A study of patients and their primary caregivers' involvement in a psychoeducational support group (PSG) was perceived to be necessary because of an experience as a group leader by one of the authors. Information about mental illness, its management and the services available, as well as the need for a supportive group setting in which relatives can discuss their difficulties, is important to patients' rehabilitation. Such educational programs are being implemented slowly in psychiatric settings and many have been evaluated objectively (Baker, 1989; Koontz, Cox, & Hastings, 1991). This article presents descriptive findings from a study designed to explore the experience of family members attending a psychoeducational support group and the perceived benefits of attendance.

Data were collected via indepth interviews from four families who had attended the PSG. Interviews were tape recorded and analyzed for recurring themes by adapting a method of analysis designed by Colaizzi (1978). This study focuses on five themes: hope, universality, adaptation and acceptance, and empowerment. It concludes that psychoeducational support groups are of significant value for families.

With the emphasis of reintegration of clients into the community, families once again must cope with their mentally ill relatives at home. These families need—and will continue to need—more concrete help from health professionals than they have in the past.

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Liberman (1989) concurs with this by stating that, “the burden of care for people suffering from chronic schizophrenia has moved from hospitals to families and other community agencies” (p. 200). Anderson, Hogarty, and Reiss (1980) state that “the presence of a mentally ill family member has a profoundly disruptive, disorganizing effect on family life. The family is faced with the challenge of providing for the needs of its ill member while negotiating the inevitable conflicts among its healthy members, all within an atmosphere fraught with confusion, stigma and secrecy” (p. 491).

The major reasons for providing PSGs are to combat these difficulties. Bernheim and Lehman (1985) support this by stating that two of the reasons for providing such programs are, “the high levels of burden experienced by families in caring for their ill relative, and families’ identified needs for more information and constructive advice about the patient’s illness and treatment” (p. 31).

Knowledge of the illness and treatment would not only assist family members in developing their coping strategies, it also would provide a more positive experience with health professionals who are providing the psychoeducation. Anderson and colleagues (1980) concur with this by stating, “family psychoeducational programs inform families about the illness and treatment, create a collaborative atmosphere between family and professional, and encourage practical problem solving, and creation of a structured home environment to reduce stress” (Anderson et al., 1980, p. 498). Palmer-Erbs & Anthony (1995) state that “nurses must be prepared to participate fully in programming that emphasizes the development of a partnership relationship and a movement toward consumer and family involvement highlight a core value in nursing practice” (p. 36).

Literature Review
Much has been written about the effect of mental illness on families, and the role families play in rehabilitation of patients (Baker, 1989; Bhaskaran, 1985; Clausen 1981). Falloon and Shanahan (1990) state that “schizophrenia is a major public health problem which often means a lifetime of disability for the sufferer and which usually represents a major drain on the resources of a family” (p. 63). Brooker, Barrowclough, & Tarrier (1992) believe that health education is a “cornerstone for the other aspects of psychosocial intervention” that aim at reducing the family’s stress. Bernheim and Lehman (1985) stated that “families have consistently identified the lack of basic education about the nature, treatment and prognosis of mental illness as a serious gap in the service delivery system” (p. 76).

Many educational approaches have been explored by researchers (Brooker et al., 1992). The Knowledge About Schizophrenia Interview (KASI), a semistructured interview guide, was used by Brooker and colleagues to focus on knowledge the families needed. They believe that if the families received information about diagnosis, prognosis, symptoms, management, medication, and etiology, they would understand that “this odd behavior, far from being controllable, was often a likely consequence of illness.”

The KASI interview was used in this study as an interview guide to provide group leaders with an understanding of the family’s perception of the illness prior to receiving some formal education. This approach is supported by Tarrier and Barrowclough (1986) who reported the need to assess and to take into account the “relatives’ perceptions of the illness,” before “embarking on the task of giving information.” Brooker et al. (1992) state that one of the advantages of the KASI may be the identification of relatives with beliefs and attitudes that could result in actions detrimental to the patients’ well-being, and who consequently require further advice and support.

In reviewing the literature, the authors found that previous research related to family and psychoeducation was based on the evaluation of knowledge gained from attending such groups (Baker, 1989; Koontz et al., 1991). It is evident that PSGs have been researched using quantitative research methods in regard to what the families have learned—such methods providing data regarding “knowledge learned.”

