, the short title for the *Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association. Below is the official DSM-IV criteria as presented in *Understanding Schizophrenia* by doctors Richard S. Keefe and Philip D. Harvey....(Schizophrenia Update, April 1997)."

"–Working Memory and Schizophrenia. Researchers at the National Institute of Mental Health are exploring that part of the brain's functioning that impacts on "working memory," which correlates information for the understanding of language, as well as other mental tasks and operatins. One of the characteristics of patients with schizophrenia is momentary confusion and an apparent breakdown of working memory in many instances....(Schizophrenia Update, July 1997)."

"–News on New Medications. There are more indications that the eagerly awaited experimental medications for schizophrenia will gain FDA approval soon. The *Detroit Free Press* in its November 11, 1997 issue said that we are on the verge of federal approval for Serlect (generic name "sertindole") and Seroquel (quetiapine). At this writing in late November we are uncertain what date FDA approval will come, though arrival of the medications in pharmacies should come soon after such approval. An interesting point in the Detroit newspaper is that a third new antipsychotic medication is in line for FDA approval. This medication is called Zeldox, with the generic name Ziprasidone. New information on these medications will be printed here as events happen...(Schizophrenia Update, December 1997).

Personal Stories of Packages of Services

> "Scott's Story:..Anyway, I got sober by entering treatment and Alcoholics Anonymous about a year later....While traveling, it seemed like God's voice entered into my thoughts and told me to do something if I wanted real peace and power in my life. That being, to run my car off the road and leave the rest to Him. I did this only to find no peace, but a totaled car and a trip to the state mental hospital. Since that time, I've been dealing with a disease called schizophrenia. It has been an uphill struggle. At the time of this writing, I believe I've found a way to pull myself out of a psychosis and feel connected like before the alcoholism and schizophrenia. Today I feel peace, own a thriving business, and have a wonderful relationship with my wife. We're in the process of planning a family. This has been accomplished by the philosophy of Schizophrenics Anonymous, Alcoholics Anonymous, and a few special people in my life. Thank you to my wife and family, Pam N., Joanne V., Perry E. And Dr. W., for your patience and support (Blue Book '94, pg. 20-21, Blue Book '97, p.16-17)."

> "Fran's Story: I am schizophrenic. I have been hospitalized four times in the past..While I was in a foster care home, I read a pamphlet that described my symptoms perfectly. Before I read it, I did not know I had schizophrenia. The pamphlet said that schizophrenia was incurable, but could be controlled with medication. All of my relapses were from going off my medication. From that time on, I have decided to be well. I never go off my medication or ever have it adjusted...I know I still have the disease, but am controlling it with medication....my doctor and social worker are located at a center called the Gathering Place...my social worker at the Gathering Place heard about Schizophrenics Anonymous and suggested I get involved in it. Since I have met Joanne V. and the members of her group, my life has been transformed (Blue Book '94, pp. 22-23; Blue Book '97, p.17-18)."

> "Paul's Story: In the past, I have had two psychotic breaks...Then I received treatment at Clinton Valley Center, a state mental hospital, and it took about a year outside to recover from the shock....the doctor and I talked about schizophrenia. The medicine, Haldol, took away all the symptoms....I got sick again, experiencing a complete new set of hallucinations...I went back to the doctor to resume the medicine. Then I discovered the S.A. group to help me battle schizophrenia. The group has helped me psychologically to fight my symptoms (voices), and the medicine does the rest (Blue Book '94, p. 24; Blue Book '97, p.19)."

> "David's Story: My relationship to the Schizophrenics Anonymous group? It's two years, every Sunday, including game nights, Christmas parties and picnics....we have also had some excellent speakers, especially the doctor from Lafayette Clinic, who brought us up to date on the latest research....There was even a time when my treatment was affected. I complained at a meeting that I was feeling catatonic during a family reunion. Joanne suggested that I talk to my doctor about it. It's not my practice to talk to my doctor between my monthly sessions, but I have him and call and told him the way I was feeling. At the next session, he gave me a little more medication in my injection. He did it only once but my symptoms cleared up. Next month he went back down to the previous level (Blue Book'94, p. 26; Blue Book '97, p. 20-21)."

> "Paula's Story: My mother was told I would never leave the hospital....for twenty-five years, I was in the state mental hospital more than I was home, until about two years ago. At that time, I was in a medical hospital with IVs and unable to keep anything on (sic) my stomach. I decided if I was ever going to be helped, I had to

want to be well because all the doctors and therapists could not help me unless I helped myself and really wanted to live. I know I have a long way to go but I am now working with my doctors and therapists and helping other schizophrenic people (Blue Book '94, pp. 27-28; Blue Book '97, p.21-22)."

"Laura's Story: My name is Laura. I am a paranoid schizophrenic working for recovery. Prior to starting the group (Schizophrenics Anonymous), I had lost my job and had no social life. Once I began, within four months, I had enough confidence in myself to begin again. So I enrolled in college and became a leader of a chapter of S.A. The first semester I had to withdraw due to my illness. But with the help of the group and my therapy, I managed to stay out of the hospital (Blue Book '94, p. 29; Blue Book '97, p.22)."

"Tamara's Story:..It was a difficult battle, and I have to give credit to the Psychiatrist I've had for the last 21 years, and the Clinical Social Worker, I've known since my first psychotic episode when I was 13...I learned from my mistakes, which cost me several jobs, and along with my Psychiatrist, we experimented with different medications. Fortunately, we found a combination of medications, which kept me out of hospitals........(Blue Book '97, p. 22-23).

"Jeff's Story...The medications they put me on helped and my life began to improve...I had a fine doctor who adjusted my medications and was discharged....four years later I stopped taking my medication and landed in a state hospital for thirty days...I started attending a day program for people with mental illness. One of the people there suggested that we begin a Schizophrenics Anonymous meeting. I co-led the group and it helped me get along better with people. It also makes it easer for me to accept my schizophrenia (Blue Book '97, p. 24)."

"Kathy's Story...I had a therapist who recommended to me that a support group would be good for me. So, I joined Joanne's SA group down in Southfield (Blue Book '97, p. 24)."

"I've been going through a period of stress in which the stressors were activities that I felt I couldn't eliminate or were situations impossible to avoid. Despite being an SA member and a group leader for years and actively promoting the common sense SA philosophy to other members, I fell into my old mind set of 'touching it out' and hoping that it would all just go away. Eventually, I called my psychiatrist who advised me to rearrange the dosage schedule of my medication and then gave me some advice to help lower stress. After a couple of ways I felt a little better. My symptoms were still there but easier to dismiss and my thinking was a bit clearer. I should have called my psychiatrist sooner but when stress begins to pile up, it clouds my judgement. I had to relearn that stress can't be challenged or ignored, it has to be reduced (Group Leader Circular, May 95)."

"This month David M., a long-time member of SA, will be observing the tenth anniversary since his last psychiatric hospitalization. In November 1985 David was in the hospital for a month, and has not been admitted since. He has undifferentiated schizophrenia, has been in treatment since 1960, with numerous hospitalizations and a history of self-destructive behavior. David reports that while in the state hospital in 1985 the attending psychiatrist said, "David, I wish that you would take care of yourself really well." David said that for the first time he decided to cooperate fully with the professionals at the hospital. Below are seven things that David says he did to stay out of the hospital (and to feel better)...2) I cooperated with treatment. I stop fighting the medication and became a believer in psychiatric treatment. I discussed my problems with my psychiatrist and prepared for each visit with notes and a list of questions....7) I joined Schizophrenics Anonymous. At SA I learned to accept my illness, and learned that despite this illness, I can engage in many growth-oriented activities. I also enjoyed all the fellowship (Group Leader Circular, Nov 95)."

"From the Founder...Although I was able to accept my vision loss, I began to experience a depression. Along with a short stay in day-hospital, I relied on my therapist and the six steps of SA to help get me through it all. SA provided me the right perspective and hope for 'recovery' to adjust to this major life trauma (SA Forum, Fall '97)."

APPENDIX F

APPENDIX F

Cross-Case Coding - Differences

HOW DO SA MEMBERS DESCRIBE THE DIFFERENCES BETWEEN THE ROLES OF TRADITIONAL SERVICES AND SA IN THEIR RECOVERY?

Knowledge Base is Different Between SA and Traditional Services

Professional Education & Training is Different

Professional Education & Training is a Strength (3)

"I think doctor is a much better educated than A and the others [180216]"

"The psychiatrists are good. They're gonna know a heck of a lot more about the medical side of the illness than we're ever gonna know. They know more about the illness...they know more about the recent advances, the things that are gonna happen...Therapists are gonna know a lot about, say about your personal therapy and they're gonna know about cognitive therapy and they're gonna know more about methods of, scientific methods of theories of psychotherapy [210100]."

"My therapist, when I first started seeing her, the difference was she went to college for it. She knows a little bit more, a little bit more output about it. Like you're going to school, you put all this time into studying about it. It's something you've got to want to do [300202]."

Professional Education & Training has Limits (5)

"And even if you are seeing a psychiatrist, psychiatrist only knows what the textbooks tell him...Well, as good as my psychiatrists are, my social worker, the only thing they've got going for them is a lot of education. They still don't know and sometimes they come up with suggestions that I suppose are meant to help. Sometimes it's insulting [010211]."

"And when there's more than two, people who have been there... not, not to say anything negative about professionals but they know from books and internships and stuff, residencies and everything. But they maybe haven't felt in their, for weeks, months, years on end of pain. You know, they haven't felt the stigma and then these folks [SA] have [070105]."

"They're [SA] more like a buddy instead of being a parent. I try to think of the doctors as being like your parent. They tell you what to do, whether you think it's good for you or not. SA is kind of like the buddy that you can sit down and talk to and kind of work things out, where the professionals are just gonna do it [tell you what to do] because they know better because they've had all the schooling and everything else [110103]."

"I think a lot of professionals don't know about SA. That's why I said I've had trouble with the thing...If they would have believed in it 100%, I think I would have more people come by now. They don't know about us and they're scared of us. The professionals say, what is this group? I've had people talk to me even at Turning Point, they had stopped me and another member, she was also in and out of Turning Point. And she said that group isn't for you. It's not right for you. You shouldn't be going there. And she had a masters degree, I guess in social work or whatever. She said no, no, that's not for you. And we disagreed, because it even says on the pamphlet, not just schizophrenia, but also related disorders. And she said

> no, both of you shouldn't be going there...Well, because she didn't really realize the philosophy or had never even sat in on a group. Because we even ask people to sit in on, like a lot of people, social workers, we take a vote, at DLM's we did through, because a lot of people from the hospitals and clinics just to find out what it was and what we did. I don't know why. She never really explained why, yeah, if they would sit in, more people, if they would sit in on it and find out [120103]."
>
> "And I think the thing that strikes me most is that social workers have been trained in mental health but not in mental illness. They don't know how to deal with mental illness. They just assume that they know what people ought to be like because they know what mental health is. But they are not familiar with all the side lines of mental illness [410140]."

<u>Professionals Unable to Empathize/Understand</u> (6)
"He [professional] doesn't know what the voices are telling you. Cause he hasn't had any talk to him...they can't have empathy. Been there haven't really done that, you know. People at Schizophrenics Anonymous have [010211]."

"Because I can relate to these people. They [SA] can relate to me and my psychiatrist and my therapist cannot. You know, no matter how much I try to make them understand, they will never know what it's really like...just like if I had my arms and legs chopped off and I had to see a therapist about it, I would rather see a therapist that was in the same position than I was than someone who was not because they wouldn't understand and that's how I feel, I want someone who understands ...I'll call somebody from my meeting. I'll call them and talk to them and that always makes me feel better. Because even when I was able to call my therapist before, she was this old lady that was my therapist and really wasn't like a friend. But with the program I have people to call that are friends. Maybe they don't have all of the answers in the world but they are there for me if I need them and I know that they understand because they went through the same thing [100110]."

"Well, sometimes, sometimes it helps, you talk to people instead of, you know, sometimes it helps to talk to people who maybe aren't um, whatever you know, employed...Just need to talk to people [140211]."

"...this one guy that I knew who doesn't come up here any more, he always had kind of a resentment for therapists because they [professionals] were giving him advice but they hadn't been in the same boat before [250210]."

"I think you know, they [professionals] haven't experienced the illness. They're looking at you in a little different way although they're all very kind and compassionate, but you can tell, you know, feel...Like I always say you never know until you go through it yourself. And a lot of people have a big distrust of doctors [280115]."

"Because I like the socialization I get with other schizophrenics. It's hard for me to make friends because I have all these symptoms on top of my head and they want to come out right away. I mean, I want to talk about them right away. I want to get feedback and tell people, you know, and connect with reality somehow. The best place to do it is over at the SA meetings and the social groups afterwards because people who don't have the illness don't really, they shy away from you and they don't really... I'm not saying you don't, but most other people don't understand what it's like to have schizophrenia [330205]."

Setting Characteristics are Different Between SA and Traditional Services

SA Structure is Different from Traditional Services

SA is consumer (non-professional) led (11)

"You know, you can talk about abstract symptoms, but we're [SA Leaders] not trained professionals...well, first, about group therapy, you got the group leader. You know that he or she is a professional, he or she is the leader. He or she gives advice and you're supposed to follow it. SA, we're like collective mind...Nobody there is a professional. I mean, we're all consumers, you know. And I tell them that...No professionals [070105]."

"It's non-professional [SA] which is frightening to some people [080102]."

"It's peer led. You know, there's no professional there...and it was run by a peer person and there's other peer people there. And they gave a lot of support to me which I needed, I needed all the support I could get. It was a very difficult time in my life. So I got a lot of support and love...Because it's not professional, I'm not talking to a professional [120103]."

