

A Family Approach to Severe Mental Illness in Post-War Kosovo

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This study describes the effects of a psychoeducational multiple-family group program for families of people with severe mental illness in post-war Kosovo that was developed by a Kosovar-American professional collaborative. The subjects were 30 families of people with severe mental illnesses living in two cities in Kosovo. All subjects participated in multiple-family groups and received family home visits. The program documented medication compliance, number of psychiatric hospitalizations, family mental health services use, and several other characteristics, for the year prior to the groups and the first year of the groups. The families attended an average of 5.5 (out of 7) groups, and 93% of these families attended four or more

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meetings. The uncontrolled pre- to post-intervention comparison demonstrated decreases in medication non-compliance and hospitalizations, and increases in family mental health service use.

The program provided training for mental health professionals, led to policy change in the Ministry of Health, and resulted in dissemination to other community mental health centers. This study provides preliminary evidence that a collaboratively designed and implemented psychoeducational, multiple-family program is a feasible and beneficial intervention for families of people with severe mental illness in impoverished post-war settings.

BACKGROUND

After the Serbian regime's ethnic cleansing of Kosovo and the NATO defeat of Serbian forces in 1999, Kosovo faced enormous public mental health problems. Kosovo had only 19 psychiatrists, one psychologist, no psychiatric social workers, 140 psychiatric hospital beds, and no community mental health clinics. This was far below World Health Organization (WHO) minimal standards for a developing nation with over two million people. This lack of professional capacity was due to the fact that between 1989 and 1999 the Serbian authorities had denied most Kosovar professionals access to health care institutions, education and training, and contact with international professional and scientific organizations and colleagues. Kosovar professionals refer to this time as "ten years lost." For Kosovar mental health professionals, recovering from war has been less difficult than making up for the injustice and deprivations associated with these lost ten years. According to a WHO report from 1999, mental health services in Kosovo were in such a desperate position that it was not legitimate to even have hope. "The people are severely traumatized and a mental health system is almost non-existent. . . . There is little hope for the future of mental health" (Urbina, 1999).

In winter 2000, the Kosovar Professional Education Collaborative (KFPEC) was founded by Stevan Weine, Ferid Agani, and John Rolland through a collaboration between the University of Illinois at Chicago, the University of Prishtina, and the American Family Therapy Academy (Rolland & Weine, 2000). The collaborative aimed to support

and enhance the family work of Kosovar mental health professionals and to design and implement family-oriented mental health services in Kosovo. Simply put, the KFPEC aimed to help Kosovar mental health professionals to achieve a position from which they could hope to build a system that would address Kosovo's mental health needs under conditions of low resources. The KFPEC was supported through foundation, university, and private donations. The collaborative model of this project was congruent with collaborative models used in other difficult social contexts, including HIV/AIDS prevention among urban minority communities (McKay et al., 2002), building children's mental health infrastructure (Bell & McKay, 2004), and improving poor peoples' access to HIV/AIDS care (Farmer, 2003).

The KFPEC was based upon a family strength and resilience approach that assumes that the family has a powerful, and often positive, role in shaping the response to adversity (Landau, 1982; Rolland, 1994; Walsh, 1998). By choosing to focus on the family and its strengths, the collaborative staked out a position that was closer to the family-centered "practical knowledge" of Kosovars than to the individually centered "scientific knowledge" of modern psychiatric practice (Scott, 1998). Kosovars have long relied first and foremost on their extended, intergenerational families to address mental health problems, including severe mental illness. Because mental illness in Kosovo has been associated with tremendous shame to the whole family, families would often try to keep the person closed up in their homes. When families reached out for help, they often consulted with traditional

healers or local religious persons prior to or instead of mental health professionals.

Mental health services were very limited and were hospital-based rather than community-based in Kosovo, as they tended to be throughout South Eastern Europe. The war put additional burdens on families (most of whom experienced trauma, loss, disruption from family and community, and economic difficulties) that made caring for a mentally ill family member even more difficult. The war also put additional severe strains on the few existing mental health professionals and organizations. However, the 1999 liberation and establishment of the Provisional Institutions for Self-Government of Kosovo created the possibility of building a new public mental health system concordant with both international standards and the Kosovar social and cultural emphasis on families.