Research Design and Methodology
The authors chose phenomenology as the research method because other
papers have identified quantitatively the benefits of improved knowledge for the family (Koonz et al., 1991). This study fills a gap in nursing knowledge by focusing on the lived experience of families attending a PSG. It identifies their attitudes, beliefs, and attributions about the illness and the PSG, and further provides supporting evidence on the benefits, as perceived by them, rather than the professionals who conduct the groups.

Ray (1985) states that “phenomenology’s purpose is to seek a fuller understanding through description, reflection, and direct awareness of a phenomenon to reveal the multiplicity of coherent and integral meanings of the phenomena” (p. 173).

The PSG in this study ran for 11 weeks with a total of six families in the group; two registered psychiatric nurses and a medical officer participated as group leaders. The sample consisted of four families who agreed to share their lived experience of attending their first psychoeducation support group and by consenting to having their interviews recorded.

Two families wished to be excluded from the study. One family had a member who had difficulty expressing herself as a result of a cerebrovascular accident 3 years prior to the commencement of the study. A second family had a member with various medical problems who required frequent surgical interventions. This resulted in their experiencing increased personal stress and unavailability at interviews.

All interviews were held in the families’ homes, as requested by the participants, as this established a more relaxed and open environment. Interviews were of an unstructured nature, with no time limit set, to allow family members to exhaust their description of the phenomena in question. Participants were interviewed as a family but individuals were able to express individual feelings and experiences. The use of phenomenological methodology accepts both the subjective and objective experiences, and endeavors to understand the total meaning that the experience had for those involved.

**Data Analysis**

Analysis of data was performed by adapting a method designed by Colaizzi (1978). Approaching the data analysis in this manner revealed five common themes: hope, universality, adaptation and acceptance, and empowerment.

**Hope**

The phenomena of hope was one of the first clear themes to emerge as the data were analyzed. Hope is related to dependence on others, choice, wishing, trust and perseverance, and courage, and is future oriented (Marriner-Tomey, 1989). The following comments were taken from a member of one family to support the finding of this theme.

You’d had a bad week or something had happened, but then you were able to talk among yourselves or other families and it just made you feel that at least there’s hope, and I think that’s what it gives you all along. Not only for us, but for John.

When John was first diagnosed, the literature and the pamphlets I was given, made me feel that John’s life was over. I really felt very sad for John. I thought that life isn’t worth living for him any longer; but understanding, having it all explained in so much detail—there is hope, there is a chance for his life to get a better balance. It’s not all bad, is it?

I think that made us feel a lot better.

Having all the symptoms explained to me and the medications explained, and having a look over the various facilities was very good, because you could see...well, it gave me a lot of hope. Some literature that we’ve had has been very good, but some books that we’ve picked up, you know, we’ve seen schizophrenia written on something and we’ve picked it up and read it, and they’ve been downright depressing. I felt that the whole 11 weeks gave me far more hope than I’ve ever read in a book. I wish we’d been able to attend a group like this 4 or 5 years ago, that would have saved us a lot of sleepless nights.

It eased our minds, there is hope. Prior to this we were given no hope—we felt that there was none whatsoever. Everything was black, but now there is hope.

It makes you realize that there is a light somewhere, that one day there will be something to look forward to, and that it’s just not all black, there is a bit of light there at the end of that tunnel. Before the group I thought, “This is it, the end of the world.” Yes, [the group] definitely made me feel a lot better.

The expression of hope by individuals encouraged others in the group to become hopeful, so that they, too, perceived “light at the end of the tunnel.” The honesty that was shared among the leaders and the family members enhanced the sense of hope to be developed. Effective nursing practice is characterized by hope and optimism that all clients, no matter how debilitated, have the capacity for growth and change. This sense of hope that the majority of nurses have, or should have, must be passed on to the families of these clients so that they, too, may develop a sense of hope.

**Universality**

Yalom (cited in Moller & Wer, 1989) describes universality as one of his 11 therapeutic factors in group therapy. It exists, according to Yalom, when group members feel a “common human bond” as they realize others have experienced similar thoughts, feelings, and actions. This sense of universality also enhances a sense of catharsis for family members in that, often for the first time, “group members are able to express thoughts, feelings, and fears not previously expressed, and feel understood and
accepted by others.”