"Well, there aren't any physicians or psychiatrists or therapists at the SA meetings [130115]."

"They told me that anybody was welcome to join and that it was just for schizophrenics, not therapists or doctors or anything. Just regular people...We aren't, we aren't professionals [140211]."

"The only thing I'd mention is that there are no professionals there. It's just consumer run and they seem to like that [200100]."

"Well, this is run by someone with a mental illness so I guess that's one major difference...AND ARE GROUP THERAPY SESSIONS USUALLY RUN BY Usually a therapist. [250210]."

" I was very impressed and happy that there was a group for us to go to, that we could discuss without doctors and social workers and such around, you know...But you don't have professionals there [280115]."

"It's [SA] run by people, you know [320213]."

"There aren't any professionals running it which makes a big difference [340205]."

"Because it's not, it's not therapy as such. It's a self support group. It's run by the members of the group and they are supported by the structured format of the meetings and the literature and the principles and the goals of SA [410140]."

SA format is not as Structured (11)

"I think SA is different from an outpatient therapy that I was going to by the fact that, for the fact that we [SA] don't set goals. We do in a way, we talk about the SA pamphlet as our goal, but I mean like a goal that concerns financial, economic, and social, social would be included...[020211]."

"Gosh, I'd say it's [SA] not the same. It's not nearly as structured [030211]."

"I like the easy-going-ness of meetings, you know. You don't feel threatened or I didn't feel threatened at all. You know, like if it was, just this guy with a PhD like they do sometimes in hospitals, you know [110103]."

"...Different. It's not so cold and clinical. It's more relaxed, loving, comfortable. Because I have gone to formal, you know, ones in the hospital, I didn't care for them. I went twice and that was it. I didn't get anything out of it. GROUPS THAT WERE RUN BY PROFESSIONALS? Yeah, semi professionals or whatever. They lent their rooms out in hospitals for these support groups and they are too rigid, too cold, I didn't get anything out of it. I didn't like their programs or philosophy or whatever you want to call it [120103]."

"That's the most important thing to talk about is how I feel I like this kind of therapy better than I appreciate any kind in the hospital. They make me work too hard in the hospital. Well, in the hospital, they're always having us do some task or something. And I can't handle that [140211]."

"A group is more open communication and a therapist is more...personal [240210]."

"It [SA] was a smaller group, much smaller group, much smaller. And I found it was helping me much more. Like I say, I found what people were experiencing more what I was experiencing than in that manic depressive group. They were quieter, quieter compared to the other...It's more open...I don't know why professionals tend to be more, not so much anymore, rigid, and what do you call it...More structured, I guess, a little bit more [280115]."

"It's like a little club, in a way. It's an informal club [410140]."

"It's [therapy] much more intense. It's much more, you know, it's like five days a week. It's much more time to spend. It's [SA] much more casual, relaxed. The meetings, maybe there should be a meeting a day but there are like different things going on [440238]."

"You know, it's [traditional services] such a routine. 8:00 medication, 7:30 breakfast, you know, it's such a routine...Some traditional stuff, it's not, it's uncomfortable, I guess you'd call it. Because everything's kind of this is how it goes and that's the way it goes, you know. With the Schizophrenics Anonymous, you do the basic things but then you have room for discussion too. And sometimes with the traditional stuff, you just say that and that's the end of it. [450238]."

"It [SA] is not as tightly controlled. If A gets something going and we are all working at it, she doesn't presume to dominate it. She lets it go its own way [480216]."

Control of Process

Member Control within SA (7)

"[SA] You get to walk in, you can get up and walk out anytime you want to. Stay the whole thing...then you get on with your life [010211]."

"In the hospital they sit there all day and you have your choice of whether to go to the meetings or not....well, as far as I'm concerned, the hospital is just to keep you safe from killing yourself or hurting anybody else. As far as therapeutic goes and getting you better, it doesn't help unless it's a long term, active group hospital where they force you to go to groups and stuff like that [100110]."

"We have the six steps and then you pick what step you'd like to tell us about. You know, as little or as much as you like about yourself at that particular time of the day or week or month, what you're going through [120103]."

"We can relate to one another and express what we did if we want. And if you don't want to say nothing, you can pass. It's your option [290202]."

"You go to a meeting, if you enjoy the meeting, if you want something more out of it, there's more meetings. If you're tired of meetings, you can come here and play pool and listen, talk to people [300202]."

"But you can draw up a meeting. That's what's the beauty about it. If there's a issue that you wanta discuss, you call up a meeting [440238]."

"With the Schizophrenics Anonymous, you do the basic things but then you have room for discussion, too [450238]."

<u>Lack of Control for Members within Traditional Services</u> (4)
"Well, maybe like you saw somebody, you really wanta do something, tell a psychiatrist or a social worker and they'll say, oh, you don't wanta do that. You just said you wanted to. It may not be a good idea, but at the same time you wanted to. If it isn't hurting somebody else, it isn't necessarily hurting you, why can't you do it?...Well, I guess it's the difference between telling somebody with authority, that you wanta do something and they say you can't, and telling a peer something you wanta do and they're more likely to feel like if it's not something that they wouldn't do, at least it doesn't mean that you shouldn't do it [010211]."

"They're [SA] more like a buddy instead of being a parent. I try to think of the doctors as being like your parent. They tell you what to do, whether you think it's good for you or not. SA is kind of like the buddy that you can sit down and talk to and kind of work things out, where the professionals are just gonna do it because they know better because they've had all the schooling and everything else [110103]."

"In the hospital, in group therapy, everybody tries to outdo everybody else. But here, you're accepted, if you want to speak, you can speak if you want. Nobody's going to jump on your case, nobody's watching you critically. To me, that's wonderful [340205]."

"Some traditional stuff, it's not, it's uncomfortable, I guess you'd call it...because everything's kind of this is how it goes and that's the way it goes, you know...And sometimes with the traditional stuff, you just say that and that's the end of it [450238]."

Cost

SA is Free (5)
"If you'd like to join us, it doesn't cost anything [120103]."

"plus it's free [130115]."

"Talk about it and other people will give them advice on how to deal with it. So it's like free counseling. That's what it's like, it's like free counseling [220202]."

"He [psychiatrist] supported me but I could have gotten that same support from SA and SA is free [330205]."

"Here you just, I bring cookies every week [340205]."

Traditional Services are Not Free (2)
"Well, another thing, of course, is money. You pay your therapist and hope the person likes you [340205]."

"And then therapy was only 20 visits a year, I had to pay for it [350100]."

SA is More Available

SA is More Accessible (3)
"It helped me when I got very little other support at the time because it took quite a while to get into therapy and into doctors when you didn't have anything [120103]."

"Well, I need support. All I have is my family and sometimes they don't understand my illness and what I'm going through. And I only see the doctor every six weeks so I need that weekly support. Sometimes I need it more than once a week, when I start feeling sad. So I need that weekly support that I get from hearing the group members' stories and their problems and fears [190213]."

"It helps, it helps to have a place to go during the week because things come up, and I can't just call the doctor all the time or see her. I was seeing her once a week but sometimes in the middle of the week, you know, you need some support [280115]."

SA is Open to Anyone (3)
"So we don't refuse anyone...we don't turn anybody away. But they must have a major mental illness to join [120103]."

"They told me that anybody was welcome to join and that it was just for schizophrenics, not therapists or doctors or anything. Just regular people [140211]."

"But it's, but it's open to anybody who wants to recover from schizophrenia in particular or a related mental disorder [410140]."

SA has no Time Limits (3)

"Well, whenever you're hospitalized, hospitalized for certain period of time. Maybe a week, or months...and once you get in, you don't necessarily know how long it will be before you get out again...it's [SA] still not gonna last more than an hour. Then you get on with your life [010211]."

'The differences is you've got one hour with her [therapist] and then that's it. You're on your own. Here's, there's really no time limit [300202]."

"...when you go to the therapist and the doctor....you only get so much time...and then therapy was only 20 visits a year ...[350100]."

SA Process is Different from Traditional Services

SA Fosters Shared Experience (21)

" you know, sometimes when you're going through a delusional time or something, it's hard to know who to trust and it's easier... it's still hard but it's easier to trust somebody who also has had those problems. Especially when you're going through a rough time and your judgment's not so good [030211]."

"I think just sharing with other schizophrenic people, hearing what their lives have been like and the hell they've gone through. That, for me, is the biggest part of it. It draws me to it because I can share my own story with them and they understand. They know what it's like to hear voices that nobody else hears or they know what it's like to get paranoid and think the whole world's talking about you and be convinced of it and not be able to shake the feeling, even though people reassure you, it doesn't mean a thing. That's touched me the most. Just hearing people's stories. The hell they've gone through. That's the most important thing I've gotten from it...Once you've felt that terror, you've never felt anything like it in your life and I know everyone there [SA] has felt that. We share that and that's something we can't share with anybody who hasn't experienced it. I can try and relay that to you but you'll never understand unless you've heard a voice screaming in your head or saw something that nobody else saw that was hideous and scared the shit right out of you [050111]."

"WHAT DO YOU THINK YOU'VE LEARNED AS A RESULT OF HAVING A MENTAL ILLNESS? That I'm not alone with the illness.....WHAT DID YOU LIKE ABOUT IT [SA]? That I know I'm not alone, not always......IN WHAT WAYS DID YOU THINK THE GROUP WOULD BE HELPFUL FOR YOU? I know I'm not alone with the illness.................A lot of people pass. WHAT DOES THAT MEAN EXACTLY? They don't want to talk. And I try to get them to talk but they don't want to. And I say it's helpful. You're not alone and everything. ANY WAYS THAT YOU THINK THAT IT [SA] COULD BE IMPROVED? People talking more. HAVE YOU THOUGHT OF ANYTHING YOU MIGHT DO TO HELP THAT TO HAPPEN? Saying you're not alone [060104]."

"And when there's more than two, people who have been there... not, not to say anything negative about professionals but they know from books and internships and stuff, residencies and everything. But they maybe haven't felt in their, for weeks, months, years on end of pain. You know, they haven't felt the stigma and then these folks [SA] have...we can offer a unique perspective because we've all been where they are at or have been. They can get unique advice from the inside which you won't be able to get from [the professionals], you know...we can offer you a perspective because none of us are professionals and we've all been at the same place, you know, we all take medication. A lot of people come and ask, have you ever bought a drug called so and so. Usually someone's taking it or has had some personal experience with it. That's very reassuring [070105]."

"I was like oh, my gosh, I'm going to meet people that are just like me and this is incredible because when I was in school, nobody was like me. Even when I was in hospitals, there wasn't very many schizophrenics there. There were a lot of alcoholics and drug addicts but there wasn't a lot of schizophrenics...Because I can relate to these people. They [SA] can relate to me and my psychiatrist and my therapist cannot. You know, no matter how much I try to make them understand, they will never know what it's really like...just like if I had my arms and legs chopped off and I had to see a therapist about it, I would rather see a therapist that was in the same position than I was than someone who was not because they wouldn't understand and that's how I feel, I want someone who understands...I'll call somebody from my meeting. I'll call them and talk to them and that always makes me feel better. Because even when I was able to call my therapist before, she was this old lady that was my therapist and really wasn't like a friend. But with the program I have people to call that are friends. Maybe they don't have all of the answers in the world but they are there for me if I need them and I know that they understand because they went through the same thing [100110]."

"I didn't really have a whole bunch to say but I could understand that people were going through the same thing that I was and I didn't feel so isolated which was a big step right there, you know, feeling like you are not alone. That was a big thing...YOURSELF? Yeah, I realized that I wasn't alone. You know, because I felt I was all alone. I felt isolated and that's a terrible feeling, you know. You feel like you're shut out from the world...I think the thing that I most got out of it is the feeling of not being alone. You know, there was nobody sitting around the table to judge you or point a finger at you for things that you've done wrong. We could all relate, you know, and I think the big issue of being able to relate to one another is a big step. You know, having something in common. And let's face it, that's what most relationships are based on is something in common, you know?...Yeah, because you know for me, just listening those first couple times, I automatically sensed, well shit, I'm not so different after all. And just that feeling of not being alone is something because there was experiences that I was scared to talk about...WHAT DO YOU THINK THE MAIN PHILOSOPHY OF SA IS? I think that being not alone [110103]"

"Because she [SA leader] also has a mental illness and she was very warm and a loving person. You know, I felt relaxed. Not just like a professional. See, she was like a peer, had been there, and that is the difference probably ...There's not just one type of schizophrenia anyway. You know, or clinical severe depression, because schizophrenics also share a lot of the same symptoms with one another so we can identify. And we've all gone to see doctors. We've all gone to Community Mental Health or have seen private psychiatrist or therapists. We've all had hospitalization and been on medication, so we all identify with one another...Then, you know, we would hash it all out. You know, you wouldn't feel alone. Like I would think is it just me that they're doing this to and they said no...And helping to solve your problems and you didn't feel so isolated or alone, you know? ...I learned from other people that I'm not alone [120103]."

"I don't know. I felt like, I don't know, just, I think it's helped me, being able to talk more. Not just with psychiatrists but with people like me that have some similar problems [180216]."

"Because it addressed my illness and it gave us guidelines to structure our lives and it also made us aware that we weren't alone. And that's a big factor. When I'd get phone calls, they'd say oh, my gosh. You have the same symptoms I do and you're working and you're, and I didn't think anybody else had those symptoms...That there are varying degrees of illness and that we're not alone. And a set back doesn't mean that you're not successful and success has a lot of different meanings...WHY SHOULD THEY JOIN? So that they're not alone. I would sometimes when I would talk to people that would call me, discuss symptoms and give them the idea that the people who come to SA groups do much better after they become involved because of the fellowship and understanding that they don't get from their families or friends. The understanding, I guess, of what each other has been through [200100]."