Through this collaborative initiative, American professionals who specialized in family-centered approaches to mental health were able to encourage the Kosovar professionals to draw upon this practical knowledge inherent in Kosovar daily life. American professionals could also help them supplement their "practical knowledge" with "scientific knowledge" concerning families and interventions. The philosophical basis included an understanding of the value of the traditional extended-family structure of the Kosovar society, allowing for the development of culturally appropriate collaborative interventions (Landau, Mason, & Griffith, 1982).

The collaborative's work was also based on the assumption that Kosovar professionals were the principal actors and that the American professionals' role was to be supportive, educative, and facilitative. Thus it sought to differentiate from approaches that over-rely on the one-way transmission of knowledge from short-term visiting international experts (Weine, Agani, & Cintron, 2003). The first year of the collaborative's activities focused on collaborative training for 36 Kosovar mental health professionals (psychiatrists, nurses, psychologists and social workers) in a family systems and resili-

ence-based approach to community mental health (Rolland & Weine, 2000). These persons were based largely in Prishtina, the capital city of Kosovo, which has a university medical center. Kosovars were equal partners in designing, implementing, and evaluating the training activities (i.e., all presentations and publications were done jointly by Americans and Kosovars). In the second year, the collaborative shifted its focus to developing family-oriented mental health services. The collaborative's Kosovar-American leadership group was responsible for planning and overseeing all activities.

The literature on post-war mental health has primarily focused on trauma-related mental health problems and their clinical treatment (Mollica et al., 2001). However, mental health in post-war countries also faces major changes concerning services for people with severe mental illness (Silove, Ekblad, & Mollica, 2002). In impoverished, post-war countries, such as Kosovo, the provision of mental health services to people with severe mental illness is often complicated given that there are severe deficiencies in public health infrastructure and community mental health services (de Jong, 2002).

Humanitarian interventions have also been critiqued for primarily engaging in short-term emergency assistance approaches that do not contribute much to developing public health infrastructure and community mental health services (Maynard, 1999; Weine et al., 2002). Through partnering with local mental health professionals committed to addressing the public mental health needs of Kosovars, the collaborative aimed to contribute to the building of effective and feasible public mental health services in Kosovo. The collaborative chose to build family services that centered on psychoeducational multiple-family groups, which have been used to address families with severe psychiatric disorders, families with a medical illness, urban families, and also refugee families (Campbell & Patterson, 1995; McFarlane, 2002; McFarlane et al., 2003; McKay et al., 2000; Steinglass, 1998; Tolan & McKay, 1996;

Weihs, Fisher, and Baird, 2002; Weine et al., 2003b; Weine et al., 2003c).

This text reports on one specific collaborative project that began in the second year of the collaborative's activity (2000–2001). This project addressed what Kosovar psychiatric leadership had identified as the highest priority need: community based mental health care for people with severe mental illness. They strongly believed that despite the high rates of war-related trauma and mental health consequences in the general population (Agani et al., 2000), the public mental health system had to prioritize making adequate community-based services for the severely mentally ill (Agani, 2000). Thus, this project had two primary aims. The first was to provide community-based care for people with severe mental illness by mobilizing their families to participate in a network of community-based support services. This initiative aimed to develop a network of collaborative services and to foster professional relationships between the University of Prishtina-based mental health professionals and the seven regional community mental health centers, which were being implemented in the current phase of development of the overall mental health system in Kosovo. The second aim was to enable Kosovar mental health professionals trained through the collaborative to continue to grow, consolidate, and implement these family-based skills in their professional work. They would achieve this by serving as trainers and supervisors for those engaged in the development of an infrastructure of community-based services at multiple levels and in multiple dimensions, including outpatient services, protected apartments, inpatient services, and preventive services that specifically draw upon community and cultural resources.