General comments, such as “We didn’t feel alone with our problem any longer,” “[It is] a great help to see how other families deal with problems that have developed,” and “[We were] able to talk to people who understand the problems that we have,” were evident throughout the interviews.

The following are more specific statements that families made in relation to the phenomena of universality.

At first when it was diagnosed, we felt that we were the only people in the world with this problem. To see other people’s experiences, the way their family members were experiencing their schizophrenia, the different effects it has on different people—talking to those people, and among yourselves, it just felt easier.

It also was a very good meeting with other parents who had problems similar to ours, and going through a similar experience that we’ve been through over the last few years. It gave more confidence in each other, to listen to what each other was saying, and to the staff at the same time. I found those sessions extremely profitable.

The night we spoke, about three or four people came up to me and said they admired us for what we said and for what we’d done. It opened their eyes a lot. I think it helped them.

This comment was in relation to a family who spoke one night about their experiences with their son over the past 5 years. This family vividly described their battle and their triumph of learning to cope with their son’s illness. As a result of this family’s honesty and openness, a great bond and admiration for them emerged, also giving that sense of hope to those families still struggling to cope with the illness.

One family commented that “it was good to be able to talk to other people who understand what you’re going through and can give you different ideas of how to go about things. You know, you might be able to help someone else in some sort of way.”

Adaptation and Acceptance

Adaptation is defined by Kneisl and Wilson (1992) as, “the result of interchange between the organism and the environment involving modification of the organism that enhances its ability for further interchange; involves assimilation and accommodation” (p. 988).

For families dealing with a member diagnosed with schizophrenia, this requires change, understanding, and acceptance. Acceptance means, “refraining from judging and rejecting...it requires (families) to be able to examine, explore, and understand their coping mechanisms without feeling the need to cover up or disguise them” (Kneisl & Wilson, 1992, p. 988). Comments, such as “I became aware of when to let go.” or “It helped us to understand the traumas that our son is going through.” or “After the communication session I thought about what I was going to say to him. Before, I was inclined to tell and order him to do things,” reflect acceptance.

As society does, the family often has misconceptions about the nature of mental illness and often is led by society’s stigmatized view of mental illness. This is supported by a family member’s comment: “I realize that they are ‘real people,’ not the ‘mad’ people in the movies.”

A family openly discussed the adaptation and change that occurred for them as a result of attending the 11-week group:

At first I told people that Bill had a breakdown, because it was easier for me to cope with and I didn’t have to explain anything, the stigma attached, I felt that it was protecting Bill by saying he’d had a breakdown. But after attending the course and listening to everybody else, I now say that Bill has schizophrenia. It’s also helped us to understand how we can help Bill. You just can’t imagine how much it improved our knowledge and acceptance.

Another family had adapted and accepted reality by realizing that rehabilitation for their son will only occur if he accepts and requests help.

The feeling that I got as far as rehabilitation is that it appears to be about 10 years down the track—when Richard says, “Hey, I’ve got a problem. I need help.” But to try and force him to do it would be complete and utter waste of everybody’s time and would probably set him back more than it would bring him forward. We got the message that nothing’s going to change until this person says “Hey, I need help.”

We accepted that it could be 12 months, 2 years, even 10 years. Having accepted that, we then had to change our lifestyle to cope with it, and worrying about silly things (dirty bedrooms, not doing minor jobs)—forget it, it’s not worth the hassle. This, to us, helped us. It really wasn’t a catastrophe. Life must go on. The group...well, it strengthened us.

A member of a family commented: “I’ve got more understanding of what’s happening and just different things that we were told, different ways of going
about things, some of them have definitely helped. Just thinking it makes you realize that there is a light.”

**Empowerment**

According to Kneisl and Wilson (1992), “self-help, self-care, and psychoeducation are consistent with trends towards realignment of power, control, and responsibility with givers and receivers of health care” (p. 15). Empowerment of family members through education increases the family’s knowledge and understanding and ability to deal with the illness, enhances the family’s chance of living a life as normal as possible. “Knowledge is an awareness or perception of reality acquired through learning or investigation” (Marriner-Tomey, 1989, p. 3).

Families often lack knowledge and understanding of their family member’s illness, resulting in a perception that they are unable to change the situation, that it is beyond their control. Two forms of control are described in the literature, internal and external locus of control (Barry, 1984). The person who feels powerless perceives events as being outside of his or her control and being caused by fate, luck or chance, or powerful others.