"Well, when you're in a support group and you talk about it, it makes you feel like you're not alone, like you're not the only one that wouldn't do it. It helps out that way when it doesn't make you seem like you're crazy or anything...I think it'd let them know they're not alone. That there's other people going through the same problems that they're going through............That if they're interested in making some friends, they can meet some friends their age. And I think the most important thing is they'll know that they're not alone. That other people have the same problems that they go through and you can talk about it at the SA group...Going to SA has helped me realize I have a problem, where I'm at in my life, that I'm not alone [220202]."

"You're not alone...Well, we take medication. We all take medication. We don't work. We know how to deal with day to day not knowing we're going to have a job. And we're all on some type of public assistance, dealing with Medicaid and all this stuff. We're all seeing our doctors....Well, a lot of times, I don't know about others, well, yes, some of us, we're hesitant to say things to our doctors or workers. Because sometimes they tend to wanta... oh, you're going to the hospital, you're going to day care, you know. You don't really need that right then, you know...You just wanta discuss things and some things may be about family, you know...Maybe there's some empathy or more understanding of what you're going through [with SA]. Like I always say you never know until you go through it yourself. And a lot of people have a big distrust of doctors ... Yeah, I was impressed and happy that there was a group that we could go to just to discuss all these things that everyone had pretty much the same experiences. Like, you know, the hospitals, we'd have group therapy. There's all different kinds mixed together. You know. Some that aren't so severely ill that you're kinda shocked, you know. And I was shocked and it upset me. There were some others. But this group, we were all having similar experiences. It was just nice that there was a place you could go to. And everybody kinda understood you and what you were going through [280115]."

"Coming to the meetings, I hear things and I say things that you don't even tell your doctor. But the things that we talk about, we say things and I'm not the only one, there's been more than one person who tells things that we don't even tell the doctor. Because we can relate. There's nothing that either someone or several people in the group haven't done or its happened to them...There's a great difference I can see. We are more open minded here. We're comfortable here. We can talk more freely. We're not scared to talk. Especially when it comes to personal problems or suicide. Personal things like that, we're open minded and that's why I'm very comfortable here [290202]."

"And I really enjoy talking out loud now. But anyway, I think what the group is, it's like the notice says, you're not alone. There's other people like you. And there's other people reaching out for help, too...I like the way she runs [the meeting] because she knows, she's been there and she's been through what I've been through and she know [300202]."

"Just that people who have mental illness like me, the fact that I was not alone in my illness...THE SA GROUP. Yes, I feel safe about saying things to them, you know. And they might have different, same experience I have and so at least I'm not alone, you know [320213]."

"Well, before it was I have schizophrenia and I'm all alone. Now it's like I have schizophrenia but I'm one of many....Because I like the socialization I get with other schizophrenics. It's hard for me to make friends because I have all these symptoms on top of my head and they want to come out right away. I mean, I want to talk about them right away. I want to get feedback and tell people, you know, and connect with reality somehow. The best place to do it is over at the SA meetings and the social groups afterwards because people who don't have the illness don't really, they shy away from you and they don't really... I'm not saying you don't, but most other people don't understand what it's like to have schizophrenia [330205]."

"There's somebody to listen to you [SA group] when you have problems and may have a solution for you. They take the time to understand because they're going through the same thing you're going through....I feel like the mental health services should have SA groups. They should have groups like that, where they come together with their personal problems. Because there are so many who are so depressed and nobody's talking to them out there [traditional services] in the world and they're gonna go to no groups and maybe if they do go to this group, maybe they'll hit on the nose about depression. And there he is, sitting there so depressed and they may call on him to talk. And guess what? Someone will know that he's depressed once he starts speaking. You know, whatever he might think, or may know that he's depressed and they can go ahead and talk to him and try to get him on the right track with the group. Get him out of his depression so he won't do nothing he'll regret, you know, later...They get a chance to voice their feelings. You only get a chance to say what's wrong, what's ailing you [in traditional services]. And then maybe someone in the [SA] group will have a solution. Something they may not have. You know, they may know what to do. What do I do? What do I do with these feelings I have? Who do I talk to? The average person, they'll talk to you but, you know, they really don't understand as much as another person that do have the same problems. That's understanding right there [in SA] [360204]."

"What do I like the most about it. Well, the most thing that I like about it was the people have the same illness I have and I was able to understand more. That I was not alone. There was people out there hurting just like I'm hurting...You learn about the brain and misfunction in the brain. You learn about the voices and different things that happens to us. Like the FBI after us, thinking people reading your mind and you find out that you're not the only one suffering from all those things [380138]."

"I think that maybe I don't know. I have problems. I had a problem similar with a lot of them coming. I think maybe I'm a little bit helpful, I think. Well, we have, one group session and in that group session my problem is the same kind of problem a lot of the people in the group have. It's about money or employers, work, constructive activity. And having enough money to, you know, even get through the month. I brought that up. A lot of people said we all know what you're talking about, girl. You know. Cause they, you know, a lot of us aren't going to work. Not going to work can really make you feel a lot like incompetent and just spend the time trying to think about what do I do today. That was when a lot of people agreed that they identified with that problem. Made them feel better, just knowing that someone else has this problem..."Well, how does this help? You don't feel alone in the world, you know. I guess that's the main object of the whole thing [390238]."

"It's a good group to belong to. You can meet other people that might have things in common with you [450238]."

"So, going to group meant that, they didn't even have to say anything to me directly, there was that commonality. They know where you've been and you know where they've been. Even though we didn't need to talk about each other's shoes and if I'm coming into a group and A sees that I am a stressed one, right away she starts talking to me, diffusing the anxiety. Collecting and disposing of the rubbish and disorder that is within me. It's a catharsis. Excuse the expression. But if you had a pimple on your cheek you would want to pop it right? That's almost want happens in SA with our brains. Sounds ugly but it is a purifying, it's mental hygiene at its best. That is what it means to me [480216]."

"And just remember there are other members that need help. You're not alone. [490204]."

<u>SA is supportive</u> (9)
"I'll call somebody from my meeting. I'll call them and talk to them and that always makes me feel better. Because even when I was able to call my therapist before, she was this old lady that was my therapist and really wasn't like a friend. But with the program I have people to call that are friends. Maybe they don't have all of the answers in the world but they are there for me if I need them and I know that they understand because they went through the same thing [100110]."

"And it was run by a peer person and there's other peer people there. And they gave a lot of support to me which I needed, I needed all the support I could get. It was a very difficult time in my life. So I got a lot of support and love...you know, as little or as much as you like about yourself at that particular time of the day or week or month, what you're going through. And then we offer support and help, you know, as much as we can because we're not professionals [120103]."

"Well, I need support. All I have is my family and sometimes they don't understand my illness and what I'm going through. And I only see the doctor every six weeks so I need that weekly support. Sometimes I need it more than once a week, when I start feeling sad. So I need that weekly support that I get from hearing the group members' stories and their problems and fears [190213]."

"So my group is kind of unique because I'm not as elated about psychiatry and professionals as maybe central SA is. I never had a doctor spend more than 5 minutes with me. Never had a therapist and I think other, the support part of meeting with people with the same symptoms, the same lifestyles, or going through the same miseries is much better preventative medicine than therapy or seeing a psychiatrist...the steps of SA have helped and also the friends and socialization have helped. We try to encourage each other and slap each other on the back once in a while. Give encouragement when we are down and praise when something good happens [200100]."

"Our people, we don't, we go in basically with caring attitude. There is a lot of, you know, at the same time I'm saying that we don't, you know, the group leaders aren't responsible for saying I'll be available to anybody at any time, there actually is, when the group is working well, there is a lot of mutual support [210100]."

"And when we discuss our problems during group, it helps out when it's open table because there's always someone who gives helpful advice in how to deal with it [220202]."

"Well, Schizophrenics Anonymous is where you can bring out your feelings better. But if you're with a mental health worker, all you talk about is you instead of schizophrenia ...Like mental health helps people out, like giving them medication and stuff. But in a Schizophrenics Anonymous group, you get to talk about your problems and plus have people support you. At mental health all you got is your mental health worker and you talk to her or him and they don't, you know, really know... they know what you want to do but they kind of shy away [260214]."

"It was inspiring to see people talking and encouraging each other, you know, and the way they were tolerant of the others who were not as well, you know. Kind and... a lot of empathy. Encouragement [280115]."

"I like SA better, you know. They're more compassionate, you know [320213]."

<u>SA Fosters Helper-Therapy</u> (7)
"It [SA] gives something and I try to give to them everyday. Every single day. I owe them that. You know, it's kind of a mutual thing here. You give and take. It works out...Right now I am fairly stable so hopefully

they'll take some of my stability and run with it because I can share now. When I'm not stable, then I'll take theirs and run with that [050111]."

"I'm able to give them [SA members] advice, they're [SA members] able to give me advice [070105]."

"I found it [SA] very helpful to me. And I found I could help others there, too [280115]."

"I find when I go to a meeting, maybe I need help that one day or somebody else will. It's my way, you know, of giving back...A therapist is there to help you independently...A meeting is like going to a therapist but instead of seeing one person, you're seeing a group of people. And they all give you output....I would say it's just like seeing a therapist but instead of getting one output, you're getting many outputs and people can help you [300202]."

"I think when you go to your therapist, you're expected to talk while he or she listens. But here, it's a give and take. You listen and you talk. And it's when you listen it's sort of like giving a gift to others [340205]."

"I think I helped a lot of people. I know I've helped a lot of people. And a lot of people have helped me in return [350100]."

"Well, you know what they're going through and they might know what you're going through, you know...we can help each other out [450238]."

Level of Closeness Between Members & Providers (5)
"They're [SA] more like a buddy instead of being a parent. I try to think of the doctors as being like your parent. They tell you what to do, whether you think it's good for you or not. SA is kind of like the buddy that you can sit down and talk to and kind of work things out, where the professionals are just gonna do it because they know better because they've had all the schooling and everything else [110103]."

"They're [members of SA] a lot closer to me. The people here can get a lot closer than the doctor does, and the therapist or the treatment specialists or whatever [140211]."

"Oh, yeah. We are more of a fellowship, people in our groups, if groups are working well, we become friends. We don't become friends with therapist [210100]."

"And another thing, we do say the Our Father and the Serenity prayer. Everyone's for it, it's a 100% majority voted for it, and we voted. It was unanimous. And that brings us close, it's just so awesome when we are together holding hands, to me its spiritual. It feels closer together [290202]."

"If I still get a job or if I'm kicked off of social security, I would find a job and still find some way to get to the meeting because for me, it's like seeing my therapist, but it's a little bit more special because you're meeting your friends up there too at the center. We're all friends. I don't want to miss out on nothing [300202]."

Ability to Talk About Illness

SA Provides Ability to Talk about Illness (6)

"My therapist was afraid to talk about it. We weren't allowed to talk about it because when we talked about it, it was like that's going to make you sick and I guess the theory years ago was if you talked about it, you'll get sicker. And I still meet people here whose parents believed it and doctors believe it, that you can get sicker by talking about it. And the one thing that they do usually find out is if you talk about it, things get better. You can share more insight and gain more power over it ...the therapists didn't let me talk about my symptoms. We weren't allowed to talk, I was strongly reprimanded because I saw the same male therapist for like 7 years before SA. Six or 7 years ...and whenever I'd bring up a symptoms, and that was commonly taught at that time, from what I learned in books, is that you don't talk about it. If they talked about their symptoms, they became worse is what they thought. a decade ago, and before that especially...and in therapy it was, you know, that was yesterday, that was yesterday. Don't talk about yesterday. Talk about now. What's happening tomorrow. What are you going to do tomorrow? Go to school. [080102]."

"Because she [SA leader] also has a mental illness and she was very warm and a loving person. You know, I felt relaxed. Not just like a professional. See, she was like a peer, had been there, and that is the difference probably...It's safe, no one takes notes on what we say [120103]."

"That's the most important thing to talk about is how I feel I like this kind of therapy better than I appreciate any kind in the hospital. They make me work too hard in the hospital. Well, in the hospital, they're always having us do some task or something. And I can't handle that [140211]."

"I don't know. I felt like, I don't know, just, I think it's helped me, being able to talk more. Not just with psychiatrists but with people like me that have some similar problems [180216]."

"Well, Schizophrenics Anonymous is where you can bring out your feelings better. But if you're with a mental health worker, all you talk about is you instead of schizophrenia...Like mental health helps people out, like giving them medication and stuff. But in a Schizophrenics Anonymous group, you get to talk about your problems and plus have people support you. At mental health all you got is your mental health worker and you talk to her or him and they don't, you know, really know... they know what you want to do but they kind of shy away [260214]."

"Well, a lot of times, I don't know about others, well, yes, some of us, we're hesitant to say things to our doctors or workers. Because sometimes they tend to wanta... oh, you're going to the hospital, you're going to day care, you know. You don't really need that right then, you know...You just wanta discuss things and some things may be about family, you know...Maybe there's some empathy or more understanding of what you're going through [with SA]. Like I always say you never know until you go through it yourself. And a lot of people have a big distrust of doctors [280115]."

