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Manifestations of death consciousness and the fear of death in children suffering from malignant disease

By

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The consciousness of death and the fear of death are analysed, and their symptoms, especially as they manifest themselves in children with chronic lethal disease, mostly tumours and leukaemia, are described. Fear of death is not often expressed by direct verbal communication; sometimes it is manifest in allusions, jokes, plays, dreams, etc. Basically, it is a fear of separation. One should struggle against it until the last moment with occupational therapy, regular teaching, free visiting time, frequent permissions to go home, activity, affection and love.

In a certain phase of the personality development of children the fear of death comes to the fore.

A healthy three to five-year-old child experiences death only as a contingent change, not as a permanent law of nature. In a given situation he experiences that he may be threatened.

Five- to nine-year-old can imagine death but they do not see it as hopeless and irreversible. From nine on they recognize it as an inevitable natural biological process. In the case of children growing up without disturbances, the thought of death recedes into the distant future, in keeping with the real situation. For the child with a malignant disease in a hopeless state it can become an imminent threat to his ego, and this is what happens in most cases.

"Consciousness of death" can be defined as cognizance of the finiteness of individual existence. The difference between consciousness and fear of death is very distinct. Very small children may experience a fear of death, of annihilation at a very primeval, animalistic level before they die, although they do not even know the expression. Small children may show interest in their environment up to the last moment if they do not suffer too much, if their consciousness is clear and their environment has a beneficial effect on them. At other times children of the same age are apathetic or experience grave separation anxieties. Partly, this stems from the hospital environment which entails separation from the home and from the parents, but partly it is the experience of definite separation, the transition to death.

Death-consciousness and fear of death in healthy and sick children can only be compared to a limited degree.

Suffering, the decline of their powers, interior organic sensations, boredom, separation from the parents, the sight of other patients, the loss of their companions, all accelerate the development of death-consciousness and also the fear of death. It is induced and developed especially rapidly by the anxiety of the parents, and the behaviour of their environment only helps to support and reinforce it.

Fear of death is often concealed in the statements of even very small children who ask or hope for new or more intensive treatment or protest against a particular treatment because somebody who died afterwards had received it, or they protest against being isolated. It is very rare that a patient calls me and says, "I feel that I'll die and I am very scared".

It is difficult for a child to bear the tension caused by fear alone, even more difficult than for an adult, so he tries to communicate it to others. The wish to communicate is a strong drive: he looks for a companion and helper in his fear. Expressing his fears would ease his burden if the communication were received properly. So he tries to communicate his fears to his environment in different ways.

From 1970 to 1975 we worked with 64 children suffering from malignant disease and their relatives at our Leukaemia Therapy Centre. We found that children communicated their consciousness and fear of death in the following ways:

1. semi-direct verbal communication
2. direct verbal communication
3. verbal allusion
4. joking
5. symbolic verbal communication
6. symbolic drawing
7. symbolic story
8. symbolic play
9. direct play
10. metacommunication
11. identification with a dead relative or patient
12. allusion with action
13. forecasting
14. hidden knowledge
15. dream
16. transfer to another person.

Here are some brief examples of these different means of communication.

1. Semi-direct verbal communication. A. B., aged 15 (myeloid leukaemia), to his mother: "I have seen small children die, I may also die. Perhaps this is the last time that I am asking you for something, perhaps this is the last time that you are asking me for something".

2. Direct verbal communication. O. H., age 12, (lupus erythematosus) two years prior to his death: "I know that I'll die, they are only lying to me when they say they'll cure me".

3. Verbal allusion. S. H., 5 years 4 months (lymphosarcoma), 6 months before his death: "Don't buy me any more toys, I won't need them".

4. Joking. T. M., age 8 (myeloid leukaemia), four days prior to death: "I know that people don't die of this disease, only accidentally . . .".

5. Symbolic verbal communication: Z. H., age 13, (myeloid leukaemia), one day prior to death: "Sometimes a green fruit drops unexpectedly".

6. Symbolic drawing. Skeleton in coffin, grave, death with scythe, soul leaving the body, hearse, murder, execution, etc., often appear in a variety of forms.

7. Symbolic story: M. S., age 7, (lymphoid leukaemia), 6 months before death: "And the little girl stepped into the river and the water carried her away and away. Weeks and months passed and the water just carried her on. She never reached the shore."

