

Report

Children's Forum

An Interview with Eight Children

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Report no 60

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Abstract:

Objective. Childrens forum (CF) is a session for information and inquiry for children between the ages of 2 and 18 whose parents are in-patients at the psychiatric ward. The aim and scope of this study was to investigate the usefulness of CF for the children, six to eight months after participating.

Method. Eight children, ages 10 – 16 were interviewed. All of the interviews (semi-structured and theme-oriented) were done in the family's home without the parent (s) being present.

Results. The results showed considerable improvement in the areas of communication and relational skills between parent and child.

Conclusion. The improvements that have taken place can be directly linked to the CF program content: the acquisition of knowledge, vocabulary, and concepts along with skills in the ability to apply their new insights in communication about taboo-laden topics.

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Introduction

Voksne for barn (1) claim that more than 100 000 children in Norway grow up with parents suffering from mental illness. Among the approximately 40 000 adults who at any given point in time are hospitalized for mental illness, some 15 000 children are directly affected as next of kin. Mental illness is often associated with unstable family structure where children attempt to conceal the dysfunction and protect the mother/father from responsibilities and duties the child perceives as being too difficult for them to fill.

A person suffering from a mental illness is often more or less preoccupied with his/her situation. The illness can affect the sick parent in a way which corrupts the development and maintenance of adequate emotional bonding to the child. Many children describe their experiences as confusion and feelings of helplessness. This emotion seems to be connected to the loss of a role model. The child needs a stable adult who can provide sound guidance when addressing their wishes, needs and challenges they pose in the context of their socio-cultural community. Being comforted when afraid or hurt, caring for others and sharing various "happenings" in life, are critical in the developmental process. If the parents fail to help their child to grapple with a difficult and stressful situation effectively, the child will be left to his/her own devices, lacking the emotional maturity and appropriate behavioral repertoire required to meet the given circumstances. What Bowlby (2) coined "*attachment security*", is of fundamental importance to normal development and secures intimacy and trust between child and adult. It is a parental duty to organize and structure arenas for learning, and it's a demanding task. Many who suffer from illness are so consumed by it that they lack the surplus energy required to provide this to their children. Due to this, many children report feelings of not being seen, heard or acknowledged. Rutter & Quinton (3, p. 853) claimed that for the last fifty years there has been an awareness that "*mental disorder in parents may be associated with psychiatric disturbances in their children*". The problem seems to most prominent when the illness damages the emotional relationship and there is a general depravity of attention and response. Not being seen easily creates fear, feelings of guilt, and a feeling of being unwanted.

Mental illness continues to be taboo-laden and secrecy is commonly the result. In turn one will often lack experience in dealing verbally with it and often be at a loss for words. Not

having the words needed to convey one's reality is obviously a problem. Many children can't manage to conceptualize and create a sense of order in their verbally "*nonexistent*" perception of reality. Pennebaker (4) has conducted many experimental studies that document health risks due to emotional inhibition, and health benefits from telling about traumatic experiences. Children's knowledge of their parent's illness is often sparse and arbitrary and without any clear idea about what is wrong. Many children deal in isolation with their painful and unanswered questions. In spite of our knowledge of this, these children have until recently been a neglected group. Nordic and international follow-up and longitudinal studies show that children who grow up with one or two parents who are mentally ill have a higher incidence of developmental disorders, illness, and reduced quality of life (5, 6, 7, 8).

The child's situation is additionally complicated when mother or father's illness coincides with the absence of other important persons such as the other parent, grandparents and friends, or when the family is in disharmony, experiencing economic problems, are socially isolated, unemployed, or struggle with chemical dependency issues. Children appear to cope less well when the mother is ill and worse when both parents are ill. Experiencing several risk factors simultaneously or in close proximity, such as a sick parent combined with chemical dependency and frequent home-relocation can result in a mutual reinforcement of detrimental effects and a heightened risk. It's not unusual for children to blame themselves for their parent's illness and their shortcomings. Children attempt to cover up, take over parental responsibilities, and can in this regard appear to cope well with their situation.

