

Pediatric palliative care - The role of the patient's family

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Abstract

Whenever a child suffers, what does she or he cry? Mother! What does that mean? Palliative care is not a type of medicine based on objective evidence or statistics. The only relevant standard is the very individual quality of life. Nobody knows better what this actually means but the patient himself. Thus, if the mother's presence has the biggest impact on a child's wellbeing or comfort, she herself is the most valuable treatment modality. In nearly every publication dealing with pediatric palliative care, it is stated that palliative care does not only imply care for the sick child but also for the parents and the whole family. Usually, it is pointed out that they are suffering a lot as well. But helping them does also mean: helping the child! Of course, it means higher efforts, obligations and costs for the healthcare system. Thus the justification of this effort may be put in question; in particular, it may be argued that disorders of family members should, if necessary, be treated as such. But this is only one side of the coin! In the following, we will, based on published literature, look at the role of mothers, fathers, and siblings for the wellbeing of an ill or even dying child. As a conclusion, we will learn that if it is our task to give a dying child the best available care, helping mothers, fathers and sibling is an inevitable part of it.

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CHILD

Separation of a child from his or her parents is a trauma by itself

One of the first of all experimental studies ever performed in children has often since served as an example of moral ambiguity: asking, which was the "original" language of mankind, in the 13th century, emperor Frederick II ordered a group of orphans to be raised without being allowed to hear any spoken words from their nurses. What was the result? As the legend says, all children finally died, since they never experienced normal human intercourse^[1]. And at all times it has been observed that children who were separated early from their mothers had a lower chance to survive to adulthood^[2].

In the twentieth century, in child psychology, a number of different concepts have been created to describe children's development. While Jean Piaget's concept rather focuses on the development of intelligence and mind, Sigmund Freud's stage model described psychosexual development^[3,4]. It is the model of Erik Erikson, however, that puts the gradual development of autonomy in the focus-and thus the opposite of autonomy, attachment^[5]. In the small child, he or she will experience whether his or her needs are fulfilled by the caregivers, which will teach him to develop basic trust or mistrust. Becoming older, the child develops a will, gradually helping him to satisfy his needs by himself. However, this process is always safeguarded within the context of the caregivers

providing security or, in the negative context, mistrust, shame, or guilt^[5].

It was the child psychiatrist John Bowlby^[6] who further described the role of autonomy and attachment for a child's capacity to deal with stress. As he wrote, no variables have more effects on personality development than the experiences within the family^[6].

Interestingly, one of the worst traumata for a child is to be separated from his or her caregiver. This type of trauma was in particular analysed by Bowlby's coworker, M. Ainsworth^[7,8]. Ainsworth showed that the degree of trauma the child suffers depends on the type of separation, e.g. if the child feels to be handed over to a reliable other person, whether the child is convinced that the parent will soon come back, *etc.*^[7]. From her and work of others, it becomes apparent that not only being separated from the caregivers means trauma, but also that being with them gives strength^[8-10].

Bowlby found that grief in children over 6 mo of age separated from their parents contains the same categories as grief in an adult^[6]. We thus have to keep in mind that separation itself means to do harm to a child and hurts the principle of *nil nocere*.

By the groundbreaking work of James Robertson^[11] and others who empirically studied separation, since the 1970ies new landmarks were established for the rules within hospitals, and rooming-in stepwise became common standard in hospitals, as it is nowadays.

If we conclude that the presence of the parents is important for a child at any time, what does this mean in an extreme situation of trauma, in terminal disease? Do the parents-besides being present-have an additional function that might require professional help, in order to make them fit for this function?

WHAT IS THE AIM OF PALLIATIVE CARE?

While in other areas of medicine, different treatment modalities can be compared by measurable outcomes such as cure rates or survival time, by which individual variability can be overcome statistically, in palliative care, the aim itself is defined individually. For one patient it is prolongation of survival time, for the other pain relief, for the third it is to be at home, or what ever. It depends on the patient which disease symptoms should be treated first or which positive resources may be uncovered to enforce salutogenesis^[12,13]. This may be particularly true for pediatric palliative care^[14].