8. Symbolic play: M. S., age 9, (myeloid leukaemia, metastases) 5 weeks before death: she furnishes a flat, the family is sitting at home when the grandmother enters and says: "I brought this pine tree, I dug it up from the garden, you can put it on top of the cupboard, it's dead."

9. Direct play. M. O., age 6, (lymphoid leukaemia, during grave relapse, in a critical state): putting a doll to bed, "She is very ill, the doctors are doing their best to cure her but they can't". (The child is still alive.)

10. Metacommunication. P. E., age 4, (myeloid leukaemia), 4 days before her death the nurse told the child "If you swallow this pill, you'll get well". The child looked attentively at the nurse, then covered her eye with her right hand, and let her left hand fall in a weary, hopeless gesture.

11. Identification. T. M., a boy with lymphoid leukaemia in the hours before his death, pulled up his legs, clasped his knees with his hands, bent his head forward and rocked himself. The doctor on night duty who had seen him observed a few months later in the case of M. L., a 14-year-old boy suffering from myeloid leukaemia, going through the same motions in the terminal phase. He asked him: "What are you doing?" The boy replied: "I am thinking of T.".

12. Allusion with action. G. M., age 13, (lymphoid leukaemia with metastases), 10 days before his death he started to play the same music again and again on a tape-recorder: "I have never been on a railway at the fun fair" and "Music of the dead" from a film.

13. Forecasting. B. B., age 3, (myeloid leukaemia) repeated throughout the whole of Friday: "Don't come to me on Sunday because I am going home". She died on Sunday. (The instinctive anticipation and forecasting of the time of death occurs in a small percentage of parents and in an even smaller proportion of children.)

14. Hidden knowledge. S. V., age 13, (myeloid leukaemia), after his death his mother found a note among the boy's papers; he had listed the names of his fellow patients over two years and marked with a cross the names of those who had died.

15. Dream. G. M., a boy of 13, (lymphoid leukaemia with metastases), dreamt that he had to get out of the car in a foreign country and swim across the sea.

16. Transfer to another person. O. H. age 12, (lupus erythematosus). His mother, had influenza, the boy was afraid that she would die. When his doctor travelled by plane he was afraid the plane would crash.

TABLE I

Percentage distribution of the methods of death communication

Communication	per cent
semi-direct verbal communication	6.8
direct verbal communication	7.5
verbal allusion	13.6
joking	3.5
symbolic verbal communication	5.2
symbolic drawing	4.4
symbolic story	2.0
symbolic play	17.5
direct play	6.0
metacommunication	11.6
identification	1.2
allusion with action	6.5
forecasting	0.1
hidden knowledge	7.5
dream	4.4
transfer to other persons	2.0

A child may communicate his fear of death in several ways. So from Table I we can learn only at what frequency the children avail themselves of different means of communication.

The distribution of the children's communications addressed to the different members of their environment is seen in Table II.

We do not know about communication between siblings but it most likely occurs.

We did not mention the communications to psychologists because only few of them work with children suffering from malignant diseases. In addition, the number of communications depends on the attitude of the psychologist. The child believes namely that the topic of death must be handled ,,as it is done usually in the presence of the white-coats''. If the psychologist lacks the necessary experience, awareness and courage, he will not offer the opportunity of communication to the child and so much will remain hidden to him.

We observed the children's communications partly during work and play, and in the course of psychological examinations, partly spontaneously or in answer to questions put to relatives, parents, doctors and nurses. Many communications have been observed by occupational therapists staying among the children.

Feedback is made more difficult by the fact that some adults do not understand, and hence do not recognize, symbolic communications. Their mechanism of avoidance operates almost always consciously or unconsciously. Fear of death in a child is a painful experience in any case and so they like to "forget it", and hence they rarely mention their experience in connection with these communications.

Any numerical survey is made even more uncertain and incidental by the circumstance that it refers only to the cases we were able to observe and follow. The same children may have made communications at several other

TABLE II

To whom:	mother	father	adult relative	head physician	attending physician	nurse	other children
percentage	14	2	4	1	3	27	49

occasions when we were not present or obtained no feedback.

Parents, partly due to the avoidance mechanism, only mention their childrens' communications about death in the most intimate moments. In general, the most valuable material was provided retrospectively, after the death of the child, when consciousness could function more freely. In their reminiscences they did not avoid the issue, they recognized what had happened. In most cases they also found the child's hidden notes and drawings. And afterwards the relatives also revealed what they had kept secret until then: what the child had told them and how he had expressed it. It may happen also that they do not tell the parents even afterwards, but they tell us. (Retrospective examination, i.e. exploration after the death of the child is rare, and we meet the child's relatives after his death only exceptionally.)