Spitz' (9) classic studies on "*hospitalism*" documented physical retardation and increased mortality among the children who received adequate food and medical attention, but who were deprived of warm and loving care. Studies by Bowlby (10) have shown that children who are deprived of emotional responsiveness are more prone to developmental disorders in the areas of mental and physical health. Hart (11) distinctly points out that psychological maltreatment can for many individuals have enormously devastating developmental effects, cognitively, emotionally, and physically. This supports the hypothesis that humans have a species specific response repertoire which is essential for survival and which needs to be stimulated in order to ensure normal development. Today there is an increased awareness to the adverse developmental effects of emotional negligence. Deprivation from emotional response can in many cases result in feelings of worthlessness, being discarded, flawed, undesired and unappreciated.

Research on stress has over the years documented that living with stress over long periods, especially in early childhood is associated with a higher risk of developing illness (12, 13). A chaotic situation binds up energy resulting in uncertainty, lost learning, underdevelopment, and apathy. But parental mental illness does not necessarily mean that all the affected children don't receive the care and guidance that they need.

What has been done?

At the psychiatric unit at Namsos Hospital we routinely invite parents and their children ages 2 to 18 to "Children's Forum" (CF) as soon as possible after the parents are admitted for treatment. CF is a psycho-educative treatment program led by two counselors, who teach about mental illness in general and about the specific illness relevant to the parent's situation. How the illness can affect the family as a whole is also a central theme. Emphasis is placed on the normality of thoughts and feelings one can experience in their given situation, such as responsibility, guilt and shame.

The aim of counseling is to reduce misinterpretations and fortify the child's position. In the introductory phase of the session the counselor attempts to verbalize the illness and its symptoms, and the thoughts and feelings that can arise from their situation. This is done while the child and parents are in the same room. The intention is that this will function as an ice-breaker, opening a gate through which to communicate about an inaccessible and taboo-laden topic. They acquire "*new words*" to explain and understand what they experience. One objective of CF is to prevent confusion, uncertainty, and ignorance and thereby reduce the stressfulness of their situation. Then the parents give the children verbal acceptance to speak with the counselors in private and leave the room. Children who may be accustomed to accommodate parents they perceive as struggling with "*things*" are given a break and thus a chance to reflect on questions and needs they may wish to share with the counselors.

Our experience is that when the parents leave, children become more open to share their personal story, ask and seek answers to important questions. The session closes with the family gathering again. The counselors help the children to ask or tell the parents what they and the children have agreed to be most important to share with their parents. This may be a first initiative to speak about difficult and taboo-laden issues together. In the course of the session one tries to reveal areas of need and facilitate relevant treatment programs. The family is offered one or more additional sessions when needed or desired. CF is not therapy, rather a educational program with preventive effect. The program is based on the assumption that talking to and informing children about their often unpredictable circumstances and their parents illness is a protective measure.

Several studies on the national and international level show the positive influence of working in groups where children and parents are included in order to educate and improve communication within the family. The coping perspective rests upon the importance of personal empowerment. This is also one of the explicit goals in Sammen om barns psykiske helse (14).

Clinical experience in our hospital shows that significant preventive gain can be made from early intervention – before problems become manifest. After four years we are left with the distinct impression that children and their parents feel a sense of relief when we help them communicate about difficult and taboo-laden issues. We have received positive feedback from several professional treatment settings: polyclinic, psychiatric nurses working in the community out-patient care system, and parents who have expressed relief over there being a program that includes their children. In spite of the positive feedback we still need to carry out comprehensive studies pertaining to the viability of the programs or if changes need to be made.

As therapists we need to ensure ourselves that the methodology works and is deemed helpful. Our opinion is that we need to document the effectiveness of psychiatric health care. There are few studies focused on similar intervention programs and we may therefore conclude that there are considerable knowledge "*gaps*" in the field regarding the relationship between CF type intervention and its effect. The goal is first and foremost that intervention is founded on documented knowledge, which makes it more ethically defensible to recommend. Secondly, it should serve as a basis for sound practice. Studies which focus and report on the experience of the child's experience in similar situations are scarce in Norway. Several findings from the studies mentioned provided guidelines and questions for our study.