So, if we ask for the particular aim of pediatric palliative care, we have to follow the way a child feels, thinks and suffers. While an adult might long for an injection that will give him pain relief, for a child, even thinking of a syringe might mean pain. Thus giving the child an injection may be a medical error. And if a child feels pure quality of life being comforted by her mother or cuddling with his sister, this dictates the aims of our work.

What does this mean with respect to the role of parents and siblings?

STATEMENTS OF THE LITERATURE

Numerous authors have already stressed the importance of care for the whole families in pediatric palliative care. Among these, only a selection can be cited here.

So, the WHO notes concerning palliative care for children^[15]: "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family." In 2007 the Task Force on Palliative Care for Children and Adolescents of the European Association of Palliative Care (EAPC)-IMPACT-defined European standards of pediatric palliative care, who wrote "Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. The aim of paediatric palliative care is to enhance quality of life for the child and family. It is essential that sibling support is an integral part of paediatric palliative care. Parents are central to a child's wellbeing. They should be present and involved in all aspects of their child's care, guided by the age and the wishes of the child. Parents shall be acknowledged as the primary carers and shall be centrally involved as partners in all care and decisions involving their child. Information should be provided for the parents, for the child and for the siblings according to age and understanding"^[14].

Many other authors confirm this, stressing the importance of both parents and siblings for the wellbeing of an ill child^[16-24].

ILL CHILD

What does illness mean to a child?

Depending on the situation, many sick children experience a double trauma: on the one hand, there is the pain from the disease itself, and on the other, they experience fear, fright or loneliness: in the emergency room of a hospital, for example, people unknown to the child will talk to her or him, touch him, probably even hurt him by taking blood. And what is the worst for the child: often, he or she will be separated from their mother. They will cry, and if there is any understandable word they will cry, it will be the name of their mother. In fact it appears incredible that we additionally hurt children who are already suffering from a disease, but this is daily life.

Anna Freud^[25] was one of the first psychologists to study particularly the psychological effect for a child of being ill. Since her times, and due to the work of herself and others, fortunately the daily routine in hospitals has changed a lot, allowing the presence of parents on the hospital wards, however, the basic problem of an ill child of course remains the same. During infancy, any tension, need, or frustration is probably felt as pain^[25]. As Freud puts it, "The child is unable to distinguish between feelings of suffering caused by the disease inside the body

and suffering imposed on him from outside for the sake of curing the disease. He has to submit uncomprehendingly, helplessly and passively to both sets of experiences. In certain instances factors of the latter kind, with their high emotional significance, may even be decisive ones in causing a child's psychological breakdown during illnesses, or in determining the aftereffects^[25]. For a child, being treated might even be the biggest reason of discomfort in the whole illness. Anxiety is provoked by the specific vulnerabilities of each developmental struggle^[8]. For example, reaction to disease of older infants and toddlers is heightened by fears of abandonment in the face of potentially overwhelming pain. In this situation, Solnit^[26] described the parents' role during illness as "irreplaceable." For young children who have not achieved object constancy, typically children under 3 years of age, the absence of parents during illness creates dual anxiety. Physical pain is amplified by the loss of the "love object"^[27]. On the other hand, pain and discomfort will be reduced significantly by the simple presence of the mother, and by the feeling of comfort they can receive by no other person but only her. Thus no other aspect has comparable impact on their quality of life^[6,7,25].