Professionals Uncomfortable with Mental Illness (3)
"My therapist was afraid to talk about it. We weren't allowed to talk about it because when we talked about it, it was like that's going to make you sick and I guess the theory years ago was if you talked about it, you'll get sicker. And I still meet people here whose parents believed it and doctors believe it, that you can get sicker by talking about it. And the one thing that they do usually find out is if you talk about it, things get better. You can share more insight and gain more power over it...the therapists didn't let me talk about my symptoms. We weren't allowed to talk, I was strongly reprimanded because I saw the same male therapist for like 7 years before SA. Six or 7 years ...and whenever I'd bring up a symptoms, and that was commonly taught at that time, from what I learned in books, is that you don't talk about it. If they talked about their symptoms, they became worse is what they thought. a decade ago, and before that especially...and in therapy it was, you know, that was yesterday, that was yesterday. Don't talk about yesterday. Talk about now. What's happening tomorrow. What are you going to do tomorrow? Go to school. [080102]."

"Well, Schizophrenics Anonymous is where you can bring out your feelings better. But if you're with a mental health worker, all you talk about is you instead of schizophrenia...Like mental health helps people out, like giving them medication and stuff. But in a Schizophrenics Anonymous group, you get to talk about your problems and plus have people support you. At mental health all you got is your mental health worker and you talk to her or him and they don't, you know, really know... they know what you want to do but they kind of shy away [260214]."

"Because I like the socialization I get with other schizophrenics. It's hard for me to make friends because I have all these symptoms on top of my head and they want to come out right away. I mean, I want to talk about them right away. I want to get feedback and tell people, you know, and connect with reality somehow. The best place to do it is over at the SA meetings and the social groups afterwards because people who don't have the illness don't really, they shy away from you and they don't really... I'm not saying you don't, but most other people don't understand what it's like to have schizophrenia [330205]."

Consumer Distrust of Professionals (2)
"There was a time when I didn't feel safe with doctors. Or any psychologists, no matter what they would say. I thought they were out to hurt me. I thought they were out to tell my mom and dad, you know, heh, he's dong this. I think you ought to keep him in longer in a mental institution. I feared all doctors [020211]."

"Well, a lot of times, I don't know about others, well, yes, some of us, we're hesitant to say things to our doctors or workers. Because sometimes they tend to wanta... oh, you're going to the hospital, you're going to day care, you know. You don't really need that right

> then, you know...You just wanta discuss things and some things may be about family, you know...Maybe there's some empathy or more understanding of what you're going through [with SA]. Like I always say you never know until you go through it yourself. And a lot of people have a big distrust of doctors [280115]."

SA is More Able to Help Member (4)
"They [SA] seem to help me a lot more than anything else. Seems to be the best kind of therapy for me [140211]."

"Well, A is a very nice woman. She tries to help you. Actually, I think a better thing is LC, my case manager. We talk, just one on one. I get more out of that than SA...well, it's one on one, so I feel more comfortable talking about more personal things [180216]."

"It was a smaller group, much smaller group, much smaller. And I found it was helping me much more....I found it very helpful to me [280115]."

"I find this [SA] more therapeutic [290202]."

SA is Empowering (1)
"it's [mental health services] not known as an empowering group at all...it [SA] is very empowering because it frees you from the ball and chain that you carry around as a mental health consumer in other agencies...I've learned a lot over the years. When I began I learned a lot. I was able to put the disease in perspective, where before that I was just a victim. So it did that [080102]."

SA Members Acknowledge Different Areas of Responsibility for SA & Traditional Services (13)

"Then this time, after I had him and I started going back to SA and I said please, I need this group. It's the only thing that's ever helped me, through all the hospitals, all the medications...So I not only was on medication but I needed other help, too. So that's what made me go back to SA after all that [100110]."

"Well, changing medication. You know, only a doctor can do that. Also, when me and JG have had problems in the past, relationship problems and stuff like that. There's some things that you have to see a professional for, you know? [110103]."

"Yeah, if DZ and I have relationship troubles we can't really go into detail about it. Because he's sitting there and I'm sitting there, you know? They tell you not to go really into detail about that, if you're dating or engaged or married, whatever the relationship is. Just touch on it, don't go into... just like religion or politics or sex or sports [120103]."

"So it's not group therapy. If you want group therapy, you have to go to a clinic or a psychiatrist. Well, a psychiatrist gives you medication and talks about your symptoms. Therapists help you deal with emotional parts of it. And SA helps you, helps you talk about your problems [130115]."

"Well, I need support. All I have is my family and sometimes they don't understand my illness and what I'm going through. And I only see the doctor every six weeks so I need that weekly support. Sometimes I need it more than once a week, when I start feeling sad. So I need that weekly support that I get from hearing the group members' stories and their problems and fears [190213]."

"...the support part of meeting with people with the same symptoms, the same lifestyles, or going through the same miseries [as in SA] is much better preventative medicine than therapy or seeing a psychiatrist. I do agree that medications are wonderful. It, I wouldn't be able to make it without medication so I have to have a psychiatrist....[200100]."

"And there's things that they [SA] might be able to help you through more than your doctor. You know, without throwing more medication at you or this or that. Alternative ways to cope with something...And they [SA] seem to give me more coping skills than my doctor does [280115]."

"My therapist, I would talk more about the family. I'd like to save the kind of personal, personal time and help with personal problems with the group and when it comes to family, I share that with the therapist because I don't want to tie up the time here [290202]."

"I'm a little bit more cautious with my doctor. With him it's like a business deal. You walk in and tell him how you're feeling and he gives you medication and you're out [300202]."

"Well, I think that you can go to SA but you should always still be seeing a doctor for medication. And if you've really got it bad at that time in your life, you may need more healing and you may want to go to a person that you can talk to like a psychiatrist or somebody you can talk to who knows about the illness [330205]."

"Well, yeah. My psychiatrist mostly for the medicine and she tries to take care of things that goes wrong. But my therapist really is the main person that I really talk to more than the psychiatrist...[380138]."

"Outreach treatment... you know, I just didn't have a lot of outpatient treatment. I would go see the psychiatrist. He'd fill out my prescription. Refill it. Mostly I would talk to him; he wouldn't talk to me [410140]."

"That would be the psychiatrist, of course, I go for the medication [440238]."

" [SA] Group is different from my social worker and case manager, in that, group is what can I say it is a somatizing experience. The body of our concerns seems to be there. The peak of my physical experience seems to be my social worker. The peak of my emotional experience seems to be my case worker. And they understand these things [480216]."

APPENDIX G

APPENDIX G

Cross-Case Coding Similar

HOW DO SA MEMBERS DESCRIBE THE SIMILARITIES BETWEEN THE ROLES OF TRADITIONAL SERVICES AND SA IN THEIR RECOVERY?

SA and Traditional Service Structure are Similar

Meeting Schedule (1)

"They're similar in the way that we have a group and sometimes and sometimes not, they're allowed to say what they feel. In other words, if they get their turn, if they don't get their turn, they won't say anything. And I guess the outpatient program I was going to was like a group, too, also. And we'd all sit around and say, and discuss, you know, well, I'm set with this and I feel this way and I wanta do something about it [020211]."

Everyone Getting a Turn (1)

"Sure, everyone gets a turn, I guess [070105]".

Inclusion of Steps in Program (1)

"Well, they do have steps. Most of them all share steps of some sort [120103]."

Process is Similar between SA and Traditional Services

Ability to Share in Both Systems (7)

"They're similar in the way that we have a group and sometimes and sometimes not, they're allowed to say what they feel. In other words, if they get their turn, if they don't get their turn, they won't say anything. And I guess the outpatient program I was going to was like a group, too, also. And we'd all sit around and say, and discuss, you know, well, I'm set with this and I feel this way and I wanta do something about it [020211]."

"How I've been doing. And my symptoms. SO YOU TALK ABOUT SYMPTOMS IN BOTH [060104] Yes."

"Like I said the support and the friendship and be able to open up my feelings [120103]."

"Talk about it and other people will give them advice on how to deal with it. So it's like free counseling. That's what it's like, it's like free counseling...I see them as being the same pretty much. Yeah, I see them as being the same. I think, because when I go in to see my counselor or my psychiatrist, I talk about my problems, too. And I talk about what's going on and I also bring it up to the support group so I feel it is pretty much the same. I feel like it's like being in counseling [220202]."

"Well, usually you, in a traditional setting, you go to a therapist or the doctor or something like that. I guess it's not a whole lot different from a group therapy session. It's a little bigger, there's a few more people...It's a lot like that. Like group therapy...everybody has their say and you get feedback and things like that [250210]."

"The reason I keep coming is that, well, I still need it. But I'm not as desperate for it. It's like seeing a therapist. Even though you get things off your chest, you still go back because you like to talk about it and you also like to feed it back [300202]."

"It's the same because therapists is bringing out your problems. It's the same thing in SA. You talk about your problems and your illness. That's what you're doing with a therapist, too [380138]."

Providing Support (5)
"It's all a support system for people [060104]."

"They're both looking out for your best interest. And one thing that I learned from the doctors is that if you have side effects over two to three days, you should tell your doctor. I like to relay that story to my group, you know? And I like to think that they're both for each other, they're trying to make you a normal person, both of them working together. OK.You know, you got your medication and you've got your health but you know, that's not gonna do it all for you. Just like going to SA is not gonna do it all for you. You need both. OK. And I'm a firm believer in that [110103]."

"Support groups. SO THEY BOTH PROVIDE SUPPORT? Right [240210]."

"Oh, I think it's probably very similar to other mental health establishments...well, it's in the method of their giving their affirmations and their comments during the meeting that I would imagine other mental health places offer the same type of thing [310210]."

"He [psychiatrist] supported me but I could have gotten that same support from SA and SA is free [330205]."

Focus of Efforts in Both Systems (1)
"All concerned with the same subject. Mental health [140211]."

Both Systems Agree with Consumer (1)
"They always agree with you, always. And I get that from staff, you know. Doctors and therapists and everybody, they all pretty agree with me [140211]."

APPENDIX H

APPENDIX H

Cross-Case Coding - Interactions

HOW DO SA MEMBERS DESCRIBE THE INTERACTIONS BETWEEN THE ROLES OF TRADITIONAL SERVICES AND SA IN THEIR RECOVERY?

SA Provides Information About Traditional Services

Dealing with Traditional Services (4)

"Because they've had resources with certain agencies.....because they've had experience with agencies that have helped them with a certain problem....and some have been in therapy longer. Have known about their illness for longer than I've known about mine. So they, they're able to help because of their experiences in that way [010211]."

"I learned about different mental illness, different disorders. Learned about different medications, how to deal with the community mental health therapists or doctors because, you know, sometimes you can have problems [120103]."

"We've had people, like when I first started, they weren't on social security at the time and they tell you who to go to and how to fight for it and how you can make your case better for yourself, and when to get it...and they teach you how to get some insurance for yourself. Where to turn for insurance. Because everyone's gone through the same problems. We get people new all the time that are still working full time. They're having problems holding down their job because they were having mental, schizophrenia problems and stuff. And so the support group helps out a lot [220202]."

"Well, we can encourage each other to tell each other what we do to handle our days. How we handle Medicaid problems, medication problems. How we deal with our families. The way they deal with us, you know. Of course, the doctors, how we deal with them [280115]."

Available Services (3)

"I guess I learn about different treatments constantly and I'm able to listen to different members' problems and I've learned a lot of information that I withdraw as needed, so I know I have tons, you know, recognizing different side effects and things like that, and that's from the experience [080102]."

"Medications come up also. We'll compare, oh, hey, you ought to be taking more of this or try this new thing, it's great. Well, he'll [leader] tell us go to this bookstore and get this information. He tells us who's in charge of the mental health in the area and about hospitals, who to call about hospitals [340205]."

"Or I've got this problem with medication. I didn't know how to deal with it. Or when you go to the therapist and the doctor, you only get so much information and you only get so much time. But I think it's, one thing that really disturbed me, one thing that really kept me going with wanting to be in SA was I wanted to learn more about the different types of programs that were out there. Just in case I ever had a relapse. So I would know where to go. And more importantly, I wanted to learn, what was I gonna say? [350100]."

SA Provides Information About Medication

Medication Compliance (6)

"We reaffirm what the doctor says, unless of course the doctor is crazy and then we'll tell you to consider going somewhere else [070105]."

"I've learned to take my medicine and if I have any problems, to discuss it during group...I also see a psychiatrist that I go to twice a month. That helps out a lot, too. And he always has suggestions. If I should be in a down mood, which I haven't really been feeling like that in a while. But if I felt kind of down, I have a counselor that I go, and a psychiatrist I go to see [220202]."

"Because it [SA] keeps yo out of the hospital because they let you know that medication is very important....To always take my medication until my doctor wants to reduce or take me off it. By doing that, I'll stay out of the hospital...I believe the medication can be addictive but it might give me the common sense I need to keep me from doing what I did...Because it keeps you out of the hospital because they let you know that medication is very important [240210]."

"Medicine, do take your meds. Don't miss your medication. That's very important [290202]."

"I did try to encourage a girl, you know, to make sure she's taking her medication. She wasn't agreeing with what her doctor was trying to have her do [390238]."

"In fact, the first step is I surrender, I admit I need help. I cannot do it alone. So we have to admit that we have the illness or a related illness and we need the help of other people. And I also explain that in SA we rely on professional help. And if the doctor wants it, we comply with taking medication. To keep our illness in remission [410140]."

<u>Types of Medication</u> (4)
"I learned about different mental illness, different disorders. Learned about different medications, how to deal with the community mental health therapists or doctors because, you know, sometimes you can have problems [120103]."

"Of course, we do get newsletters which have information about new medications and things. More about the illness, you know. What to expect down the road, that type of thing. As we grow older, do medications do to us and how the illness progresses and things like that [280115]."

"I've gotten a lot of information from mental health association. I'm not as in the dark as I used to be...the varying ranges of symptoms and the ranges of medications and what people do to help themselves [200100]."