1. What influence did CF have on parent-child communication?
2. Did CF contribute to improved every day coping skills for parent(s) and child (ren)?

Method

Inclusions and exclusions criteria

Since we were interested in investigating the effects of CF over time, we chose in the outset to focus on the family that started in the CF program exactly six months ago. Then we continued with the nine families that had participated in the program proceeding sequentially back in time. These were contacted by mail. Two families declined from participating while eight consented to be included in the study.

The families were offered the same CF intervention, but with a new variety of topics depending on the parents' illness and what the participants themselves shared or inquired about. All of the interviews (semi-structured and theme-oriented) were done in the family's home without the parent(s) being present. The results of the parent interviews will be presented in another report. The children were not informed about the findings from the interviews with their parents. The interviews lasted approximately 30 minutes. They were recorded on tape and transcribed. Among the families interviewed there were five having children over age 10 and who were interviewed with the parents consent. Qualitative studies are, in our opinion, well suited to bring forth the retrospective experiences of children over a given time period. Qualitative interviews are also good sources of information about how things have progressed with parents and children after the initial sessions with CF.

We assumed that the ten year old age period is critical in relation to the ability to tell about one's own experiences, and that children under that age would have problems remembering so far back in time. Our sample consisted of four boys and four girls with an average age of 12 1/2 years. There were seven children under the age of 10 who were excluded from the interview.

Child interviews demand subtlety in their introductory phase. It's important to set aside the normative /judging part of the adult role, and concentrate on establishing a trusting relationship, pose relevant questions, be attentive and show a genuine interest. The child must feel at ease if one expects to extract valuable information.

One should also be aware that children who have been subject to neglect and have lived under conditions charged with emotional tension and communication problems over time, can fall behind in their development in this area due to deficient conceptual understanding and lack of information. Children who have lived under duress can also exhibit a generally lower level of functioning than what would be expected according to their age (15).

The interview guide was formulated based on what we considered to be pertinent with reference to the focus of our inquiry, exemplified here by the following topic specific division:

- A) **Organization of CF.** Do you remember Children's Forum and the ladies? Were you able to understand what they said?.
- B) **Communication.** Has what we talked about been helpful to you? Did you learn new words that could help you to explain or ask about things? Have you talked to your Mom or Dad about their illness after their admission for treatment? Have Mom/Dad talked to you about their illness and asked you how you are doing?

- C) **Knowledge.** Did you learn anything? Do you remember what we talked about during the session? Did you get a better understanding of what was the matter with your Mom/Dad? Did you understand that Mom/Dad had to stay at the hospital for a while? Did anyone explain to about their treatment, and if so, what?
- D) **Security.** Were you anxious before the session and what were you anxious about? Did it get any better? What do you think made it change? Did you have any trouble sleeping, concentrating on your school work, or just relaxing when Mom/Dad was admitted for treatment? What? Did participating in Children's forum help you? What helped? Do you think Mom/dad got better from their stay at the hospital? Do you think Children's Forum can be helpful for other children?

Results

Organization

All of the children remembered participating in Children's Forum, and remembered the "ladies" who led their session. Five of the children claimed that what they talked about during the session helped them later on. Three denied "*I don't think so*", however later on in the interview they reported using things they had learned in the session in interactive situations with both peers and parents. One of these children answered readily when asked at school about their parent's illness.

Six of the eight remembered the time alone with the counselors. "*It was kind of cool. It can be hard to talk about certain things that have to do with your parents when they're there. You could hurt their feelings*". It was also stated that it was easier to concentrate when nobody else was present. The two who reported not remembering being alone with the counselor said it was all right to be alone with them. None of the interviewees had suggestions for changing the Children's Forum session. Three would have liked additional sessions, two weren't sure and the others answered no, "*because I've been to the public nurse afterwards*".

Communication

Six of the children stated clearly that CF had contributed to making it easier to talk to Mom or Dad about the situation relating to their parent's illness. In response to questions as to whether they had learned new words they could use in order to explain or ask, three said yes. One of them who had learned new words said the following. "*Yes, but Mom has also taught me lots of new words, too.*" Four of the children report having asked Mom or Dad about their illness after they were admitted and four of the children report their parents having talked to *them*, while six claim that they talked more often with their parents after CF. Six of the eight children say their parents ask them how they are doing on a regular basis. One couldn't remember, but her sister "*yes, but I do*".