All these experiences led to the conclusion that seriously ill children communicate and know much more about their approaching death than we can assess.

The attitudes of children concerning the fear of death and their manner of communicating it depend on their age, personal character, their social-cultural background and, chiefly on the way the people around them behave.

As a rule, adults do not want to acknowledge the fear of death in children. One of the bases of their avoidance is their own unresolved experience of death which asserts itself in everybody, in their attitude to death and the dying. In the case of children the fact that we deal with a budding personality, a life hardly begun, and so-called "innocence", makes it even more difficult. It is unnatural to end one's life in childhood and therefore the death of a child is much more shocking; this is a strong factor in every group.

The parent experiences his child's death as his own partial death. The fact that the parents cannot protect him from annihilation and fear, only aggravates their own torments. If the child speaks of death the parents show vegetative symptoms of anxiety, they turn pale, tremble, perspire, they may even panic or suffer a state of psychic block.

Doctors in general experience their inability to save the child as failure and frustration; the child's fear of death makes it even more difficult to bear, so they too skirt the issue.

The nurses who care for the sick children come physically close to them over a long period of informal togetherness, but empathy, the imminent danger, their helplessness and their own unresolved fear of death make them incapable of receiving the communication.

Owing to the above motivations we have observed the following reactions and modes of behaviour in adults who received children's communications about death:

they pretend not to have heard
they pretend not to have understood
they change the subject

they start doing something
they rebuke the child
they tell him "not to talk so foolishly"
they play down the problem
they try to brush it aside with humour
they react with false optimism
they aggressively refuse to talk about the subject.

In our experience the attitude of the environment exerts a strong influence on the children's manifestations. If their direct verbal communications are rejected they resort to hints and allusions.

If the child himself is afraid of putting it into words, if he fears reality, he feels his way, starts with hints and allusions; direct communication follows when the tension becomes unbearable. Older children often joke and play things down. This may be a means of achieving detachment or an attempt at working out the problem. If the environment is unable to tolerate either this playing down of fears, or joking and allusion, older children will respond with symbolic communications, and later, when they realize their situation — total rejection — they will tak erefuge in identification addressed only to themselves. This means that the child has to acknowledge and realize that he has been left alone with his problem, his fear of death. He cannot even make an allusion to somebody. He tries to reduce tension by playing an identification scene to himself.

Children thus rejected and left alone with their fear of death, finally receive death with violent emotional outbursts or apathy. It may also happen that the child recognizes the fear of adults, wants to spare them and plays the optimist or conceals his death consciousness and behaves calmly and passively without depression and negativism. In the case of smaller children, the order is mostly inverse: symbolic communication dominates their play and drawing. Verbal allusion is rare and comes unexpectedly, apparently without any emotional emphasis.

An example: the mother of a leukaemic child told us: "He said, quite lightly as if it had no importance at all although he is still in kindergarden: 'anyway mum, I'll never come back from hospital'. Then I felt my hand tremble, I could hardly step out of the room, I ad my heart in my mouth and I was unable to answer".

We selected this case because it shows clearly something we have already mentioned which is very frequent, namely that mothers in general react with strong vegetative symptoms of fear even to the hints and allusions of their children. From this we can conclude what the child may learn from the behaviour of his mother: that his state is really serious, that death is very frightening and, finally, that one is not allowed to speak of it. This may explain that the child varies his methods of communication or withdraws into himself.

The nurses and doctors working with patients suffering from malignant disease also feel that permanent

avoidance is not a right attitude. The unsolvedness of the task is an additional emotional burden for them. According to surveys conducted in eleven institutes, various attempts are being made everywhere but they cannot find a solution to the problem.

We may sum up by stating that the death consciousness and fear of the sick child is much greater than it appears on the surface. One of the decisive components of concealment is the fear of adults, their helplessness with regard to children's fears of death. This only makes it more difficult for the children to bear their fears of death.

Working with terminally ill children it seems that a certain empathy is necessary, together with a rational, psychologically reasoned supportive attitude which realizes the situation, and explores and follows it in every detail.