Psychoeducation programs help families regain the capability to evaluate what is within or beyond their control and empowers them to work collaboratively with health professionals. If caregivers of the “ill client” perceive increased control as a result of improved understanding of the illness process, this will undoubtedly affect the family’s ability to change in response to the ill member’s needs. Many professionals do not recognize that the caregivers are—or should be—an intricate link in the management team. This is supported by one family’s statements: “This is the first time in many years that we have battled with our daughter’s illness that anybody has really bothered about us as caregivers. I felt that was very important, because we can do so much more for the people that we’re caring for if we understand the problems. In other circumstances, we’ve just been completely ignored.”

Another family, felt that at last, “we seem to have people in the system who want to help the parents and caregivers and listen to them.”

The emotive component was evident throughout the interviews when all of a sudden the foreign language of psychiatry had been explained in “layman’s terms.” For families, the overall comments were based on the fact that the “group really explained the illness, giving us guidelines on how to handle a particular problem.”

One family who had experienced their daughter’s illness for nearly 10 years initially wondered why they would require 11 weeks of education, but as the group progressed they realized “there was just more and more to learn...and to have it explained in a language that we could understand.” A second family commented that attendance at the PSG resulted in their experiencing a greater insight into the problems that the patients, themselves, suffer. Often, families feel alone and have a sense that this is the end of the world but, as found from these interviews, families were given hope, a sense of universality, and were empowered to understand and to deal with the illness.

**Discussion**

Families involved in this study had intense intimate contact with the mental illness and numerous health care providers. This involvement was controlled by the negative stigmas, stereotyping, and myths that predominate in most social groups. The phenomena encountered by participants via the PSG demonstrate that, in the content of their dialogues, an obvious positive change in their beliefs systems occurred. This PSG produced positive changes and choices; their thoughts and beliefs directly effecting a positive change in quality of their life and the life of their family member with a mental illness.

For families, the phenomena of hope, universality, adaptation and acceptance, and empowerment are described vividly. With such positive connotations one has to wonder why these experiences are not instilled at an earlier stage of the family’s involvement with mental health services.

In reflection, the authors believe that more nurses should be required to recognize the significance and benefits of working with the family through education and support. If nursing is an educational instrument, then one of the roles of a nurse is that of teacher. Peplau (cited in Marriner-Tomey, 1989, p. 206) defines the teaching role as, “a combination of all roles and always proceeds from what the patient knows...develops around his interest in wanting and ability to use information.” According to Peplau, the nurse, as a group leader in the PSG, embarks on an experimental teaching approach, “using the experience of the learner as a basis from which learning products are developed.”

Families require some basic factual material, but they also require the knowledge that they are significant players in the provision of care. They need to realize that they know their family member, and what is important and significant in the care of that individual. Unfortunately, many nurses often have a distorted picture of the patient—they are only seen in the confines of the environment where the nurse and patient interact. Nurses should feel comfortable enough to step outside the confined setting and begin to gain a holistic perspective of the client; that means involving the family or significant caregivers in the delivery of holistic care of the client.

Nurses embarking on working with families in an educational mode must have the knowledge required to share with the families, and be motivated to give that time to them. Kneisl and Wilson (1992) state that psychiatric nurses cannot be “limited to client-oriented activities designed exclusively to
control symptoms and increase the capability of individuals to adjust satisfactorily to the existing social condition. Instead, psychiatric nursing must be involved in social goals that advance health holistically.” (p. 6).

Many families stated that they had struggled with their family member’s illness for years, and never really understood what was happening or why. The authors ponder about the number of families of mentally ill people who still have these questions. But, how does one reach them?

Families do blame themselves, and appear to carry this blame and guilt with them for too long. Attending a PSG assists in the disposal of these beliefs and, as the results demonstrate, substitutes these negative perceptions with feelings of hope, universality, acceptance and adaptation, and the empowerment of knowledge and understanding.

These findings suggest to the authors that families’ educational needs were being met and, as a result of this, families left feeling that they had greater ability to cope, understand, and deal with an illness that had been perceived as being an endless “black hole.” Educating the family opens the door of knowledge, allowing the light to enter a seemingly dark tunnel. Education allows the family to learn to live again with mental illness.

Perhaps these questions justify further research to ensure the improved involvement of all family and significant caregivers in the educational program.

References