EXCURS

Balint: The drug doctor

When in 1957, Michael Balint made the famous statement of the drug doctor^[28], his main emphasis was to help physicians use their personality in a better way, keeping in mind the appropriate dosage, timing and side effects. The drug doctor not only acts by comforting the patient—which still is an important part—but also by understanding the way the patient interacts with the disease, uncovering mechanisms that make him ill, and leading him to a different attitude. Thus, Balint emphasizes the physician's role as a coach. Finally, the doctor's personality becomes a drug that helps to relieve complaints or even may cure a disease. Two conditions are important for this process: the doctor has to understand what is going on in the patient and he has to be recognized by the patient as a reliable and helpful authority^[24,28].

An important result of calling the doctor a "drug" is that the therapeutical impact of his personality is no more regarded just as kind of a spurious "placebo" effect. It has become a standard of knowledge that appropriate communication between doctors and patients is an important basis for nearly every type of therapy^[28].

PARENTS

Parents are a drug

In children, Balint's statement of the drug doctor is not in the same way true as in adults. From their perspective, often, the doctor is more threatening than the disease. He comes together with the disease, he might even create fear and pain. But there is another person who is the ideal drug. The mother. Whenever a child feels pain, fear

or frustration, he or she will cry for the mother. And the mother will certainly know what the child is feeling, she will comfort him better than anybody else^[28].

For a child, the parents are the only reliable experts in any aspect of life. Probably, in no way the idea that a human being may personally represent a helpful drug for another becomes true to such a degree as in the way a mother is perceived by her child. Neglecting the therapeutic benefit of parents for their ill children would mean to simply withdraw an important drug for the treatment of the child.

But if we consider that parents are a drug—does not this mean that we are also obliged to do our best to sharpen this drug?

Parents are patients

We have to consider another fact. Parents who have a suffering child are suffering themselves. If a child suffers, or if he gets in vital danger or even dies, the own life of the parents is attacked in its very substance. And for these patients, the doctor as such may be a very important drug, in Balint's sense: If the parents are a drug for the children, and if they have to be given all possible power to act for their benefit, it is, of course, the doctors' obligation to act as their drug if they are weakened by the pain^[29].

Besides, in two ways, the role of the drug parent is principally different from the role of the drug doctor. First, a child by nature is no in dependant organism. Whatever relationship he or she has will be a more or less asymmetric one, particularly with the parents, but also with other adults. And second, while an adult may switch doctors, a child will never be able to chose new parents. This means that parents are a very strong drug, and they are a drug that can never be replaced by another^[19,29].

Parents are part of the medical care team

For ill children who experience a high amount of care from professional caregivers, these will by time also become an important part of their life. But never, of course, they may replace the unique role of mother and father. If we consider all acts of comfort, psychological support and communication as components of palliative therapy, particularly in palliative care, medical and parental care can not be separated from each other. Usually, the care for a severely ill child is done by parents and professionals together, and they have to work together to function best for an ill child^[22,30]. Thus, the parents inevitably become a part of the team^[31,32]. Still, on the other hand, they will always retain their special role in the system. And there will also have to be a team structure outside this relationship in which the professionals organize themselves as professionals^[33,34].

Several aspects of this very complex relationship have to be underlined: Unlike any other member of the caring team, the parents are absolutely irreplaceable. Still they are not professionals since they have no professional distance. They are not, as the professionals, obliged by their

employers to cooperate in a decent way with the rest of the team. They are allowed to choose another professional team. On the other hand, it remains the responsibility of the professionals to detect if the parents, by being patients under extreme pressure themselves, might develop a pathological attitude that might be harmful to the child^[22,31,35-37].

What does this mean for a child?

Although knowing that for her or him the mother and the father usually are the central persons of their life, children will of course develop a personal and human relationship to other members of the team. They may become personally attached to some of the persons caring for them. Being dependent from others by nature, children have a sharp sense for possible conflicts between the people they depend on. Feeling a conflict between mother and father means enormous fear, and thus pain for a child. The same, to a minor extend, may occur if they feel a conflict within the medical team or between professionals and parents. To work on a good relationship to the parents is an necessary component of palliative care for the children to prevent pain and to improve the quality of their life.