If adults avoid the issue, the children are compelled to accept this behaviour of rejecting the topic of death. So they keep silent and conceal their feelings while their fears grow: they react to their experiences and fears of death in connection with others and themselves and communicate these feelings in words, drawings, play, and metacommunication. Owing to the reasons mentioned above, they do not much discuss their own fears of death with adults. To their parents and the hospital staff they pretend that they do not know anything.

So they accept every superficial and even contradictory explanation about a fellow-patient who died. Their lack of interest and questioning about the disappeared child shows that the psychic climate is bad, the children do not dare to be frank.

Concealment of the problem provides apparent tranquillity to children and adults; all the stronger is the impact of the repressed feeling.

We believe that it would be a good thing to treat openly the question of children's fear of death. The initial step should be the recognition of the child's means of communication, the exploration of the psychic mechanism, One component of this is the working out of our own death consciousness and experience. It is rather done individually but the members of the staff can help each other by openly revealing and discussing theirproblems in connection with death. We must also prepare ourselves emotionally to receive the communication and work out our method of how to react to what.

This does not only apply to health workers: it is advisable to prepare also the parents for receiving and answering the communication.

If we already know the different means of communication with regard to death consciousness and fear, and are prepared emotionally, we may be able to adequately attempt to give an answer. This is a complicated and difficult task and can be solved only individually and in a differentiated way, as the complex psychotherapy of children and parents. The communications must be discussed by the team; it seems absolutely necessary to work out a common standpoint and ap-

proach. The "psychic manoeuvring" of the patient with regard to the fear of death can be followed and alleviated only jointly. The relatives, doctors, and nurses also change their roles and attitudes. Everybody should work out his own attitude to the fear of the dying patient according to his own aptitudes but consciously and adjusted to the others. If there is no jointly worked-out position, our contradictions, divergences and overlappings may plunge the patient into an even worse situation. The actual attitudes are always *ad hoc* and individual but there should be a jointly worked-out approach in consideration of the patient's personality and the details. Only a coordinated action of doctor, nurse, psychologist and parents may lead to satisfactory work with the terminally ill child.

As we have seen, most parents, doctors and nurses have no clear concept, not even an idea of what the child knows of death, how he experiences the fear of death. Neither can the child expressea sily this complicated and almost inexpressible experience; this is why, among others, he uses a special signal system.

The fear of death is difficult to explain even in the case of adults, although by general agreement we mean something by it but the definitions are meaningless and we cannot explain it in detail. The fear of death may appear in different forms, it may also fail to come about.

The relation of the fear of death to other fears such as the fear of separation, mutation, castration, etc., is uncertain. The fear of separation is one of the oldest and most important of human fears. The other aspect of it is the "instinct for holding on", as Hermann calls it, the defence against separation and isolation. The manifestation of this instinct is ever-present in adults, but in children it is also constant and fundamental. Its form of manifestation is that the dying child often begs and demands that his mother or the nurse hold his hands, read a story to him even if he is asleep or drugged. He does not need the text of the story, he needs the voice, the touch which connects him to somebody, to life. This is the struggle against separation.

This is what the nurse told about the death of a ten-year-old boy: "He got morphine and yet he was afraid, he sat up and said, staring before him petrified with fear: 'Now, now they come and fetch me and take me away'. And he clutched my hand with such force that he tore and scratched at it. I wept although we have been through this many times but you cannot get used to it. Why was he so horribly afraid? And the terrible thing was that I felt that he clutched my hand in vain, he could not hold on . . ."

In the case of sick children the decisive factor is not the consciousness of death because one can have a general consciousness of death in relation to human life without experiencing the fear of death. Decisive is the fear of separation which begins with being torn away from home, continues with the loss of companions and siblings, the time-to-time appearance

of parents, with being bedridden, boredom, pain, indisposition, the decline of their powers, hopelessness, states of anxiety, fear, and ends wiht the ultimate experience of separation on the level of consciousness or emotion.

The child cannot bear separation; this begins with his transfer to hospital and increases with the worsening of the disease until the total and definite separation — death.

We have discussed the problem of separation at length because this is the basic problem from transfer to hospital until death. We must have an extensive knowledge of the phenomenon if we want to be able to help the terminally ill and dying children. We struggle against separation until the last moment with different means: diverting attention, occupational therapy, regular teaching, free visiting time, frequent permissions to go home, activity, self-realization, and a life full of affection and love.

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