KIDS STRENGTHS
KIDS in the CONTEXT of MENTAL DISORDERS

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Leonardo da Vinci

Module 3:
The Importance of Providing Information to Parents and Children Relating to Possible Mental Vulnerability

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1. Background

Information relating to the parents about their own vulnerability and of the children (beside the availability of a stable attachment person) can be considered as one of the major supportive factors towards the mental health of children in mentally vulnerable systems. However, data shows that the majority of young children and adolescents are still not informed about the mental status of their parents (Küchenhoff 2001) and how to cope with the situation

Shame on the part of the parents, fear of stigma, losing love or respect by their children and the general taboo of mental disorders can be considered as major reasons why parents do not inform their children about what is going on in the family. Parents of small children very often report that they think their small children do not recognise significant mental health changes in the parents (Küchenhoff 2001) – or (for older children) that they do not suffer because of the burden. This is reported as one major reason why parents do not talk about their own vulnerability. However, based on practical experience in playing with and talking to children, it can be hypothesised that even though children might not be able to express changes verbally, they do observe and recognise them.

2. What do children tell us if we ask them about the mental health status of their parents supposing that they know that Mum or Dad suffers from a disease?

Children report that their parents "might seem to act in a strange way". They report that "Mum or Dad is staying in bed", they say that "Mum or Dad is closing the windows or not going out". On the other hand professionals seem to underestimate the impact of changes occurring in parents on the child (Bauer et al. 1998, Küchenhoff 2001). Sometimes children offer "own" explanations: "Mum is not able to get up, because I did not behave well." These attributions should be discussed or "corrected" carefully with the children.

2.1 The First Step of Information:
Increase the awareness of parents that children feel and observe changes.

Often children are not able to define the "illness" or diagnosis, but they are able to observe behavioural changes. As pointed out above, parents generally think and feel that children do

not recognise changes in behaviour and/or mood. The first step consists of providing the information that children, even if they are not yet able to talk, perceive changes in the behaviour, for adapting to challenges within family systems for a child means to anticipate behaviour and therefore to increase control and feelings of security. If the behaviour is changing and cannot be anticipated by the child, the child will notice this difference. Sometimes in this context it is a good idea to give some concrete examples how the children notice the behaviour and changes in the parents. However, lack of compliance from the side of the parents might induce massive conflicts of loyalty in the children.

2.2 The Second Step of Information:
How much do the children know about your mental vulnerability and how are we able to increase this knowledge for the children?

As mentioned above, most children do not know anything about their parents' possible mental vulnerability: Only 25 % of 6-10 year-old adolescents are informed about their parents' disorder or the impact of the illness on own life of the child.

-Feelings of guilt regarding behavioural changes
- possible attribution of behavioural changes and problems within the family towards ones own personality and
- the general perceived distress
- feeling insecure how to cope with the parent

are major impact factors due to this lack of information. Parents are usually able to inform their children, especially if there is a admittance to hospital: "Mum or Dad is sick and has to go to hospital".

However, explaining "what kind of disease Mum or Dad has" is difficult for the parents. Sometimes parents use medical terms like "depression" or "schizophrenia". However, with the exception of depression, which is quite common, these terms are not particularly helpful as children especially regarding schizophrenia, do not know what it is about and also parents themselves might show difficulties to explain their own symptoms. On the other hand it is important, that the situation obtains a "name" (in terms of external attribution).

Sometimes, in relation to substance abuse or acute psychosis, the vulnerable parent might not be able to or be easily motivated to tell the children him or herself about what is going on. In

this context the second parent plays a decisive role regarding the question of how to inform and how to talk to the children. If parents are able to talk about their situation later, in any case they should do this: One 15 year old boy directly asked his father, why he did not explain to him, what was going on (1 year ago), as the boy consciously saw, that something "was going on". Later the father explained, that he thought, that nobody can see the changes.

In many cases it is also supportive for the parents if a discussion about the diagnosis is performed in the presence of professionals, as parents in this context feel safer and expect that the professionals might explain to the children what is going on. Also grandparents can be involved. However, again a big burden is given to mothers (taking into account an increased ratio of single parent situations).