To accomplish these aims, the collaborative formed two services-based training teams (SBTT) composed of trained nurses and psychiatrists and one psychologist, from the University of Prishtina. These teams worked weekly with staff at two regional centers for mental health in Gjakova and Ferizaj (medium-sized cities in Kosovo that are approxi-

mately two and one hour's drive from Prishtina, respectively). The specific activities of these teams included: home visits to families; support and psychoeducation multiple-family groups; on-site supervision for community nurse teams; and monthly all-day training sessions in family-focused community mental health.

This text examines the consequences of the collaborative's SBTT project. The central questions addressed were: (1) What was the rate of engagement and what factors predicted engagement? (2) What were the time changes associated with group participation? (3) Can we build statistical models that identify factors and processes associated with the intervention's outcomes? (4) What were family members' views of the multiple-family groups? and (5) What were the policy consequences of the multiple-family group program?

METHODS

Subjects

In Gjakova and Ferizaj, the SBTT teams worked together with community mental health center (CMHC) staff and identified chronically mentally ill patients who in the past year had frequent hospitalizations and/or no stable residence or family support. A total of 30 families were chosen to participate (15 in Gjakova and 15 in Ferizaj). Of 30 patients, there were a total of 10 adult females (33%) and 20 adult males (66%). The average age was 40.6 years ($SD = 8.7$). Thirteen (43%) were single, never married, 7 (23%) were married, 9 (30%) were divorced or separated, and one (3%) was widowed. All subjects were diagnosed with schizophrenia on clinical interviews and all had active psychotic symptoms.

Multiple-Family Groups

Families in the program were invited to participate in seven sessions of family psychoeducation about chronic mental ill-

nesses. Patients and all family members were encouraged to attend. However, if not all were able to attend (e.g., due to work or childcare problems), the others were still encouraged to come. These groups were held at the local community mental health center and were run by a local psychiatrist and nurse under supervision of the SBTT teams and the American consultants.

The groups were designed collaboratively by Kosovar and American professionals and manualized. The psychoeducational multiple-family group design was consistent with the goals, principles, and methods of family psychoeducation (McFarlane et al., 2003). As McFarlane and colleagues describe, psychoeducational multiple-family groups incorporate family psychoeducation, family behavioral management, and multiple-family approaches. The aims of the groups were twofold: (1) to help family members understand the nature of mental disorders and acquire the skills necessary to provide home care and support for severely mentally ill clients; and (2) to develop a wider family-support system through connecting families with other families in similar predicaments. Multiple-family group presentations included the following topics: (1) psychiatric symptoms and clinical course of chronic mental disorders; (2) medication use and side-effects; (3) the role of psychosocial factors in precipitating or preventing relapse; (4) solving common problems and responding therapeutically to client's symptoms of mental illness; (5) responding appropriately to crises from exacerbations of client's symptoms; (6) collaborating effectively with mental health professionals in client's treatment; and (7) resilience-building and strength-based approaches to the treatment of severe mental illness.

The two University of Prishtina-based services training teams provided support to the staff at the local community mental health centers (CMHCs) through: (1) a once-monthly all-day training session in community mental health; (2) three once-monthly half-day consultations with identified service provider groups (i.e., outpatient, inpatient, protected apartment, preventive); and (3) on-

going availability for phone and e-mail contact with local service providers.

American professionals played multiple roles, including: (1) collaborating and mentoring University of Prishtina faculty in developing and conducting family programs and in enhancing skills for multifamily group discussions; (2) providing regular on-site visits workshops, recommended readings, and case consultations to assist University of Prishtina faculty in developing teaching, supervisory, and consultation skills for resilience-focused and family-centered community mental healthcare; (3) providing regular consultations in community mental health program design and management of systems problems; (4) providing administrative supervision and mentoring to Kosovar leadership; and (5) facilitating and mentoring writing efforts initiated by University of Prishtina faculty.

The project also provided modest financial support (35 Euros per month per family) to these families to provide shelter and food for the chronically mentally ill person(s). Local professionals provided an ongoing network of community-based training and supervision for the families, as well as a link to mental health services through the CMHC.