Knowledge

Further on in the interview we ask again if they had learned anything in the CF session, and this time everyone answered yes. Four of the children are explicit in telling what they'd learned. Two remembered learning things about mental illness, its symptoms and treatment. To remembered "*It's not the kids' fault that the parents are sick*". Four of the children experienced gaining a greater understanding what was wrong with their parents after the session, and everyone understood that Mom or Dad needed to stay at the hospital a while. One child put it like this "*It has to do with electrical currents in the brain in order to reset*

something in there". The sister added *"it was anxiety"*. One girl said that she had told her classmates about CF in one of her school classes and that her teacher had commented *"well isn't it astounding how many doctors there are in the class today"*. The girl was obviously proud about being able to tell so much and said *"what I had learned turned out to come in very handy"*.

Security

Five of the eight participants reported feeling tense or scared prior to CF and six said that things got easier as the session progressed. The interviewer/counselor in CF said to a typically quiet boy *"but during CF you were very talkative"*, and the boy replied *"yes, because I wasn't afraid to talk to you"*. Six of the eight children said they had had various problems like difficulty sleeping, with concentration, and problems at school due to Mom/Dad's illness. *"Most of my troubles happened at school. There were lessons all the time. The others in my class didn't want to leave after school was out, and always started asking me what I was going to do"*. (the boy had changed, couldn't concentrate and had problems explaining himself). One child told about bad dreams with *"thundercloud"* and that after CF they didn't come as often. Now he read children's books in bed. Everyone answered *"yes"* when asked if participating in CF had been helpful. One explained it like this: *"Yeah, if you know what's going on then maybe you feel like you're more in control and then you get stronger"*. Everyone believed that the others profited from being at the hospital and five were able to describe what they considered helpful. They mentioned medicine, electric current to the brain and that their parents had some time alone. One said *"I was a little in doubt, but understood after a while that they (the nurses) knew what they were doing"*. Another said *"Mom has to take her medicine. She tried stopping but then she got so sad"*. All of the children believed that CF would be helpful to the other children who had parents admitted for treatment. *"Yes, you get to know some stuff and talk to people who know things about the psyche"*. Security arises also through the signal effect of reduced silence and having permission to express feelings about difficult issues.

The study shows that six of 15 children from families who participated received a distinctively different follow-up care due to their being discovered *"early"*. Three children from two families were followed up through the child welfare office, two children from two families participated in a BAPP course (course lasting 10 weeks for children and their parents with mental illness and/or chemical dependency problems). One child had a period with weekly conversations with a public nurse.

Discussion

The key objective of the study was to reveal whether or not CF has had any lasting and significant impact on parent-child communication, and to see if CF contributed to improved coping skills for parent and child when meeting everyday challenges.

The view of children and their competency has gone through vast changes up through history. Earlier they were perceived as being unreliable sources of information. Today the focus on children has changed drastically when comparing to what it was just years ago. When children are interviewed they ought to be informed about the background and underlying objective of the interview and that they have the opportunity to withdraw from it whenever they want. In order to achieve the highest degree of reliability as possible, we carried out the interviews in the children's natural environment, in this case their homes. The goal of CF methodology is that it should serve to prevent and the development of pathological symptoms. Even though the child may understand, organize and structure its version of reality differently than an

adult, our point of departure was that children are not only thinking, reflective and competent, but also necessary contributors for the betterment of clinical practice.

Children are loyal towards their parents, but our experience shows that they open up and talk in the CF session when the parents express their consent and allow them to do so. An example is the boy who said that “*that’s because I’m not afraid to talk to you*”. He meets someone who is comfortable when talking about thoughts and feelings that can arise in his daily life situation, and about his mother’s illness. He experiences acceptance and a shared knowledge of it. The child is invited to partake in the conversation, but not coerced. It is the adult in CF that takes on the responsibility for breaking through the taboo and initiating talk about “*the difficult stuff*”. The child in turn recognizes the topics that are brought up and is actively supported for expressing his/her feelings and is thereby encouraged to speak more freely. The method includes essential elements of the prevailing view of the foundation for harmonious psychological development.