Generally, it is the right of the child to know about the mental health status of the parent. This mental health status has a significant impact on the child's life. However, information has to be given

a. based on a **informed consent with the parents** and
b. in a **child appropriate** (developmentally appropriate) way.
c. Taking into account issues of **privacy and data-protection**, e.g. if parents on the one hand do not allow information and if on the other hand from the welfare point of view this seems necessary. Legal counselling for the professionals – in such situation – is necessary (What am I allowed to do as a professional)?
d. Taking into account issues of **own vulnerability** (sometimes it might be helpful to inform older children that – based on existing vulnerability of the parents – own substance abuse could trigger own psychological disturbances).

2.3 The Third Step of Information:
Who and how to inform children in a developmentally appropriate way.

In the best case parents directly talk to their children, however sometimes parents ask professionals to assist them. Unless there is a danger for the child, parents should give their consent, that the child will be informed about how the professionals perceive the situation. If parents show limited compliance, this issue can be difficult for professionals, as the child might experience a conflict of loyalty (whom to believe?).

A. When starting a conversation with children the following principles should be taken into account:

- ***The principle of feeling safe and secure***: Whenever a dialogue with the child or the family regarding possible mental vulnerability is initiated, the basic principle is that both parents and the child feel safe and secure. This means that, unless there is a danger to the child, parents should give their agreement to talk with the child, that the surroundings are friendly and that the parents are totally informed about the situation e.g. that there is no risk of losing custody etc.

- ***The principle of understandable language***: The information provided for children should be given in a language appropriate for children, depending on their developmental age. Children under four years of age should be given information which uses metaphors or analogies, such as:

  "Dad is suffering from the sleeping disease. He has to sleep a lot and it is difficult for him to wake up; Mum is suffering from the crying disease (both depression). Dad is suffering from a drinking/smoking disease (substance abuse); Mum is suffering from the disease of jumping thoughts (schizophrenia); Dad is suffering from the I-have-to-do-things-disease (bipolar disorder); Mum is suffering from an anger disease (e.g. personality disorder)"

  Within this context it is also important to enter into a dialogue with the child on how the child perceives symptoms, or sometimes also on how the children themselves or the professionals can perceive or see these symptoms.

- ***The principle of curability***: It is important that after the information about a possible illness or disease the child immediately gets the information that (if possible and true) this disease can be cured, that there are doctors who can help Mum or Dad, that there are medications which help Mum or Dad to reduce his/her symptoms. Here the child can be guided by questions (What do you do, if you are sick? E.g. I stay in bed, I take medication, I go to the doctor). If the parent odes not show compliance it can be explained, that the sickness makes, that mum or dad thinks she or he is "not sick".

- ***The principle of external attribution***. This step consists of informing the child that the perceived disease of the mother or father has nothing to do with the child him or herself, highlighting the issue of underlying love and attachment, even though this topic is still discussed controversially: Some children might also experience "false" definitions of love, e.g. personal borders could have been endangered, basic needs not met. They might not have felt "love", but they heard from outside, that this is "love". If parents do not show compliance or if they are not able or willed to accept support, this cannot be seen as a signs of love. This issue has to analized very carefully, as this myth of "love" might create conflicts of loyality within the child: "My mum is supposed to love me, but then how can she "kill" herself. It might be helpful, if the child is able to recognize also "positive aspects" in his or her parents, beside other emotions. In this context it might be important to inform the child that he/she is not responsible for the treatment, e.g. for taking drugs or calling the doctor for the parents. The father, grandparents or medical doctors then might be responsible for the medication.

- ***The principle of self-help***: This means that informing the child should also include the aspect of "What can I do if Mum/Dad is not feeling well?" In this context the child should also create self-help strategies or "crisis-plans": go to the grandmother, go to play with the neighbours, the uncle.. in order to feel safe.

- ***The principle of future orientation***: It does not help (very young) children to know the details of the pathogenesis or biology of the mental illness. What is important for children is the prognosis and the concrete information on what can be done regarding the treatment of the beloved parent. In this context it is helpful to mention that there are special doctors who can give medication and treat parents, that there is a hospital where parents can be cured and where we can visit them (if parents and children wish to do so), that there are special drugs which help to reduce the disease.

