

A child of a terminally ill parent - adjustment and grief

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This paper presents a treatment of a girl (age 9) whose parents voluntarily turn to a psychologist after the father of the girl was diagnosed with terminal cancer with life expectancy of six to twelve months. The girl reported no appreciable diseases. She is the only child in the family, has high intellectual capacity and never reported any socio-emotional difficulties. The case study gives an overview of the counselling work with the mother and psychological support to the child through several stages: (1) coping with the illness; (2) bodily and mood changes of the father; (3) side-effects of the father's treatment; (4) severe health deterioration of the father; (5) father's approaching death; (6) father's death; (7) grief and adjustment. The girl and the mother reacted to all aforementioned stages in very different ways, thus the interventions were also focused on invoking mother's emphatic understanding of the girl and preserving their relationship. The girl went through three stages of grief: (1) perceived loss of the father through the deterioration of his psychophysical condition; (2) perceived loss of the mother, who is all too busy looking after the father;

(3) the death of the father, which makes the subject relevant for a deeper understanding of the emotional processes of a child in such a complex traumatic situation. An integrative therapeutic approach was used as method.

Key words: *grief, adjustment, parental death, parental terminal disease*

Sažetak

U ovom radu prikazan je tretmanski rad s djevojčicom (dobi 9 godina) čiji se roditelji samoinicijativno javljaju psihologu nakon što je ocu postavljena dijagnoza terminalne faze karcinoma s perspektivom životnog vijeka od šest do dvanaest mjeseci. Djevojčica je urednog razvoja, jedino dijete u cjelovitoj obitelji, visokih intelektualnih kapaciteta i bez ranijih socio-emocionalnih teškoća. Prikaz slučaja uključuje prikaz savjetodavnog rada s majkom i psihološke podrške djetetu kroz nekoliko etapa: (1) suočavanje s bolešću; (2) očeve promjene tjelesnog i emocionalnog tipa; (3) nuspojave liječenja; (4) značajna pogoršanja zdravstvenog stanja oca; (5) približavanje smrti oca; (6) smrt oca; (7) tugovanje i prilagodba. Djevojčica i majka značajno drugačije oživljavaju sve opisane faze te se intervencije usmjeravaju i na majčino empatijsko razumijevanje djevojčice te očuvanje njihovog odnosa. Djevojčica prolazi kroz tri ciklusa tugovanja: (1) percipirani gubitak oca kroz pogoršanje njegovog psihofizičkog stanja; (2) percipirani gubitak majke zbog stalne okupiranosti skrbi o ocu; (3) smrt oca, što temu čini značajnom za dublje razumijevanje emocionalnih procesa djeteta u ovako kompleksnoj traumatskoj situaciji. Korišten je integrativni terapijski pristup kao metoda rada.

Ključne riječi: *tugovanje, prilagodba, smrt roditelja, terminalna bolest roditelja*

Introduction

We all lose someone or something at some point in our lives, i.e., we all suffer a loss (Profaca, 2010). “The grief work is an intrapsychic process that occurs after the subject loses the object to whom it is attached and in which it learns to completely let it go” (Laplanche and Pontalis, 1992, p. 411). The aim or the outcome of mourning is not to forget the deceased person, but to accept the fact that the person is no longer (Arambašić, 2005), which is the process. According to Profaca (2010), loss and mourning are not exclusively related to the death of a person. One can lose many things and feel grief for it. Arambašić (2005) argues that one can lose material things, but there are also some more abstract losses such as the loss of self-esteem, the loss of perceived identity, etc.

For person who suffered a loss, any loss is difficult and it is not for others to assess his or her grief. In other words, it does not matter who or what we lost but what was our attachment to the lost object like. Many authors suggest that there are two exceptions to this rule, namely the death of a child and the death of parents in childhood, both of which are universally difficult losses. Following the parental loss, children have to take responsibility and assignments in their immediate family that once belonged to their parents, and the feelings of helplessness and fear for the future are especially strong (Lake, 2000, according to Abramušić, 2005).

The grieving theories are many, however, the best known is the theory of grief by Kubler-Ross and Kessler (2005) from 70s of the last century, which has been empirically and clinically corroborated many times since. According to this theory, the grieving occurs in stages, as follows: (1) denial i.e., shock; (2) anger and rage; (3) sadness, depression (4) experimenting the new reality and (5) integration of loss.