Assessments

The SBTT team worked with the local CMHC staff to gather information on patients based on review of patient records and consensus of CMHC team members. The data gathered included: demographics; clinical diagnosis (ICD-10); medication compliance (oral and depot); number of hospitalizations; family member's use of mental health services; and frequency of family crisis. The team determined the status of each of the latter four variables for both the year prior to engaging in the multiple-family group and the first year of family engagement in the multiple-family group. Participant's quotations were taken from field notes recorded by nurses who functioned as participant-observers of the multiple-family groups for training purposes and from direct observation by members of the

collaborative. Participants (patients, family members, and professionals) gave verbal informed consent for the use of the above information (including quotations) as approved by the Institutional Review Board of the University of Illinois at Chicago.

Analysis

The four aims of quantitative analyses were to determine answers to the following questions: (1) Are families engaging in the groups? (2) Do family or patient characteristics predict patterns of engagement? (3) Are there time changes in outcomes associated with attending the group? and (4) What factors or processes are associated with changes in the intervention's outcome? For the first aim, descriptive statistics were used. For the third aim, a paired *t*-test and McNemar's test were conducted. For the second and fourth aims, a group of variables was subjected to either multiple regression or logistic regression. The analysis also encompassed qualitative and policy aims: (1) How did family members' experience the multiple-family groups? (2) What were the policy consequences of this?

RESULTS

Engagement

The overall level of involvement in family groups was as follows: 30 of 30 (100%) families attended at least one group; 28 (93%) of these families attended four or more meetings; 19 (63%) attended six or more meetings; and 8 (27%) attended all seven meetings. The mean number of groups attended was 5.5 (*SD* = 1.5; range 1 to 7). In most cases, the groups were attended by the patient and several family members (parents, spouses, siblings, and children), including the primary caregiver in the family. Most groups had a total of between 30 and 40 persons in attendance.

Patterns of Engagement

Multiple regression for family atten-

dance in groups tested the independent variable of family attendance versus 10 dependent variables (all the pre-group variables). A significant model was constructed in which these two variables achieved significance: Ferizaj site ($\beta = 1.78$; $p < .0021$); and medication compliance ($\beta = 1.11$; $p < .0513$). The overall model achieved significance ($F = 5.87$; $p < .0077$).

Time Changes

Comparing the year of the group intervention with the year prior to the intervention, there were multiple significant changes including: decreased hospitalization ($t(29)=4.89$; $p < .0001$); increased medication compliance ($\chi^2(1) = 16.2$; $p < .0001$); increased use of combined oral and depot medications ($\chi^2(1) = 19.0$; $p < .0003$); increased family members' use of outpatient mental health services ($\chi^2(1) = 6.0$; $p < .0143$); increased family crisis ($\chi^2(1) = 8.3$; $p < .0039$). (See Table 1.)

Modeling Outcomes

Multiple regression for group outcomes tested the independent variable of decrease in hospitalizations versus 10 dependent variables (all the pre-group variables). A significant model was constructed in which these two variables achieved significance: family crisis ($\beta = -0.53$; $p < .0314$); and hospitalization ($\beta = 0.82$; $p < .0001$). The overall model achieved significance ($F = 159.4$; $p < .0001$).

Multiple regression for group outcomes also tested the independent variable of post-intervention hospitalizations versus 10 dependent variables (all the pre-group variables). A significant model was constructed in which these two variables achieved significance: family crisis ($\beta = 0.54$; $p < .0314$); and hospitalization ($\beta = 0.18$; $p < .0006$). The overall model achieved significance ($F = 10.5$; $p < .0004$).

Table 1.
Multiple-Family Group Effects

Variable	Year Before Group	First Year of Group	Comparison
<i>n</i>	30	30	–
Number of Hospitalizations	2.0 (<i>SD</i> = 2; Range = 0 to 8)	0.4 (<i>SD</i> = .7; Range = 0 to 2)	$t(29) = 4.89; p < .0001$
Medication Compliance (any meds)	11/30 (37%)	29/30 (97%)	$\chi^2(1) = 16.2; p < .0001$
Medication Compliance (oral plus depot)	8/30 (27%)	27/30 (90%)	$\chi^2(1) = 19.0; p < .0003$
Family Members Receive Mental Health Services	15/30 (50%)	21/30 (70%)	$\chi^2(1) = 6.0; p < .0143$
No Family Crisis	24/30 (80%)	14/30 (47%)	$\chi^2(1) = 8.3; p < .0039$