- ***The principle of emotional autonomy***: In order to reduce the risk of the child's external attribution, it is also important to talk to the child about his/her feelings regarding possible symptoms. The goal of informing children **is not to let them accept or excuse the possible symptoms of the parents**, e.g. in the field of drug abuse or addiction. Children are allowed to also express their anger about e.g. possible drinking and their

disappointment, e.g. if the drugs do not help or if the parents again have to be admitted in hospital. It is important to differentiate between the informative aspects and the emotional aspects of the child. With relation to self-help, it can also be discussed here what the child him or herself can do to cope with e.g. possible negative emotions.

However there is the risk, that children excuse everything, if they know that their parents are "sick". They might also feel guilty, if they are angry, taking into account, that my mum is "sick". Even if parents do not seek help and behave e.g. "rude", it is helpful for the child, if the parents afterwards feel sorry about it and explain their "exacerbations" to the child. Especially regarding future feelings of guilt this aspect is very important.

3. How to explain mental vulnerability to children depending on their developmental age:

- ***Age group 0-2***: In this age group it is important to describe possible symptoms based on the experience of the child

  "Mum is sick, possibly she has pain in her head, like adults have it sometimes and she will go to the doctor. If Mum/Dad is sick, you cannot help the but Dr. X. You can play with or go to the other parent or grandparents."

- ***Age group 2-4***: In this age group the information can be provided by the above mentioned "sleeping disease", "crying disease", "anger disease" with the extension that this disease has got nothing to do with the child him or herself.

  "This illness is in her/his head and Dr. Y can help her. Now she has to go to the doctor who will help her – like Dr. A helped you, when you had fever. It means that Mum/Dad is sometimes angry, that he/she sees things which do not exist (like in a dream, but mum does not sleep. Or that he/she is very sad and has to cry or is very tired. Mum/Dad has medicine and doctors for this disease. If Mum/Dad is not feeling well, I can attend the kindergarten or play with the child next door, the grandparents or the other parent. If Mum/Dad drinks too much beer and then behaves strange, I can also tell Mum/Dad that I don't like his or her drinking. If mum or dad becomes angry about it , I can also tell it to my teacher…

- ***Age group 4-6***: In this age group children generally notice changes in the behaviour and are able to describe them. With regards to possible symptoms, children can be asked how they observe and perceive it when the mother or father is not feeling well.

Technical terms can be introduced like “depression” with the explanation of the feeling of tiredness, symptoms of not getting up, sometimes being irritated (as a possible decompensation towards expressed needs of the child). Also the metaphor “Mum/Dad seems to be in a bad “movie”or like a dream can be used. Often children use the description of “puzzle parts” which do not fit together in Mum/Dad’s head . Generally at this age, based on children’s knowledge of body functions (e.g. based on books about the body), it can also be explained that the disease is a disease of the nerves and that Mum/Dad is feeling in a different way because the nerves are different. At kindergarten age, the picture of a rucksack is sometimes used to assess the distress: “What kind of worries have you got in your rucksack?”

- In the school-age group, general biological descriptions could be given in terms of transmitter activity, increase or deficit of certain transmitters, which subsequently produce symptoms. Most children understand the concept of nerves, of transmission of signals and the functions of transmitters. Children also understand that transmitters could be increased or decreased and that this lack of balance could cause behavioural or emotional symptoms. Examples could be discussed if there are too many transmitters “between” the nerves or a decreased number.

- In the age group 10-14, the description can generally be based on biological explanations (if adequate). However, it should be considered that adolescents are very sensitive towards possible stigmatisation and so it should also be discussed what this diagnosis means and what impact it has on their daily life as a student or within their peer group. Also the issue of own vulnerability (Can I also get sick?) might be addressed: Children have the right, to hear the truth: mostly there is a higher vulnerability for children. However, a careful dialogue regarding personality differences (but also similarities towards the own parents) and own resources (what can I do to remain healthy) is able to open thoughts, emotions and actions towards own resilience.

4. The impact of diagnosis and information

Information for children regarding the mental vulnerability of their parents creates a new framework of attribution and interpretation for the child: If Mum/Dad is angry it is not because of me, it is because of the nerves which function differently in his or her head. If the

child is insecure, whether mum or dad are angry about misbehaviour of the child or because of their mental status, the availability of another healthy attachment person is important: He or she could help the child, to "check" his or her "reality" and perceptions.