DO YOU GUYS GET INFORMATION ABOUT SCHIZOPHRENIA, LIKE PAMPHLETS OR INFO ON NEW MEDS. "Yes, we do. Yes, we do." OKAY. AND DO YOU FIND THAT HELPFUL? "Do I find that helpful? That's the most important part about the whole program...it has information and it can only go so far though because the latest medication that they discover for our illnesses and they only come out with them every once in a while, you know [370204]."

<u>General Discussion about Medication</u> (4)
"we'd each get a sheet of some new information on new medicine or something [250210]."

"We can even discuss medicines. We can discuss medicines even. And we can exchange ideas on medicine. I think it's fabulous...I really never accepted it. I always passed it off as medical until I came here. Because I had no idea what symptoms were. The doctors would never tell me anything. Bipolar disorder they told me, but I didn't even know what it was. I didn't know the definition until I came here. And now I know by coming here, there's steps that I need to take, there is hope for recovery, whereas before I didn't...I was seeing all these doctors and getting all this medicine, I had no idea what was going on , why I was getting medicine or anything. And now I understand more and I'm open minded. And I like to help other people in a similar situation [290202]."

"Medications come up also. We'll compare, oh, hey, you ought to be taking more of this or try this new thing, it's great. Well, he'll [leader] tell us go to this bookstore and get this information. He tells us who's in charge of the mental health in the area and about hospitals, who to call about hospitals [340205]."

"Or I've got this problem with medication. I didn't know how to deal with it. Or when you go to the therapist and the doctor, you only get so much information and you only get so much time. But I think it's, one thing that really disturbed me, one thing that really kept me going with wanting to be in SA was I wanted to learn more about the different types of programs that were out there. Just in case I ever had a relapse. So I would know where to go. And more importantly, I wanted to learn, what was I gonna say? [350100]."

Side Effects of Medication (2)
"I guess I learn about different treatments constantly and I'm able to listen to different members' problems and I've learned a lot of information that I withdraw as needed, so I know I have tons, you know, recognizing different side effects and things like that, and that's from the experience [080102]."

"I've learned more about the illness...and I would learn new medications to ask my doctor to go on. I learned more about tardive dyskinesia. People who had it would talk about it and how to try to prevent it. There really isn't a way to prevent it, I guess, but to stay away from certain medications [330205]."

SA Encourages Members to Communicate with Traditional Service Providers (7)
"I try to encourage members to be honest [with traditional service providers]. I try to be honest. I don't think I've ever really concealed anything of major importance that I can recall [070105]."

"One night, there was one man having a lot of problems with side effects. He was rocking and he was new to us too. And he was rocking and rocking and the whole group, the [SA] group, a couple of the guys jumped in and told him what he could say to the doctor, that he should tell his doctor, because there were things available to help him...I think we [SA] send people out more empowered to deal with their doctors and deal with their therapists and less intimidated by the diagnosis...ask questions and doubt. If you have a doubt, you're allowed to say so. They believe in medication but they don't, I interpreted it as we believe in medication but we also believe in...we encourage people to have frank discussions about the side effects...they [SA] don't just say it's wonderful, keep taking your medicine, and don't open your mouth and ask any questions, you know? So engage your doctor in frank discussions is encouraged by SA [080102]."

"Well, we would have discussions about what voices are because everybody had a different opinion of what voices are. Or if someone would say the birds are talking to me or I talked with the dog next door, right away more stable people in the group would suggest that they see their doctor and that they may need a medication change or hospitalization. And that they see their doctor right away [200100]."

"Well, we just tell other people, when they say their symptoms are getting worse or too many side effects, we can always say well, try this, it might work, or ask your doctor is what we always say [250210]."

"But the group encourage, when you have symptoms, the group will encourage to talk, to tell your doctor because a lot of us are afraid to tell our doctors. Like if you become suicidal, or we don't want to live, or we are having a severe side effect and we're afraid to tell our doctor, the group will encourage the person...Of course, a doctor gives the medicine and that's very important. Like I said, if the symptoms are strong or you have symptoms, we encourage them to tell the doctor. And we explain why [290202]."

"Well, in the beginning, I used to talk about delusions a lot. And people would ask me questions about the delusions. The bottom line was, are you taking your medication? I always do take my medication because I don't want delusions. Yet I was still having these delusions and I didn't know what to do. People were saying maybe you need an adjustment in your medication which really hadn't occurred to me. I wasn't really sure how to handle all my symptoms until I went to the group and they began to tell me do this. I get my doctors to prescribe me this. They're so full of suggestions...I've learned more about the illness...and I would learn new medications to ask my doctor to go on. I learned more about tardive dyskinesia. People who had it would talk about it and how to try to prevent it. There really isn't a way to prevent it, I guess, but to stay away from certain medications [330205]."

"Oh, yeah. We give each other advice. But it's never like hey, take this. It's like ask your doctor about such and so medicine. A lot of people have trouble because they don't want to take it [340205]."

Members Recognize Need for Both SA and Traditional Services (10)

"It's the best of both worlds...well, one thing that an SA leader should never forget is that SA is an adjunct. You know, we have our limits. The treatment comes from the doctor but if you don't, I mean, you can be on the right medication, but if you've been sick your whole life and you don't know how to socialize. Coming to a group, I mean, you might be symptom free but we can give you pointers...we're like a supplement to their treatment but at the same time, we can offer a unique perspective because we've all been where they are at or have been. They can get unique advice from the inside which you won't be able to get from [the professionals]...we're a supplement to seeing your doctor or your other professionals [070105]."

"and SA truly, with all the years of therapy and the psychiatrists and different meds, SA was step one for me. It truly was. The other [traditional services] sustained me, but it did not do anything for the recovery [080102]."

"And I don't think SA should ever try to do it all, I think it just should stay where it's at now...and, one thing that I learned from the doctors is that if you have side effects over two to three days, you should tell your doctor. I like to relay that story to my group, you know? And I like to think that they're both for each other, they're trying to make you a normal person, both of them working together. You know, you got your medication and you've got your health but you know, that's not gonna do it all for you. Just like going to SA is not gonna do it all for you.

You need both. And I'm a firm believer in that [110103]."

"And helping to solve your problems and you didn't feel so isolated or alone, you know? I did, after the first major breakdown, I had therapy but that was it. I had no other support but the therapist and it was very lonely. Even though I had a job, I felt isolated because no one understood. I was afraid to tell people, you know, how they would react. So I was very, very depressed. Even though I had therapy and stuff, that wasn't enough [120103]."

"...it's not in place of psychiatry or professional help...I do agree that medications are wonderful. It, I wouldn't be able to make it without medication so I have to have a psychiatrist...the symptoms that are the most difficult is the paranoia, but the medication helps me cope. The steps of SA have helped and also the friends and socialization have helped. We try to encourage each other and slap each other on the back once in a while. Give encouragement when we are down and praise when something good happens [200100]."

"Learned from being in SA. The illness isn't totally catastrophic. You can get better. With support, with support. As an adjunct to your doctors, you know...well, we take medication. We all take medication. We don't work. We know how to deal with day to day not knowing we're going to have a job. And we're all on some type of public assistance, dealing with Medicaid and all this stuff. We're all seeing our doctors [280115]."

"But the keys I found out worked out was seeing my therapist, seeing my doctor to get my medication and coming to these meetings...If you listen to your therapist, listen to your doctor and come to group, this meeting, with all three of them combined, it really, I have forgot my past. I'm more focused on my present and future now. This gives me hope [300202]."

"Well, I think that you can go to SA but you should always still be seeing a doctor for medication. And if you've really got it bad at that time in your life, you may need more healing and you may want to go to a person that you can talk to like a psychiatrist or somebody you can talk to who knows about the illness [330205]."

"I think both are important, at least to me [340205]."

"It's just talking about experiences in the group and they'll give you feedback on how you feel or think or whatever. Where in therapy, they try to make you uncover or discover whatever it is that's going on. And sometimes you don't want, you can't discover it if you don't know what you're trying to discover. So you need both. You need to go to both so that one complements the other. Any questions you might have from being in the group, you can then take back to your therapist. And can ask for detail on how to explain it. So it's kinda like informal and formal [350100]."

APPENDIX I

APPENDIX I

Within-Case Analysis: Case Summaries

Personal Narratives With No Reference to SA and Traditional Services

04 is a 36 year old Caucasian male who is a member of SA and has been attending for less than 6 months. He has never been hospitalized. He lives independently and supports himself through his earnings and Social Security Disability. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. He is involved in a day treatment program and receives case management services. He was unable to identify any similarities, differences, or interactions.

09 is a 43 year old Caucasian male who is a leader of SA and has been attending for less than 6 months. He has been hospitalized sixteen times, with his most recent hospitalization being in December of 1994 (3 years). He lives independently and supports himself through his earnings and Social Security Disability. He has been diagnosed with schizophrenia, agrees with the diagnosis and takes psychiatric medication. He is involved in therapy, day programming, and receives medication management services. He was unable to identify any similarities, differences or interactions.

15 is a 40 year old African-American woman who is a leader of SA and has been attending SA for more than two years. She has never been hospitalized. She lives with a member of her family and supports herself with SSI. She has been diagnosed with 'stress', agrees with the diagnosis, and takes psychiatric medication. She participates in day treatment programming. She was unable to identify any similarities, differences or interactions between SA and traditional services.

27 is a 74 year old Caucasian female who is a member of SA and has been attending for more than 6 months but less than 2 years. Information regarding her hospitalizations was not secured. She lives in adult foster care and receives support through SSI and social security disability. Her diagnosis was not shared, nor her agreement therein but, she does take psychiatric medication. In addition to living in adult foster care and taking psychiatric medication, she receives case management services, is involved in day programming, and attends a clubhouse. She was unable to articulate any similarities, differences, or interactions between SA and traditional services.

40 is a 52 year old Caucasian male who is a member of SA and has been attending SA for less than 6 months. He has been hospitalized 3 times with the latest hospitalization being in June of 1985 (12 years). He lives in a supervised apartment and receives support from Social Security Disability. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. In addition to living in a supervised apartment and taking psychiatric medication, he receives therapy, case management services, and attends a drop-in center. He was unable to identify any similarities, differences, or interactions between SA and traditional services.

42 is a 43 year old Caucasian woman who is a member of SA. She has been attending SA for more than 6 months but less than 2 years. She was hospitalized once in August of 1994 (3 years). Her diagnosis was not secured, and as a result, her agreement with the diagnosis is unknown. She does, however, take psychiatric medication. She lives independently and receives support from Social Security Disability. She receives therapy and day programming services and attends a drop-in center. She did not identify any similarities, differences, or interactions between SA and traditional services.

47 is a 48 year old Hispanic man who is a member of SA. He has been a member of SA

for less than 6 months. He has been hospitalized 4 times, with the last hospitalization being in June of 1997 (6 months). He lives in a group home and receives support through Social Security Disability. His diagnosis is unknown, he does not agree with the diagnosis (doesn't believe he has a mental illness), but does take psychiatric medication. In addition to living in a group home and taking psychiatric medication, he attends day programming, receives case management services and attends a clubhouse. He was not able to identify any similarities, differences, or interactions between SA and traditional services.

<u>Personal Narratives That Identified Differences Between SA and Traditional Services</u>

01 is a 46 year old Caucasian male who is a member of SA and has been attending for less than 6 months. He was hospitalized once, in November of 1994 (3 years). He lives independently and is support by his spouse. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, he does not participate in formal programming within the mental health system. When asked about the similarities, differences, and interactions between SA and traditional services, he spoke primarily to differences between the systems and about their interaction in a limited way.

02 is a 36 year old Hispanic male who is a member of SA and has been attending for less than 6 months. He has been hospitalized twice, with his last hospitalization being in October of 1989 (7 years). He lives independently and is supported through his earnings and Social Security Disability. He has been diagnosed with schizophrenia and takes psychiatric medication but he does not agree with the diagnosis (according to interviewer notes, he doesn't think that illness should be labeled. Otherwise, he likes the label because it is the least harmful label, when you label something, it confines it to a certain mode of thinking). He participates in individual therapy.
He was one of the few members who identified some similarities between SA and traditional mental health services. He also expressed that the two systems of care are also characteristically different, in both structure and process.

03 is a 39 year old Caucasian male who is a member of SA and has been attending for more than 6 months but less than 2 years. He has been hospitalized seven times, with his last hospitalization being in February of 1986 (11 years). He lives independently and supports himself with his earnings and Social Security Disability. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, he does not participate in formal programming within the mental health system. When asked about the similarities, differences, and interactions between SA and traditional services, he was, in a limited way, able to articulate differences between these systems of care.

05 is a 44 year old Caucasian woman who is a leader of SA and has been attending SA for more than 2 years. She has been hospitalized twenty-three times (1st at age 22, therefore 23 hospitalizations in the last 22 years), with her last hospitalization being in January of 1996 (10 months). She lives independently and supports herself with Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. She participates in individual therapy, and receives medication management, case management, and day program services. She also attends a clubhouse. 05 identified some of the differences that she sees between SA and traditional services.

06 is a 42 year old Caucasian woman who is a leader of SA and has been attending SA for more than 2 years. She has been hospitalized four times, with her last hospitalization being in October of 1991 (5 years). She lives in adult foster care and receives support

through Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. In addition to living in adult foster care and taking psychiatric medication, she participates in individual therapy. She identified a similarity between SA and traditional services and also spoke to differences between the two systems.

13 is a 36 year old Caucasian woman who is a leader of SA and has been attending SA for more than 2 years. She was hospitalized once in August of 1987 (10 years). She lives with her parents and receives support through Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, she does not participate in formal programming within the mental health system but does occasionally attend a drop-in center. She was able to articulate some of the differences between SA and traditional services and recognize that they address different aspects of recovery.