The mother turned to the health institution specialised in analysing, treating and supporting children with traumatic experiences and their families. She asked for an emergency appointment, explaining that her husband, who is the father to their 9 year old child, has been diagnosed with a terminal stage malignant cancer with metastases spread to multiple organs. The appointment was schedule in ten working days.

Problem description

The mother came to the first appointment alone, since the girl was on vacation with members of her extended family at the time. She was in the stage of shock and denial, explaining that she still does not believe that the diagnosis is true. At this point, the girl only knows that the father is ill but she does not know the details and the father has not spoken to her about it. She explained that the father had hard time accepting the diagnosis, that he is depressed and in pains, having hard time getting up and performing basic daily tasks. As the mother explained, she has “spared” the girl the trouble by

distracting her in different ways. The girl did not ask questions about the father's condition. Although, it was the first time that they separated for this long, the girl parted from her parents without much trouble and went to the coast with the extended family, and the mother promised to visit her soon. The mother turned to a child psychologist for counselling about how to approach the girl and inform her about the situation.

History

The girl is nine years old and she just graduated from the third grade of primary school. She is an "A" student, and according to her mother, she likes school and learning. She is the only child in the family, living with the mother and the father. The parents are employed. The father retired few months earlier but he still occasionally works. Both of them are educated, holding university qualifications. The mother is in her middle-age and the father is older. The pregnancy, delivery and early development went properly. The girl began to walk and talk, and control bowel and bladder muscles at an appropriate age. She attended a pre-school education and has properly adjusted. She has not suffered any serious illnesses in the childhood nor has she had traumatic experiences or losses in the closer family. She attends several extra-curricular activities and is a very sociable person. She has the best girlfriend whom she hangs around every day. The family relations are normal, and the girl is particularly attached to the father whom she spends most time with. The extended family lives in another town in Croatia, where the girl was born, but the parent moved when the girl was very young, so she has memories of the life in this environment only. She enjoys visiting members of the extended family and spending time with them. The mother described her as a warm, dear and sensible child of many interests and hobbies.

Psychological analysis results

Few days following the initial interview with the mother, after the girl returned from vacation, the psychological analysis was made. In communication with the therapist the girl was warm and open but she refused to talk about the father and his illness, despite the therapist's insistence. She approached the tests with pleasure, having no difficulties in understanding and following the instruction. According to the therapist's findings, the girl has "cognitive capacity high above the average, regular visual-motor and visual-spatial perception and integration, a proper development of personality with a mild separation anxiety symptomatology, and she is currently in a high stress situation due to severe illness of the parent, going through the adjustment period". Parent counselling (with the mother only, since the father could not leave home) and intensive support to the girl were indicated. The mother is willing to join the counselling sessions on parenting, but

not ready to undergo a separate treatment/support for herself with another expert. The distance from the family and friends is a risk factor, since the mother and the girl have no natural helpers in the immediate surrounding. The psychologist appointments are taking place approximately every 10 days.

The further work is conceived as a phased-approach to work with the mother and the girl individually in accordance with objective change in the father's condition, taking into account the observations on three distinct stages of the girl's grief. (1) perceived loss of the father through the deterioration of his psychophysical condition; (2) perceived loss of the mother, who is all too busy looking after the father; (3) the death of the father.

1. Coping with the illness

The mother has need to broadly explain the health condition of the girl's father. Few sessions later, the initial shock was replaced by anger (followed by expected course of reactions), which she channelled into "the fight against the disease" to which she invests a considerable amount of energy. On cognitive level she demonstrates no denial, on the contrary, she is very well informed about the diagnosis and the life expectancy (6 to 12 months), all available therapies, side-effects, symptoms, etc. On emotional level, however, she does not accept the reality and feels that she "can win the battle".

Since according to the mother's account, the father does not demonstrate the capacity to talk to the girl about the disease, the mother was advised to talk to her about it in the father's presence. She told her once again that the father was sick and it was rather bad, but that he will be treated and that they will do whatever it takes to help him, but it is possible that over time it will get worse or better, and that they are not sure if he will be better and able to recover from this illness. She also stressed that this was different from when we get a fever, sore throat or earache (which the girl experienced). In the end, the mother asked her if she had any questions, and since she had none, the mother invited her to turn to her whenever she felt the need to ask or talk to her about it.