This first reframing decreases the child's distress, as they better understand what is going on in the family. However, it is sometimes observable that children, especially small children, do not seem to be interested in this information, e.g. by not asking further questions. This apparent "non-reaction" does not mean that the children did not perceive the information, but it can represent an active protection on the part of the child: especially young children might be afraid, if the illness (by means of talking about it) becomes "real". Older children sometimes try to "repress" the observation of symptoms. They do not ant to talk about it, as they only wish "normal" parents. In these cases it is important to ask the child during the next units or meetings what has been discussed e.g. during the last session, however not insisting too much on e.g. repetition by the child him or herself.

Information for the child is important, but it is not alone sufficient. Information has to be followed

A. by the questions what might I do about my feelings about that my parents (e.g. if they do not have time, if they drink too much, if they show anger, if they do not go out with me. It has to be pointed out that these emotions could be present and that children have the right to express these emotions. Children should not be "judged" related to their emotions. They have the right to express clear borders regarding emotional outbursts of their parents. To be able, not to judge negative emotions of the children, sometimes it is helpful for the parents to see the world with the eyes of their children (how would I feel, if my parents behave like this).

   For the children it is important to differentiate, if the reactions of the parents are due to their symptoms or due to "understandable" triggers: The child – within a dialogue – could learn to differentiate: Which behaviour do I like in my parents, which is disturbing me?
B. by questions on how to express and meet my own needs even if e.g. the situation might be challenging: what can I do to satisfy my needs even if my parents are angry, do not go out etc., where can I go, who is supporting me. In this context support plans

(e.g. information about a neighbour, telephone-numbers etc. should be available for the child).

C. by child centred strategies: Not every child has the same needs: Children might react in different ways if they are faced with stressors or challenging situations (e.g. information about a parent's mental vulnerability). An heuristic way for general types e.g. to cope with addiction (Kolitzus (1997) can be described:

   a. ***The Hero***: He or she tries to protect the parents from possible harm, takes responsibility for the parents and very often reacts in a very adult way. Confronting the hero with information might increase his/her feeling of responsibility. Information therefore has to be combined with concrete steps to decrease responsibility: I am not responsible for my parents not-feeling well and I am allowed to "remain a child" (however it might be difficult for the hero to give up his or her position.
   b. ***The Handsome Baby:*** Some children react with regression if they are faced with challenges of distress. For (mostly adolescent) parents this regression represents a relief, as they are able to avoid possible age-relevant developmental tasks and parental responsibility. In this case the child itself might satisfy the wishes of his/her parents to have a baby without problems and to feel like "real" parents. The "regressive baby might not be interested in information, as he or she might lose a lot of "secondary" attention. Informing the "regressive baby" means to differentiate clearly between the age of the child and the way to inform them and the wishes to escape this distress. So called "controlled regression" (Lets play baby for 15 minutes and then you are a 4 year old girl again) might be suitable to cover both needs of the child: firstly to react in a developmentally appropriate way and secondly to satisfy basic needs in terms of regression.
   c. ***The scape-goat:*** The behaviourally challenging child (e.g. by means of delinquent behaviour) tries to show stronger symptoms than the parents to obtain at least some attention. Information might not be sufficient to initiate behavioural changes in this group of children. If information is not followed by concrete support processes (for the child), there is a high probability that the disturbance will continue.

d. ***The clown:*** The child tries to overcompensate stress factors in the family system by means of behaviour, which – superficially – looks like humour.

e. ***The Forgotten Child:*** The forgotten child performs an inner regression in terms of fantasies (e.g. of a healthy family). The personal needs of this group of children are in particular danger, as they identify themselves as victims (and also obtain strength from this position). For the forgotten child providing information also represents attention towards the needs of the children.

For these children time, contact and needs orientation should be provided to create attachment and self awareness of their (potentially) forgotten needs as a child.

5. References

Bauer, M. et al. (1998). Psychotische Frauen und ihre Kinder. Psychiatrische Praxis, 25, 191-195

Küchenhoff, B. (2001): Kinder psychisch kranker Eltern. Psychiatrie, 2, 1-4

Kolitzus, H. (1997): Die Liebe und der Suff... Schicksalsgemeinschaft Suchtfamilie. Kösel, München