Participant Quotations

Both family members and professional staff were impressed that the multiple-family group had a positive impact on many aspects of family life. These include the following key themes, illustrated with participant quotations:

- Decreased blame of family members: “Now I know my father is not the cause of my brother’s disease”;
- Increased knowledge about mental illness: “Now we can understand what actually the disease is”;
- Improved family coping strategies: “Now we know we shouldn’t make him angry and scream at him; we should help him by giving the medications to him”;
- Decreased fear in family members: “Children are not afraid anymore. I explained them about the disease, I told them things you taught us”;
- Increased socialization: “Now we have lot of company; we accompany with people out of the Center, too”;
- Improved quality of life: “Now we are happy, we have changed in every aspect. Before, our life was disorganized and disordered. Improvement of his condition has changed our lives. It would be nothing without these meetings”;
- Enhanced hope: “I never believed that my brother would improve”; “Our life has improved; we can make plans, too. I never be-

lieved a day of joy in our life would ever come”;

- Improved relationship with doctors: “I never believed that positive changes will happen in my life, that doctors will help us this much.” A typical comment from group leaders was: “Families said this is helping us to be more friendly with other families and to cope with difficulties.”

Program Results

At the Gjakova and Ferizaj centers, the SBTT succeeded in training multiple staff members in family-centered mental health services. They were able to conduct home visits and run the groups independently (using the manual prepared and distributed by the Prishtina SBTT team). The family groups were regarded as a core activity of the CMHCs. For example, the municipal health officer explained that Gjakova, for the first time, has sustainable mental health services: “We wanted to escape from the idea that a psychiatric patient should be only hospitalized. We wanted to solve these problems inside the family. The CMHC staff works 24 hours a day. Their greatest success will be helping patients to solve problems without hospitalization.”

DISCUSSION

This study found that the families of patients with severe mental illness engaged in the multiple-family groups at high rates. We believe

that the home visits were a very important element in the engagement processes; they helped the professional staff to establish a positive connection with family members that broke through the families' overwhelming sense of isolation, shame, and despair. In the groups, these families reported how isolated they had been because of their family member's mental illness: "Nobody is visiting us, including our married daughters"; and "Our life is like a domestic-jail; my friends forgot me, relatives consider him crazy and forgot us all." Although family members were enormously burdened by caring for their loved ones with mental illness, they reported that over the years they had received little positive support for those activities from family, community, or professionals. For most of these families, the multiple-family groups provided the positive social support they lacked before.

This study found that the multiple-family group program was associated with improvements in both increased medication compliance and decreased psychiatric hospitalization. This is consistent with the literature on multiple-family group interventions conducted in peacetime settings and on research on psychoeducational approaches (McFarlane, 2002; McFarlane et al., 2003). Multiple-family groups may function in part as an access intervention, facilitating the ability of persons with mental illness (and their family members) to get appropriate mental health treatment. This is thought to happen through the multiple-family group changing the knowledge, beliefs, attitudes, and social relationships of family members with respect to mental illness and its treatment. Engagement in multiple-family groups was found to be associated with medication compliance. This is not surprising, for both are expressions of mental health help-seeking from families that have long had few places to turn for help.

The multiple-family group helps families in other ways that may be especially important in a resource-poor post-war environment known for strong families. Understanding how to approach their family member with mental illness helped many families to adjust their daily responses in order to lower conflict in the family. Knowledge about

mental illness and familiarity with mental health professionals led to more regularity in taking medications. This in turn made it easier for families to cope with ill family members whose symptoms were no longer as severe. Whether or not any of these possible changes are sustained over time, and possibly lead to changes in the course of illness (e.g., decreased relapse), would require further study. The finding of increased family crisis during the group appears paradoxical. Shouldn't the multiple-family group help to diminish family crises? Our interpretation is that before family groups, outpatient staff were far less engaged with the families, and families were less available and open to them. Hospitalization also played a role, in that when family crises began to emerge, the mentally ill family member was immediately hospitalized rather than managed in the family setting. Since the multiple-family groups started, crises involving the mentally ill family member were addressed at their home and managed with the help of family teams from the CMHCs. In other words, the multiple-family group intervention allowed professionals to recognize family crises at earlier stages, and families were supported to manage crises without necessarily leading to the mentally ill member's decompensation and hospitalization. According to MacFarlane, enhanced crisis intervention is one of the goals of psychoeducational multiple-family groups (2002).