The children of persons with mental illness are at a distinctively higher risk of developing psychological problems than children from families with mentally healthy parents. They need specially tailored programs that surpass what is commonly considered to be primary preventative measures.

The content of the interviews in this study is consistent with what is referred to in the literature. Prior to CF we registered that there was little mention of illness and the family situation in parent-child communication, children were apprehensive about asking questions and lacked knowledge and understanding of what they observed in their daily lives. They were uncertain about what they *could* ask about and felt insecure and uncomfortable in many recurring life situations. The results from the interviews show clearly that a change in the direction of improved communication and coping skills. The greatest change lying in their newly gained knowledge about mental illness, new vocabulary and concepts in addition to the know-how on how to apply it to previously taboo laden topics. Likewise, the ability to set aside emergency lies has given way to a new openness. Children understand more than we often realize and when they experience parents who lie to them or avoid certain conversations, their intuition tells them not to probe these issues or topics in the future. Openness reduces the stress for both the person who lies and the person who is hindered from asking. Solberg’s study from 2003 (16) also showed that families talked more freely with each other after having participated in support groups, making it easier to ask for help, reducing tension and thereby replacing silence with readily accepted expressiveness.

Children are keen observers, they fantasize and draw their own conclusions which are sometimes worse than reality. That’s why they may keep quiet, choosing not to ask for the sake of their parents who they see struggling. Parents may perceive this as convenient for themselves, especially when they live by the precept that silence is the safest option. They may simply believe that as long as the children don’t ask then it is most likely not a problem for them and not even consider that anyone is under strain. When parents learn that it is in fact what they’re not talking about that is hurting their children, most of them commit to making a change. They often need help to get the process started.

The children’s ability to tell their friends about their family’s situation is evidence of their having become more secure. This is clearly a more functionally adaptive behavior than keeping quiet, which can be awkward in many situations. They have acquired a common frame of reference “*something concrete in the midst of obscurity*” which they can relate to. Children under the duress of neglect need help dealing with confusion, anxiety and despair.

In summary, the children in this study have gained substantial knowledge about their parent's illness. The result is a marked reduction in stress and isolation. We assume in turn that this learning experience has reduced feelings of self-reproach and guilt for their parent's condition and in that respect improved their coping skills.

As counselors we have gained practical knowledge that can be passed on to other human services professionals who meet parents and children in similar situations. CF is founded on the fundamental belief that talking to children strengthens and protects them and that this will not be detrimental to the parental alliance. Putting experiences with mental illness into words helping children to learn and understand more makes it easier for them to sort out what in their experience is due to illness, freeing energy which can be used to meet their every day challenges.

We hope that psychiatric institutions for adults, which traditionally hasn't seriously considered the child's perspective, will do so to a significantly greater extent by asking children about how they experience and are coping with their life situation.

In our view, the programs for children offered by the Department of Health and Social Welfare ought not to lose out in competition with other "*more important*" programs. There is a distinct need for arenas where the needs of children are revealed and where referrals to appropriate intervention can be made. Our study has confirmed this need. Not attempting to take the child's perspective in such obviously difficult circumstances is psychological child neglect. All of the children would recommend this intervention form to others in similar situations. They would never have done that if they themselves hadn't found it useful.

Critical Comments

We have based our findings on the evaluative reports of children. One flaw may be a possible bias arising in that the initial author was also directly involved in the method development and in carrying out the interviews. The interviews may have been colored by a strong belief in the effectiveness of the intervention. On the other hand, it may have been a positive influence having an interviewer who isn't a stranger to the informants. In our opinion we have utilized our background qualifications and understanding of the field as a resource, thereby ensuring a smooth interview process and facilitating the expansion of our clinical knowledge in this area. Despite the results from the study indicating a sound qualitative standard, there will always be the need to secure that the intervention is effective and therefore meets professional standards ethically, and in terms of effectiveness. Improving our methods and approach requires a concerted effort toward a greater understanding of the specific mechanisms which work to bring about the desired results.

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