Thus, in pediatric palliative care, parents are drugs, patients, and part of the team at the same time; they are unique, and they are an invaluable resource. Working with the parents has to consider each of these roles at the same time, and all three are important for the child^[38].

SIBLINGS

If we study the published literature concerning the situation of siblings of severely ill or dying children we will learn that they indeed do also suffer in a multiple way^[27,39-41].

First, while their brother or sister is alive, they suffer from deprivation of love since their parents are fully occupied with the care for the ill child, or, when he or she has died, with mourning. Second, they will suffer themselves from this unbearable loss. Third, the strongest power to comfort them in their grief, the parents, will be incredibly weakened^[27,40,42]. Confronted with an overwhelming catastrophe, the sibling will have feelings he cannot deal with himself - like anger, pain, fear, depression, jealousy and others. In many cases he may - by showing a neglective behaviour - try to minimalise the emotions he cannot control - which will be misunderstood as inappropriate behaviour by the surrounding^[27]. As a result, he will feel further isolation. Unfortunately, as a final fact, most of these and other emotions and misunderstandings will end up in guilt^[23,27,40]. Feeling guilty, and filled with their unmet need for care, time and comfort, they suffer enormously^[19,23,27,42,43].

Thus, palliative care for children requires an approach that includes the family, or, as noted by the IMPaCCT statement: "It is essential that sibling support is an integral part of paediatric palliative care"^[14].

However, seeing siblings just as victims is only one side of the coin. In fact they also have an enormous po-

tential of positive resources for their ill sister or brother. In the sense of salutogenesis^[12], they are invaluable! This potential-next to all the other - even bears in itself the chance to help the healthy sibling survive, and to overcome the cruel power of guilt^[22,44].

Sister and brother are drugs

First of all the role of siblings is palliative-if the function of palliative care is to improve the quality of life: What is normality and happiness for a child? Of course they want to be with others^[21,45]. Many studies show that playing with peers has a beneficial impact on the development of a child. But it is also so the wish of most children to do so, and it is part of normality and happiness^[45,46]. Playing and communicating with peers also has a strong impact on many body functions of an ill child^[33,47]. Therefore, an experienced children's doctor will know numerous cases in which he observed a therapeutical benefit from siblings. A child, when released home from the hospital, being together with his brother or sister now, will often show much more mobility, appetite and happiness than ever during the time in the hospital^[23,33,48].

Thus siblings are a drug-different to their parents, but however helpful!

PATIENT IS THE FAMILY

A family is greater than the sum of its parts

In our Western culture, nearly all persons grow up in families. Although these not always consist of mother, father and sibling children, this is the standard regarded as normal by most. And that a child lives together with one or two persons about thirty years older, and perhaps with peers of about his or her own age, throughout the whole childhood, seems to be an important condition for normal growing-up, giving a child the stable basis for the development of her or his personality^[7,24,25,41]. Still, each family is a microcosmos of its own, with an individual history, with rituals, memories or sayings, strengths or weaknesses, individual relationships *etc.* that make it different from any other family. Having close, long lasting and valued relationships - usually including the very most important persons for a given human being - each family member is deeply involved in anything that concerns another member of the family^[33,49,50].

Medicine, and palliative care in particular, always are devoted to the individual patient, but a child always is part of the family. Thus, the appropriate way to deal with a family in which a child is suffering from an incurable disease is to try to understand all family members with their interactions, including the psychological, social, and spiritual life of a family^[30,21,41,46,51,52].

Anticipating the grief

We all know that no trauma can occur to a human being is as severe as the loss of a child^[53,54]. By no means, this trauma can be released completely. However, whether loss and grief will lead to complete psychosocial destruc-

tion of a person or whether he or she will be able to regain happiness in spite of this scar in the biography, depends on the individual conditions of the loss. For example, it is very important whether the condition of death was peaceful or traumatic, whether unsolved questions remain, and, probably most relevant, to what degree feelings of guilt—that are, to some degree, apparent in nearly every case—are torturing the mother or father, the brother or sister of a dead child^[21,27,53-57].