14 is a 44 year old Caucasian man who is a member of SA and has been attending for less than 6 months. He has been hospitalized eight times, with his last hospitalization being in June of 1992 (5 years). He lives independently and receives support from SSI. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, he does not participate in formal programming within the mental health system but was able to identify some of the similarities and differences between the two systems.

18 is a 28 year old Caucasian man who is a member of SA and has been attending for more than six months but less than two years. He has been hospitalized four times, with the last hospitalization being in June of 1996 (1 year). He lives independently and supports himself through earnings and SSI. He has been diagnosed with schizophrenia but he does not agree with the diagnosis (according to interviewer notes, the consumer doesn't know what he has, may have more anxiety deficit disorder, he's not paranoid, he doesn't hear voices). He takes psychiatric medication. He receives medication management and case management services. He was able to identify some of the differences between SA and traditional services.

21 is a 45 year old Caucasian man who is a leader of SA and has been attending SA for more than two years. He has been hospitalized eight times, with the last hospitalization being in June of 1992 (5 years). He lives independently and supports himself through his earnings and Social Security Disability. He has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. He participates in individual therapy, receives medication management, day programming services, and attends a clubhouse. He only articulated differences between SA and traditional services.

22 is a 28 year old Caucasian man who is a member of SA and has been attending for more than six months but less than two years. He has been hospitalized three times, with the last hospitalization being in November of 1995 (2 years). He lives independently and receives support through Social Security Disability. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. He participates in individual therapy, receives medication management services, and attends a drop-in center. He was one of the members who articulated similarities, differences, and interactions between SA and traditional services.

24 is a 24 year old Caucasian man who is a member of SA and has been attending for more than six months but less than two years. He has been hospitalized two times, with the last hospitalization being in March of 1996 (1 year). He lives with his mother and receives support through Social Security Disability. He has been diagnosed with schizophrenia but he does not agree with the diagnosis. He takes psychiatric medication,

participates in individual therapy and receives medication management services. In a limited way, he was able to articulate similarities, differences, and interactions between SA and traditional services.

25 is a 25 year old Caucasian man who is a member of SA and has been attending for more than two years. He has been hospitalized seven times, with the last hospitalization being in February of 1997 (6 months). He lives with family or friends and receives support through SSI. He has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. He participates in therapy and receives medication management services. In a limited way, he was able to articulate similarities, differences and interactions between SA and traditional services.

26 is a 38 year old Caucasian woman who is a member of SA and has been attending for less than six months. She has been hospitalized fifty times, with the last hospitalization being in June of 1987 (10 years...first hospitalization was in 1967, therefore she had 50 hospitalizations in 20 years). She lives in adult foster care and receives support from SSI and Social Security Disability. She has been diagnosed with borderline personality disorder, she agrees with the diagnosis, and she takes psychiatric medication. In addition to living in adult foster care and taking psychiatric medication, she attends day programming, receives case management services, and attends a drop-in center. She was only able to identify differences, and in a limited way, between SA and traditional services.

29 is a 56 year old Caucasian woman who is a member of SA and has been attending for less than six months. She has been hospitalized three times, with the last hospitalization being in July of 1992 (5 years). She lives independently and receives support from SSI and Social Security Disability. She has been diagnosed with manic-depressive disorder, agrees with the diagnosis, and takes psychiatric medication. She participates in therapy, receives medication management services, and attends a drop-in center. She was able to articulate both differences and interactions between SA and traditional services, expressed that they address different areas of recovery, and that she needed both in her own personal recovery efforts.

32 is a 44 year old African-America woman who is a member of SA and has been attending for more than two years. She has been hospitalized ten times, with the last hospitalization being in March of 1997 (4 months). She lives independently and receives support through employment disability retirement. She has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. She participates in therapy and was able to identify a couple of ways in which there are differences between SA and traditional services.

34 is a 55 year old Caucasian woman who is a member of SA and has been attending for more than six months but less than two years. She has been hospitalized thirty times, with the last hospitalization being in June of 1987 (10 years, 1st hospitalization in 1969, therefore, 30 hospitalizations in 20 years). She lives independently and receives support from Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. She participates in therapy and receives medication management services. She was able to identify both differences and interactions between SA and traditional services.

36 is a 42 year old African America woman who is a member of SA and has been attending for less than six months. She has been hospitalized ten times, with the last hospitalization being in June of 1990 (7 years). She lives independently and supports herself through her employment. She has been diagnosed with manic-depression, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, she does not participate in formal programming within the mental health

system. She was only able to identify one difference between SA and traditional services, that being SA fosters shared experiences between members.

37 is a 40 year old Caucasian man who is a member of SA and has been attending for more than six months but less than two years. house. He has been hospitalized ten times, with the last hospitalization being in October of 1992 (5 years). He lives in a supervised apartment and receives support from SSI. He has been diagnosed with manic-depression, agrees with the diagnosis, and takes psychiatric medication. In addition to living in a supervised apartment and taking psychiatric medication, he receives case management services and attends a clubhouse. In a limited way, he was able to identify a similarity and one dimension of interaction between SA and traditional services.

38 is a 57 year old Caucasian woman who is a leader of SA and has been attending SA for less than six months. She has been hospitalized once, June of 1992 (5 years). She lives independently and receives support from Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. She participates in therapy, receives medication management services, and attends a drop-in center. She was able to identify both similarities and differences between SA and traditional services and recognized that both systems of care address different areas of member recovery.

39 is a 37 year old Caucasian woman who is a member of SA and has been attending for less than six months. She has been hospitalized ten times, with the last hospitalization being in October of 1993 (4 years). She lives in a supervised apartment and receives support through SSI. She has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. In addition to living in a supervised apartment and taking psychiatric medication, she receives case management services and attends a drop-in center. In a limited way, she was able to identify a difference and an interaction between SA and traditional services.

41 is a 67 year old Caucasian woman who is a leader of SA and has been attending SA for more than two years. She has been hospitalized twelve times, with the last hospitalization being in December of 1987 (10 years). She lives in adult foster care and receives support from SSI. She has been diagnosed with schizophrenia and she does not agree with the diagnosis. According to interviewer notes, she said that the diagnosis is not true anymore. She doesn't believe that she's withdrawn as seriously affected as she was. The medication is part of the reason she's in remission but also because of all the care that's been provided for her. In addition to living in adult foster care and taking psychiatric medication, she case management services. She was able to identify many differences between SA and traditional services, including recognizing that the two systems address different aspects of recovery, and that the two systems interact.

44 is a 59 year old Caucasian woman who is a member of SA and has been attending for less than six months. She has been hospitalized six times, with the last hospitalization being in January of 1997 (9 months). She lives independently and receives support through Social Security Disability. She has been diagnosed with manic-depression, agrees with the diagnosis, and takes psychiatric medication. She participates in therapy, receives day programming services, and attends a drop-in center. She was only able to identify differences between SA and traditional services, but, in a limited way, did recognize that both systems address different aspects of member recovery.

45 is a 25 year old Caucasian woman who is a member of SA and has been attending for less than six months. She has been hospitalized twelve times, with the last hospitalization being in April of 1995 (2.5 years). She lives in a supervised apartment and receives support through Social Security Disability. She has been diagnosed with schizophrenia,

agrees with the diagnosis, and takes psychiatric medication. In addition to living in a supervised apartment and taking psychiatric medication, she receives case management services. She was able to articulate several ways in which SA and traditional services were different.

48 is a 42 year old Caucasian man who is a member of SA and has been attending for more than two years. He has been hospitalized twelve times, with the last hospitalization being in February of 1997 (8 months). He lives independently and receives support through Social Security Disability. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. He receives medication management, day programming, and case management services and attends a drop-in center. He was able to identify several ways in which SA and traditional services were different, including recognizing that they address different aspects of member recovery.

49 is a 29 year old Caucasian woman who is a member of SA. She has been attending SA for over 2 years. She has never been hospitalized. She has been diagnosed with Schizophrenia, agrees with the diagnosis, and takes psychiatric medication. She lives independently and supports herself through employment and SSI. She receives medication management services and attends a clubhouse. She was able to identify one way, implicitly, that SA and traditional services were different.

<u>Personal Narratives That Reflected a Need for Both SA and Traditional Services</u>

07 is a 48 year old Caucasian man who is a leader of SA and has been attending SA for more than 2 years. He has been hospitalized five times, with his last hospitalization being in May of 1985 (2 years). He lives independently and receives support through SSI. He has been diagnosed with Obsessive Compulsive Disorder, agrees with the diagnosis, and takes psychotic medication. He receives medication management and case management services. 07 was one of the members who was able to articulate all three dimensions (similarities, differences, and interactions) between the two systems of care. Data emerged both in direct response to the question about this as well as in other parts of his interview. He recognized the need for both SA and traditional services in his recovery efforts.

08 is a 42 year old Caucasian woman who is a leader of SA and has been attending SA for more than 2 years. She has been hospitalized two times, with her last hospitalization being in May of 1996 (1 year). She lives independently and is supported through her earnings. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychotic medication. Beyond taking psychiatric medication, she does not participate in formal programming within the mental health system. 08 was one of the members who was able to articulate similarities, differences, and interactions between the two systems of care and she recognized the need for both SA and traditional services in her recovery efforts.

10 is a 22 year old biracial (½ Hispanic, ½ Caucasian) woman who is a leader of SA and has been attending SA for less than 6 months. She has been hospitalized eleven times, with her last hospitalization being in October of 1995 (2 years). She lives independently and receives support from Social Security Disability. She has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. She also participates in individual therapy and was able to identify both differences and interactions between SA and traditional services. She recognized the need for both SA and traditional services in her recovery efforts.

11 is a 33 year old Caucasian man who is a leader of SA and has been attending SA for more than 2 years. He has been hospitalized two times, with his last hospitalization being in May of 1991 (6 years). He lives independently and receives support through Social Security Disability. He has been diagnosed with schizophrenia, he agrees with the

diagnosis, and takes psychotic medication. He participates in individual therapy and receives medication management services. 11 is a member who was able to identify similarities, differences and interactions between SA and traditional services. He expressed that SA and traditional services address different aspects of recovery and that he needed both in his recovery efforts.

12 is a 44 year old Caucasian woman who is a leader of SA and has been attending SA for more than 2 years. She has been hospitalized two times, with her last hospitalization being in May of 1993 (4 years). She lives independently and receives support through SSI and Social Security Disability. She has been diagnosed with PTSD, manic-depression and personality disorder and takes psychiatric medication but she does not agree with all of the diagnoses. According to interviewer notes, she disagrees with the personality disorder diagnosis. According to the consumer, no one could clarify it for her. She could not remember which personality disorder she was diagnosed with. She participates in individual therapy and medication management services.
12 is a member who was able to identify similarities, differences and interactions between SA and traditional services. Her perspective on this was both in direct response to the question in this regard and it also emerged in other areas of her interview. She expressed that SA and traditional services address different aspects of her recovery and that she needed both.

19 is a 38 year old African-America woman who is a member of SA and has been attending for more than six months but less than two years. She has been hospitalized two times, with the last hospitalization being in June of 1996 (1 year). She lives with her family and is supported through Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. She participates in individual therapy and receives medication management and day programming services. She was able to identify some of the differences and interactions between SA and traditional services and went so far as to say that she needs both SA and traditional services in her recovery efforts.

20 is a 48 year old Caucasian woman who is a leader of SA and has been attending SA for more than two years. She has been hospitalized four times, with the last hospitalization around 1980 (17 years). She lives independently and supports herself through her earnings. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, she does not participate in formal programming within the mental health system. She was able to identify both differences and interactions between SA and traditional services. She recognized that they both address different aspects of recovery and that she needs both in her personal recovery efforts.

28 is a 51 year old Caucasian woman who is a leader of SA and has been attending SA for more than two years. She has been hospitalized eight times, with the last hospitalization being in June of 1995 (2 years). She lives independently and receives support through Social Security Disability. She has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, she does not participate in any outpatient or day treatment services. She was able to articulate both differences and interactions between SA and traditional services, expressed that they address different areas of recovery, and that she needed both in her own personal recovery efforts.

30 is a 30 year old Caucasian man who is a member of SA and has been attending for more than two years. He has been hospitalized two times, with the last hospitalization being in September of 1991 (6years). He lives with his parents and receives support from Social Security Disability. He has been diagnosed with schizophrenia, agrees with the

diagnosis, and takes psychiatric medication. He participates in therapy, receives medication management services, and attends a drop-in center. He was able to articulate similarities, differences, and interactions between SA and traditional services. He expressed that they address different areas of recovery and that he needed both in his own personal recovery efforts.

31 is a 50 year old Caucasian man who is a member of SA and has been attending for less than six months. He has been hospitalized once, in August of 1985 (12 years). He lives with his parents and receives support from Social Security Disability. He has been diagnosed with schizophrenia, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, he does not participate in formal programming within the mental health system. Within a very limited context, he acknowledges one similarity and one interaction between SA and traditional services and that he needs both.

33 is a 35 year old Caucasian woman who is a member of SA and has been attending for more than two years. She has been hospitalized ten times, with the last hospitalization being in November of 1988 (9 years). She lives independently and supports herself through her earnings and Social Security Disability. She has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. She participates in therapy and receives medication management and case management services. She is one of the members who identified similarities, differences, and interactions between SA and traditional services, identifying that each system addresses different aspects of recovery and that she needs both in her own personal recovery efforts.

35 is a 36 year old Caucasian woman who is a leader of SA and has been attending SA for more than two years. She has been hospitalized three times, with the last hospitalization being in March of 1994 (3 years). She lives independently and receives support from her earnings. She has been diagnosed with schizo-affective disorder, agrees with the diagnosis, and takes psychiatric medication. Beyond taking psychiatric medication, she does not participate in formal programming within the mental health system. She identified both differences and interactions between SA and traditional services and recognized the need for both in her own recovery efforts.