Working with families had a markedly positive impact on mental health professionals at multiple levels. Psychiatrists and nurses became better observers of families' daily lives and successful strategies, and saw the effectiveness of the family approach in working with severe mental illness (Pulleyblank-Coffey, Griffith, & Ulaj, 2005). They came to identify themselves as professionals with a special alliance with families, took pride in their skills and in successful cases. The CMHCs came to identify family work as a central part of their mission. On the other hand, the differences in family attendance between the two sites represented administrative obstacles encountered at the Gjakova site (i.e., turnover of leadership; scheduling conflicts). This serves as a re-

minder that a multiple-family group program needs full institutional support in order to function effectively and that community mental health approaches face many structural difficulties, especially in resource-poor environments.

One other important accomplishment of the project was a change in mental health policy at the level of the Kosovar Ministry of Health. On the basis of the successful results, and through the advocacy of the KFPEC leadership, multiple-family groups and family home visits were specifically written into the Kosovar Ministry of Health's requirements of each of the CMHCs and into their annual budget. Because all activities of the project were integrated with public mental health services, sustainability of the initiative is far more likely (though by no means guaranteed). Once again, it is important to state that these accomplishments were achieved in a resource-poor society with many important competing needs. While in a first look, adding a service (psychoeducational multiple-family groups) appears to add a clinical burden to the CHMCs, in fact the opposite is the case: families become collaborators of the centers, patients are more cooperative, and the burden of managing major clinical problems is reduced.

In coordination with the Kosovar Ministry of Health's strategic plan of mental health reform, it was decided to use the successful implementation of family mental health services in Gjakova and Ferizaj as a basis for dissemination to the other five new CMHCs. The SBTT based in Prishtina and four of the trained staff from the CMHCs in Gjakova and Ferizaj formed a dissemination team. Two members from that team were paired with each of the five new CMHCs. Regional mental health directors and the directors of each of the five new community mental health centers were introduced to the program by the National Coordinator of Mental Health and the KFPEC Dissemination Team. The dissemination team has been providing weekly training sessions and supervision with the local CMHC staff (nurses, doctors, psychosocial workers), and they have begun outreach to families and are conducting multiple-family groups. The goal was for each

mental health center to conduct two rounds of groups under the direct supervision of the SBTT from Prishtina by October 2004. Through the same collaborative relationships, family approaches are being developed for use with other health problems in Kosovo, such as prevention and treatment of substance abuse and HIV/AIDS.

There are multiple limitations of this study. Because this project was organized as a service and not as research, there were investigative shortcomings in several areas. One, this was not a randomized, controlled study. Making comparisons with the group of non-engagers was not equivalent to comparisons with a true control group. Two, the sample size was small, and should not be considered representative of all Kosovar families with mental illness. Three, this study did not rely upon standard research instruments, such as diagnostic assessments. Four, the research was conducted at a time of great transition in nearly all aspects of Kosovar life. Because it is thus impossible to rule out that the effects observed were not explainable by some other factors not measured or controlled in the study design, it would be helpful to study the psychoeducational multiple-family group intervention once a community mental health system is more fully established. Future research directions should include a more rigorous study with measures, a control group, a larger sample, and a better description of the patients' and families' experiences in the group. It would also be valuable to study the dissemination process in Kosovo.

In conclusion, the psychoeducational multiple-family group program helped Kosovar mental health to reach a position of hope for providing adequate public mental healthcare for the severely mentally ill. A collaboratively designed and implemented psychoeducational multiple-family program is a feasible and possibly beneficial intervention for families of people with severe mental illness in impoverished post-war settings. Further investigation is needed to scientifically determine whether the intervention improves the course of severe mental illness and is cost-effective.

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