We know that dying children often feel the pain their suffering and death will put on their loved ones, and that they even feel guilty^[58]. For them, it would be a great help to know that they may leave in peace. This also is quality of life.

It is not a rare observation that children who are suffering from severe symptoms, behave much more adapted and calm towards the professionals than towards their parents. Often, this does hurt. The possible reasons for them may be numerous: perhaps the child feels the parents are those people towards whom he or she may behave as freely as towards nobody else. Maybe the child feels the nervousity and pain filling the parents—which in turn gives pain to the child. Maybe the child feels the unspoken accusation that he or she is going to die and thus feels guilty.

So—if there is some tension between the dying child and her or his parents, they should be supported even more. Whatever relieves their pain and fear, will also help the child^[53,54,59].

And an important part in this process often is anticipation of grief^[53,60]. Considering the fact that they will lose their child will enable them to prepare themselves. This is, of course, a very long process requiring difficult and painful steps. It allows the parents to develop strength and they get the chance to solve any open questions or problems reducing the amount of guilt that might be coming up afterwards^[59].

This will also help the child. For her or him, it will be less painful to die if he or she knows that the parents accept their death—they will not feel guilty^[54,59]. If a child suffers from the knowledge that their loss will hurt the parents and siblings, it may paralyse his or her capacity to relax, while relaxing would add a lot to the quality of life in this difficult situation^[58,61].

Making advance planning often is helpful. For example, if a child may decide where she or he wants to be buried, this will allow the child to leave her or his own traces in the world. Creating a bond at lifetime that will reassure the parents and siblings that there are no open questions, accusations or misunderstandings will help both, the dying child and the surviving family^[58].

All this is a part of the anticipation of grief. To become able to anticipate the grief, parents and siblings have to learn a lot, they have to proceed gradually. They have to develop openness and honesty within their family system, including all, they will have to bear a lot of pain; and hopefully they will finally be able to accept. It is an important task for professionals to accompany the fam-

ily in this process. It requires an enormous amount of sensibility and knowledge^[54]. This process also includes, of course, anticipatory grief on the side of the team. It is an important part in the process of forming a team together with the family^[40,54].

Or, as the IMPaCCT statement puts it, “bereavement support must commence at diagnosis and continue through the disease process, through death and beyond, for as long as it is needed”^[14].

LATE EFFECTS IN A FAMILY

Numerous studies - that can not all be reported here - indicate that the death of a child has an enormous impact on the whole life of the bereaved parents and siblings. For example, nearly one fourth of bereaved parents report significant psychosocial problems such as marital distress^[20]. More than one third of surviving siblings have problems that interfere with their health and ability to develop friendships^[20]. Further, it has been shown that parents require a lifelong effort to deal with the loss and may themselves be at higher risk of earlier death from both natural and unnatural causes^[20,56]. For most parents, the child still is present in their daily thoughts, with an intense impact on all they are doing^[19,54,59]. The same is true for the siblings^[19,50].

Of course, the phase of palliative care, from diagnosis to death—whether traumatic or peaceful—is of substantial relevance for this process.

Thus, it is also of high relevance for the whole future life of the bereaved parents and siblings that pediatric palliative care is seen as a care for the family, not the individual child alone.

CONCLUSION

Palliative care is a medicine that is absolutely centered on the patient, whose needs and demands are the standard for all measures. While for an adult, a doctor may act as a drug, helping the patient by her or his personality, for a child this function is nearly exclusively done by the mother, and the father. Parents are drugs, patients, and team members at the same time. The same is true for siblings. As a conclusion, we have to learn that if it is our task to give a dying child the best available care, strengthening mothers, fathers and sibling is an inevitable part of it.

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