REFERENCES

Alcoholics Anonymous (1981). *Twelve steps and twelve traditions.* New York: Alcoholics Anonymous World Services, Inc.

American Self-Help Clearing House (1993), Northwest Covenant Healthcare System, Denville, NJ, 07834.

Antze, P. (1976). The role of ideologies in peer psychotherapy organizations: Some theoretical considerations and three case studies. *Journal of Applied Behavioral Sciences*, 12(3), 323-346.

Bassman, R. (1997). The mental health system: Experiences from both sides of the locked doors. *Professional Psychology: Research and Practice*, 38, 238-242.

Bassman, R. (2000). Agents, not objects: Our fights to be. *Journal of Clinical Psychology: In Session,* 56(11), 1395-1411.

Bassman, R. (2001). Whose reality is it anyway? Consumers/survivors/ex-patients can speak for themselves. *Journal of Humanistic Psychology*, 41(4), 11-35.

Ben-Ari, A.T. (2002). Dimensions and predictions of professional involvement in self-help groups: A view from within. *Health and Social Work*, 27(2), 95-103.

Bennett, T., DeLuca, D.A., & Allen, R.W. (1996). Families of children with disabilities: Positive adaptation across the life cycle. *Social Work in Education,* 18, 33-41.

Berg, B.L. (1995). *Qualitative Research for the Social Sciences.* Boston, MA: Allyn & Bacon.

Bogdan, R.C. & Bilken, K.S. (1992). *Qualitative Research for Education: An Introduction to Theory and Methods.* Needham Heights, MA: Allyn & Bacon.

Bohmer, C. (1995). Failure and success in self-help groups for victims of professional sexual exploitation. *Journal of Community Psychology*, 23, 190-199.

Borkman, T. (1990). Experiential, professional and lay frames of reference. In T. J. Powell (Ed.). *Working with self-help* (pp. 3-30). Silver Spring, MD: NASW Press.

Borkman, T. (1999). *Understanding self-help/mutual aid: Experiential learning in the commons.* New Brunswick: Rutgers University Press

Borkman, T.S., Shaw, M.D., Shaw, R.A., & Hickey, A. (1985). The survivability of self-help groups for persons who stutter: A discriminant analysis. Unpublished manuscript.

Cain, C. (1991). Personal stories: Identity acquisition and self-understanding in Ancoholics Anonymous. *Ethos*, 19(2), 210-253.

Caserta, M.S., & Lund, D.A. (1993). Intrapersonal resources and the effectiveness of self-help groups for bereaved older adults. *Gerontologist*, 33, 619-629.

Chamberlin, J. (1990). The ex-patient's movement: Where we've been and where we're going. *The Journal of Mind and Behavior,* 11(3-4), 323-326.

Chamberlin, J. (1995). Rehabilitation outselves: The psychiatric survivor movement. *International Journal of Mental Health,* 24(1), 39-46.

Cherniss, C., & Cherniss, D.S. (1987). Professional involvement in self-help groups for parents of high-risk newborns. *American Journal of Community Psychology*, 15, 435-444.

Chesler, M.S. (1990). The “dangers” of self-help groups: Understanding and challenging professionals’ views. In T.J. Powell, *Working with self-help* (pp. 301-324). Silver Spring, MD: NASW Press.

Chesler, M.A., & Chesney, B.K. (1995). Cancer and self-help: Bridging the troubled waters of childhood illness. Madison, WI: University of Wisconsin Press.

Chinman, M., Kloos, B., O’Connell, M., & Davidson, L. (2002). Service providers’ views of psychiatric mutual support groups. *Journal of Community Psychology*, 30(4), 349-366.

Christensen, A., & Jacobson, N.S. (1994). Who (or what) can do psychotherapy: The status and challenge of nonprofessional therapies? *Psychological Science*, 5, 8-13.

Comstock, C.M., & Mouhamoud, J.L. (1990). Professionally facilitated self-help groups: Benefits for professionals and members. In T. Powell (Ed.), *Working with Self help* (pp. 177-188). Silver Spring, MD: NASW Publishing.

Davidson, L. (1992). Developing an empirical-phenomenological approach to schizophrenia research. *Journal of Phenomenological Psychology,* 23(1), 3-15.

Davidson, L. & Strauss, J.S. (1995). Beyond the psychosocial model: Integrating disorder, health, and recovery. *Psychiatry*, 58, 44-55.

Davidson, L., Stayner, D.A., Lambert, S., Smith, P., & Sledge, W,H, (1997). Phenomenological and participatory research on schizophrenia: Recovering the person in theory and practice. *Journal of Social Issues*, 53(4), 767-784.

Davison, K.P., Pennebaker, J.W., Dickerson, S.S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, 55(2), 205-217.

Deegan, P.E. (1990). Spirit breaking: When the helping professionals hurt. *The Humanistic Psychologist*, 18(3), 301-313.

Deegan, P.E. (1997). Recovery: The lived experience of rehabilitation. In L. Spaniol, C. Gagne, & M. Koehler (Eds.), *Psychological and social aspects of psychiatric disability* (pp. 92-98). Boston: Boston University Center for Psychiatric Rehabilitation.

Diehl, S.F., Moffitt, K.A., & Wade, S.M. (1991). Focus group interview with parents of children with medically complex needs: An intimate look at their perceptions and feelings. *Children's Health Care,* 20, 170-178.

Emotions Anonymous (n.d.) Emotions Anonymous. Retrieved March 12, 2004, from http://www.emotionsanonymous.org/

Estroff, S.E. (1989). Self, identity, and subjective experiences of schizophrenia: In search of the subject. *Schizophrenia Bulletin*, 15(2), 189-196.

Evered, R. & Louis, M.R. (1981). Alternative perspectives in the organizational sciences: "Inquiry from the inside" and "Inquiry from the outside". *Academy of Management Review*, 6(3), 385-395.

Felix-Ortiz, M.R., Jorge, R.G., Sorensen, J.L., & Plock, D. (2000). Addictions services: A qualitative evaluation of an assisted self-help group for drug-addicted clients in a structured outpatient treatment setting. *Community Mental Health Journal*, 36, 339-350.

Fontana & Frey (1994). Interviewing: The art of science. In Denzin, N.K. & Lincoln, Y. (Eds). *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage Publications.

Frese III, F.J. (2000). Psychology practitioners and schizophrenia: A view from both sides. *Journal of Clinical Psychology: In Session,* 56(11), 1413-1426.

Frese III, F.J., & Davis, W.W. (1997). The consumer-survivor movement, recovery, and consumer professionals. *Professional Psychology: Research and Practice*, 28, 243-245.

Gamblers Anonymous (2000). *GA: Sharing Recovery through Gamblers Anonymous.* Los Angeles, CA: The G.A. Publishing Co.

Gartner, A., & Reissman, F. (1977). *Self-help in the human services.* San Francisco: Jossey-Bass.

Gilden, J.L., Henrdyx, A.S., Clar, S., Casia, C., & Singh, S.P. (1992). *Diabetes support groups improve health care of older diabetic patients.* Journal of the American Geriatrics Society, 40, 147-150.

Glaser & Strauss (1967). *The Discovery of Grounded Theory.* Chicago, IL: Aldine.

GROW (1987). *GROW, World Community Mental Health Movement, The Program of Growth to Maturity*, Sydney, Australia: GROW Publications

Hatfield, A.B. & Lefley, H.P. (1993). *Surviving mental illness: Stress, coping and adaptation.* NY, NY: Guilford Press.

Hinrichsen, G.A., Revenson, T.A., & Shinn, M. (1985). Does self-help help? An empirical investigation of scoliosis peer support groups. *Journal of Social Issues*, 41, 65-87.

Hodges, J.Q., Markward, M., Keele, C., & Evans, C.J. (2003). Use of self-help services and consumer satisfaction with professional mental health services. *Psychiatric Services*, 54, 1161-1163.

Holstein, J.A. & Gubrium, F. F. (1995). *The Active Interview.* Newbury Park: Sage.

Humphreys, K. (1997). Individual and social benefits of mutual aid/self-help group. *Social Policy,* 27, 12-19.

Humphreys, K. (1999). Professional interventions that facilitate 12-step self-help group involvement. *Alcohol Research and Health*, 23(2), 93-98.

Humphreys, K., Huesbsch, P.D., Finney, J.W., & Moos, R.H. (1999). A Comparative evaluation of substance abuse treatment: V. substance abuse treatment can enhance the effectiveness of self-help groups. *Alcoholism: Clinical and Experimental Research*, 23(3), 558-563.

Humphreys, K. & Moos, R. (1996). *Reduced substance-abuse-related health care costs among voluntary participants in Alcoholics Anonymous.* Psychiatric Services, 47, 709-713.

Humphreys, K., & Moos, R. (2001). Can encouraging substance abuse patients to participate in self-help groups reduce demand for health care? A quasi-experimental study. *Alcoholism: Clinical and Experimental Research*, 25(2), 711-716.

Humphreys, K., & Rappaport, J. (1994). Researching self-help/mutual aid groups and organizations: Many roads, one journey. *Applied and Preventive Psychology,* 3, 217-231.

Iscoe, L., & Bordelon, K. (1985). Pilot parents: Peer support for parents of handicapped children. *Children's Health Care*, 14, 96-103.

Jacobs, M.K., & Goodman, G. (1989). Psychology and self-help groups: Predictions on a partnership. *American Psychologist*, 44, 536-545.

Katz, A.H. (1981). Self-help and mutual aid: An emerging social movement. *Annual Review of Sociology*, 7, 129-155.

Kearney, M.H., Murphy, S., & Rosenbaum, M. (1994). Mothering on crack cocaine: A grounded theory analysis. *Social Science and Medicine,* 38(2), 351-361.

Kennedy, M., & Humphreys, K. (1995). Understanding worldview transformation in members of mutual help groups. In F. Lavoie, T. Borkman, & B. Gidron, *Self-help and mutual aid groups: International and multicultural perspectives* (pp. 181-198). New York: Haworth.

Kessler, R.C., Mickelson, J.D., & Zhao, S. (1997). Patterns and correlates of self-help group membership in the United States. *Social Policy*, 27, 27-46.

King, G., Stewart, D., King, S., & Law, M. (2000). Organizational characteristics and issues affecting the longevity of self-help groups for parents of children with special needs, *Qualitative Health Research*, 10(2), 225-241.

Kownacki, R.J., & Shadish, W.R. (1999). Does Alcoholics Anonymous work? The results from a meta-analysis of controlled experiments. *Substance Use & Misuse*, 34(13), 1897-1916.

Krouyz, E.M., & Humphreys, K. (1999). A review of research on the effectiveness of self-help mutual aid groups [WWW document]. Retrieved from http://www.cmhc.com/articles/selfres.htm

Kurtz, L.F. (1988). *Mutual aid for affective disorders: The manic depressive and depressive association.* American Journal of Orthopsychiatry, 58, 152-155.

Kurtz, L.F. (1990a). The self-help movement: Review of the past decade of research. *Social Work With Groups*, 13, 101-115.

Kurtz, L.F. (1997). *Self-help and support groups: A handbook for practitioners.* Thousand Oaks, CA: Sage Publications.

Kurtz, L.F., & Chambon, A. (1987). Comparison of self-help groups for mental health. *Health and Social Work*, Fall, 275-283.

Kurtz, L.F., Garvin, C.D., Hill, E.M., Pollio, D., McPherson, S., & Powell, T.J. (1995). Involvement in Alcoholics Anonymous by persons with dual disorders. *Alcoholism Treatment Quarterly*, 12(4), 1-18.

Kurtz, L.F., Mann, K. B., & Chambon, A. (1987). Linking between social workers and mental health mutual aid groups. *Social Work in Health Care*, 13(1), 69-78.

Kurtz, L.F., & Powell, T.J. (1987). Three approaches to understanding self-help groups. *Social Work with Groups*, 10, 69-80.

Lavoie, F., Borkman, T., & Gidron, B. (Eds). (1995). *Self-help and mutual aid groups: International and multicultural perspectives.* New York: Haworth.

Law, M., King, S., Stewart, D., King, G., Terry, L., & Chiu, J. (1999). The effects of parent support groups for parents of children with disabilities. Manuscript submitted for publication.

Leete, E. (1997). How I perceive and manage my illness. In L. Spaniol, C. Gagne, & M. Koehler (Eds.), *Psychological and social aspects of psychiatric disability* (pp. 99-103). Boston: Boston University Center for Psychiatric Rehabilitation.

Lieberman, M.A. (1979). Help seeking and self-help groups. In M.A. Lieberman, L.D. Borman, & Associates (Eds.), *Self-help groups for coping with crisis* (pp. 116-149). San Francisco: Jossey-Bass.

Lieberman, M.A., & Bliwise, N.G. (1985). Comparisons among peer and professionally directed groups for the elderly: Implications for the development of self-help groups. *International Journal of Group Psychotherapy,* 35, 155-175.

Lieberman, M.A., & Borman, L.D. (1979). *Self-help groups for coping with crisis: Origins, members, processes, and impoact.* San Francisco: Jossey-Bass.

Lemberg, R. (1984). Ten ways for a self-help group to fail. *American Journal of Orthopsychiatry,* 54, 648-650.

Levine, M. (1988). An analysis of mutual assistance. *American Journal of Community Psychology*, 16(2), 167-183.

Levine, M., & Perkins, D.V. (1987). *Principles of community psychology: Perspectives and applications.* New York: Oxford University Press.

Levy, L.H. (1976). Self-help groups: Types and psychological processes. *Journal of Applied Behavioral Science,* 12, 310-322.

Levy, L.H. (2000). Self-help groups. In J. Rappaport & E. Seidman (Eds). *Handbook of Community Psychology,*, (pp., 591-614), New York: Kluwer Academic/Plenum

Press.

Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry.* Beverly Hills, CA: Sage.

Lincoln, Y. & Guba, E.G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation,* 30, 73-84.

Lincoln, Y. & Guba, E.G. (1989). *Fourth Generation Evaluation.* Newbury Park, CA: Sage.

Lotery, J.L., & Jacobs, M.K. (1995). The involvement of self-help groups with mental health and medical professionals: The self-helpers' perspective. In F. Lavoie, T. Borkman, & B. Gidron (Eds.) *Self-help and mutual aid groups: International and multicultural perspectives* (279-302). Binghamton, NY: Haworth Press.

Lund, D.A., & Caserta, M.S. (1992). Older bereaved spouses' participation in self-help groups. *Omega Journal of Death and Dying,* 25, 47-61.

Lynch, K. (2000). The long road back. *Journal of Clinical Psychology: In Session,* 56(11), 1427-1432.

Makela, K., Arminen, I., Bloomfield, K., Eisenbach-Stangl, I., Bergmark, K.H., Kurube, N., Mariolini, N., Olagsdottir, Peterson, J.H., Phillips, M.., Rehm, J., Room, R., Rosenqvist, P., Rosovsky, H., Steinius, K., Swiatkiewics, G., Woronowicz, B., & Zielinski, A. (1996). *Alcoholics Anonymous as a mutual-help movement: A study in eight societies.* Madison: University of Wisconsin Press.

Mankowski, E., Humphreys, K., & Moos, R. (2001). *Individual and contextual predictors of involvement in twelve-step self-help groups after substance abuse treatment*, American Journal of Community Psychology, 29(4), 537-563.

Manulyn, C., Solomon, P., and Draine, J. (1999). *Self-help groups for families of persons with mental illness: Perceived benefits of helpfulness*, Community Mental Health Journal, 35(1), 15-30.

Marsh, D.T., Koeske, R.D., Schmidt, P.A., Martz, D.P., & Redpath, W.B. (1997). A person-driven system: Implications for theory, research and practice. In L. Spaniol, C.Gagne, & M. Koehler (Eds.), *Psychological and social aspects of psychiatric disability* (pp. 358-369). Boston: Boston University Center for Psychiatric Rehabilitation.

Maton, K.I. (1988). Social support, organizational characteristics, psychological well-being, and group appraisal in three self-help group populations. *American Journal of Community Psychology,* 16, 53-77

Maton, K.I., Leventhal, G.S., Madara, E.J., & Julien, M. (1989). Factors affecting the birth and death of mutual-help groups: The role of national affiliation, professional involvement, and member focal problem. *American Journal of Community Psychology,* 17, 643-671.

Maxwell, J.A. (1996). *Qualitative Research Design: An interactive approach.* Thousand Oaks, CA: Sage Publications.

McCallion, P., & Toseland, R.W. (1995). *Supportive group interventions with caregivers of frail older adults.* Social Work with Group, 18(1), 11-25.

Meissen, G.J., Gleason, D.J., & Embree, M.G. (1991). An assessment of the needs of mutual-help groups. *American Journal of Community Psychology*, 17, 427-442.

Meissen, G.J., Mason, W.C., & Gleason, D.F. (1991). Understanding the attitudes and intentions of future professionals toward self-help. *American Journal of Community Psychology*, 19(5), 699-714.

Meissen, G.J., & Warren, M.L. (1997). Self-help groups and managed care. Building a research and action agenda. Paper presented at the Biennial Conference on Community Research and Action, Columbia, South Carolina, June 1997.

Mental Health Association in Michigan (1992). Blue Booklet.

Merriam, S. (1988). *Case study research in education: A qualitative approach.* San Francisco, CA: Jossey-Bass Inc., Publishers.

Miles, M.B. & Huberman, M.A. (1994). *Qualitative Analysis: An Expanded Sourcebook.* Thousand Oaks, CA: Sage Publications.

Mishler, E.G. (1986). *Research Interviewing: Context and narrative.* Cambridge, MA: Harvard University Press.

Moos, R., Schaefer, J., Andrassy, J., & Moos, B. (2001). Outpatient mental health care, self-help groups, and patients' one-year treatment outcomes. *Journal of Clinical Psychology*, 57(3), 273-287.

Morgenstern, J., Labouvie, E., McCrady, B.S., Kahler, C.W., & Frey, R.M. (1997). Affiliation with Alcoholic Anonymous after treatment: A study of its therapeutic effects and mechanisms of action. *Journal of Consulting and Clinical Psychology*, 65, 768-777.

Murray, R. (1996). Recovery, Inc., as an adjunct to treatment in an era of managed care. *Psychiatric Services,* 47, 1378-1381.

National Schizophrenia Foundation (2002). *Schizophrenics Anonymous: A self-help support group.* Lansing, MI

Norcross, J.C., Santrock, J.W., Campbell, L.F., Smith, T.S., Sommer, R., & Zuckerman, E.L. (2000). *Authoritative Guide to self-help resources in mental health.* New York: Guilford.

Ouimette, P.C., Finney, J.W., & Moos, R.H. (1997). Twelve-step and cognitive-behavioral treatment for substance abuse: A comparison of treatment effectiveness. *Journal of Consulting and Clinical Psychology*, 65, 230-240.

P., John. (1997). Schizophrenics Anonymous and psychiatric rehabilitation. In C.T. Mowbray, D.P. Moxley, C.A. Jasper, & L.L. Howell (Eds.), *Consumers as providers* (95-105). IAPSRS.

Patton, M.Q. (1990). *Qualitative research and evaluation methods* (2nd ed). Newbury Park, CA: Sage.

Penney, D. (1997). Self-help friend or foe: The impact of managed care on self-help. *Social Policy,* 27, 48-53.

Phillips, M. (1990). Support groups for parent of chronically ill children. *Pediatric Nursing,* 16, 404-406.

Powell, T.J. (1975). The use of self-help groups as supportive reference communities. *American Journal of Orthopsychiatry*, 45(5), 756-764.

Powell, T.J., Silk, M.D., & Albeck, J.H. (2000). Psychiatrists' referrals to self-help groups for people with mood disorders. *Psychiatric Services*, 51, 809-811.

Project MATCH Research Group. (1997). Matching alcoholism treatments to client heterogeneity: Project MATCH posttreatment drinking outcomes. *Journal of Studies on Alcohol,* 58, 7-29.

Raiff, N.R. (1978). Recovery Inc.: A study of a self-help organization in mental health. *Dissertation Abstracts International*, 40 (2-A), 1085. (University Microfilms No. 79-17472).

Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in the mutual help context. *The Journal of Applied Behavioral Science*, 29(2), 239-256.

Rappaport, J., Reischl, T.M., & Zimmerman, M.A. (1992). Mutual help mechanisms in the empowerment of former mental patients. In D. Daleebey (Ed.), *The Strengths Perspective in Social Work*, (pp. 84-97). New York: Longman.

Rappaport, J., Seidman, E., Toro, P.A., MacFadden,L.S., Reischl, T.M., Roberts, L.J., Salem, D.A., Stein, C.H., & Zimmerman, M.A. (1985). Collaborative research with a mutual-help organization. *Social Policy,* 15, 12-24.

Rawlins, P.S., & Horner, M.M. (1988). Does membership in a support group alter needs of parents of chronically ill children? *Pediatric Nursing*, 14, 70-72.

Recovery, Inc. (n.d.). Recovery, Inc. Retrieved March 12, 2004, from http://www.recovery-inc.com/introduction.html

Reissman, F. (1965). The "Helper-therapy" principle. *Social Work*, 10, 27-32.

Reissman, F. (2000). A demand side cure for the chronic illness crisis. *Social Policy*, 30, 2-4.

Reissman, F. & Banks, E.C. (2001). A marriage of opposites: Self-help and the health care system. *American Psychologist*, 56(2), 173-174.

Reissman, F. , & Carrol, D. (1995). Redefining self-help: Policy and practice. San-Francisco: Jossey-Bass.

Roberts, L.J., Luke, Rappaort, J., Seidman, E., Toro, P., & Reischl, T. (1991). *Charting uncharted terrain: A behavioral observation system for mutual help groups.* American Journal of Community Psychology, 19(5), 715-737.

Roberts, L.J., Salem, D.A., Rappaport, J., Toro, P.A., Luke, D.A., & Seidman, E. (1999). *Giving and receiving help: Interpersonal transactions in mutual-help meetings and psychosocial adjustment of members.* American Journal of Community Psychology, 27(6), 841-868.

Salem, D.A., Reischl, T.M., Gallacher, F., Randall, K.W. (2000). *The role of referent and expert power in mutual help.* American Journal of Community Psychology, 28(3), 303-324.

Salzer, M.S., McFadden, L., & Rappaport, J. (1994). Professional views of self-help groups. *Administration and Policy in Mental Health*, 22(2), 85-95.

Salzer, M., Rappaport, J., & Segre, L. (2001). Mental health professionals' support of self-help groups. *Journal of Community and Applied Social Psychology*, 11, 1-10.

Schubert, M.A., & Borkman, T.J. (1991). An organizational typology for self-help groups. *American Journal of Community Psychology*, 19, 769-787.

Schwant, T. (1994). Constructivist, interpretivist approach to human inquiry. *In* Denzin, N.K. & Lincoln, Y (Eds.), *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage Publications.

Segal, S.P., & Silverman, C. (2002). Determinants of client outcomes in self-help agencies. *Psychiatric Services,* 53, 304-309.

Seligman, M.E.P. (1995). The effectiveness of psychotherapy. *American Psychologist*, 50, 965-974.

Sheperd, M.D., Schoenberg, M., Slavich, S., Wituk, S., Warren, M., & Meissen, G. (1999). Continuum of professional involvement in self-help groups. *Journal of Community Psychology,* 27(1), 39-53.

Solomon, M., Pistrang, N., & Barker, C. (2001). *The benefits of mutual support for parents of children with disabilities,* 29(1), 113-132.

Stewart, M.J. (1990). Professional interface with mutual-aid groups: A review. *Social Science Medicine*, 31, 1143-1158.

Stewart, M.J., Banks, S., Crossman, D., & Poel, D. (1995). Partnership between health professionals and self-help groups: Meanings and mechanisms. In F. Lavoie, T. Borkman, & B. Gidron (Eds.) *Self-help and mutual aid groups: International and multicultural perspectives* (199-240). Binghamton, NY: Haworth Press.

Stewart, M.J., Banks, S., Crossman, D., & Poel, D. (1995). Health Professionals' perception of partnership with self-help groups. *Canadian Journal of Public Health*, 86, 340-344.

Tappan, M.B. (1997). Interpretive psychology: Stories, circles, and understanding lived experience. *Journal of Social Issues,* 53(4), 645-656.

Temes, R. (2002). *Getting your life back together when you have Schizophrenia.* Oakland, CA: New Harbinger Publications.

Tenney, L. (2000). It has to be about choice. *Journal of Clinical Psychology: IN Session*, 56(11), 1433-1445.

Tonigan, J.S., Toscoova, R., & Miller, W.R. (1995). Meta-analysis of the literature on Alcoholics Anonymous: Sample and study characteristics moderate findings. *Journal of Studies on Alochol*, 57, 65-72.

Toro, P.A., Rieschl, T.M., Zimmerman, M.A., Rappaport, J., Seidman,E., Luke, D.A., & Roberts, L.J. (1988). Professionals in mutual-help groups: Impact on social climate and member's behavior. *Journal of Consulting and Clinical Psychology*, 56, 631-632.

Tosland, R.W., Rossiter, C.M., Peak, T., & Smith, G.C. (1990). Comparative effectiveness of individual and group interventions to support family caregivers. *Social Work*, 35(3), 206-216.

Walsh, D. (1999). Coping with a journey toward recovery: From the inside out. In R.P. Marinelli & A.E. Dell Orto (Eds.), *The Psychological and social impact of disability* (4th ed.; pp. 55-61). New York: Springer.

Walsh, J. (1994). Schizophrenics Anonymous: The Franklin County, Ohio experience. *Psychosocial Rehabilitation Journal*, 18(1), 61-74.

Warner, R. (1996). Response to "The Role of Self-Help Programs in the Rehabilitation of Persons with Severe Mental Illness and Substance Use Disorders." *Community Mental Health Journal*, 32(1), 83-86.

Weaver Randall, K. (2000). *Understanding Recovery From Schizophrenia in a Mutual-Help Setting.* Unpublished masters thesis, Michigan State University, E Lansing, Michigan.

White, B.J., & Madara, E.J. (Eds). (1995). *The self-help sourcebook: Finding and forming mutual aid self-help groups* (5th ed.). Denville, NJ: American Self-Help Clearninghouse.

White, B.J., & Madera, E.J. (1998). *The self-help sourcebook.* Denville, NJ: Northwest Covenant Medical Center.

Wituk, S.A., Sheperd, M.D., Warren, M., Meissen, G. (2002). Factors contributing to the survival of self-help groups. *American Journal of Community Psychology*, 30(3), 349-366.

Yanos, P.T., Primavera, L.H., and Knight, E.L. (2001). Consumer-run service participation, recovery of social functioning, and the medicating role of psychological factors. *Psychiatric Services*, 52, 493-500.

York, M., & Chesler, M. (1985). Alternative professional roles in health care delivery: Leadership patterns in self-help groups. *Journal of Applied Behavioral Science*, 21, 427-444.