In the first session following the analysis, the girl spontaneously spoke about the father's illness, retelling the discussion she had with the mother. She felt that the mother and the father are very concerned, but she claimed not to have been too concerned, since she believed that the father will get better, though she has heard that he might not. She refused to play or engage in creative and projective techniques, and wanted to talk about the diseases in general. She finds it difficult to talk about it with the mother and the father, since they are concerned.

2. Father's bodily and mood changes/side-effects of the father's treatment

About a month later, the father started experiencing pain on a daily basis, and his depressive mood became more obvious. He was almost completely incapable of carrying

out the basic functions such as maintaining personal hygiene. The mother was still focused on “fighting”, denying grief and claiming that she “could not afford it”. She claimed not to have talked about her husband’s illness with anyone else other than the child’s psychologist, and she is very committed to her work. The mother explained that the girl is happy to help caring for the father, and sometimes she feels that the girl is caring for her too, which she perceives as the girl’s expression of love and attachment. The mother was advised about how to bring the girl back to the role of a child. She also explained to the girl that the worsening of the father’s condition was sometimes a reaction to the treatment, and sometimes the result of his illness, and that they were not sure if he will recover. Once again, she invited the girl to ask questions or talk about it, but she refused. Manifestly, the mother follows all the instructions, but her emotional status is not aligned with it, and the girl assumes more responsibilities of caring. She described how she shaved her dad and tried to cheer up her mum.

The girl feels that she has already lost the father because she can no longer remember what he was like before. Afraid that she might forget “the old Dad”, she gladly recounts some of their joint memories from before the illness. She claims that all this is not so hard for her as much as it is for her Mum, and she often asks herself if that is all right. She often needs emotion normalisation. The most difficult thing about this situation is that she misses her Dad driving her around, coming to her school plays, taking her to the swimming pool. She is questioning if the father will ever recover enough to be able to do all those things again. She reacts positively to the replies such as: *“I believe that you would like that and I hope he will, but there is a great chance of that not happening”*, and repeats such lines and wants to hear them over and over again. She says that when with the therapist, she “solves jigsaw puzzles in her head”. She prefers discussions on a general level, e.g., what happens to people when they cannot recover from an illness. Having touched upon the subject of death, she brought a child book on death to the next session and wanted to talk about death. During the discussion, she does not relate the topic to her father. After the initial frustration and sadness (she says she mostly cries in bed, but when prompted, she is willing to engage emotionally) about her dad not being “as he once was”, she creates a life in which her father is not involved anymore and she speaks openly about it, e.g., *“Uncle XY drives me..”, “I will go to the poor with “XY”*. In her spare time she still cares for him and the mother, but the intensity of this need is dropping. Despite her objection, during each session a game - “goofing around”, as she calls it - is introduced to stimulate joy and role of the child, with clear messages that it is all right to play and be joyful.

The mother occasionally feels angry when the girl is in the role of the child. She tries to understand her and at one level she is glad - as she says - that the girl is coping with her father’s illness better than she does, but that makes her feel more lonely in her grieving. She repeatedly refused professional support for herself, but she started talking to some adults in her surroundings.

3. Sever deterioration of the father's health condition

The father now spends most time in a hospital in another city, where his parents live. The mother and the girl pay visits to him every weeken or almost every weekend. The mother on several occasions witnessed - and the girl only once - the acute worsening of the father's condition that threatened his life. The girl has been through a crisis intervention.

The mother is overwhelmed with grief, feelings of helplessness and hopelessness. It becomes almost impossible for her to talk about her husband without being overwhelmed with intense emotions. As much as she tries to support the girl, during their conversations she often "breaks down and the child ends up comforting her". She is still preoccupied with medical condition of her husband and the ways to help him, but she gradually integrates the fact that he will die.

The girl does not like visiting the father, saying that she can barely recognise him and that she finds the scenes from hospital very difficult and traumatic. She feels that things are completely out of control and that everything is unpredictable, which is why she feels taken with fear. She prefers to telephone him or pay very short visits. Following the counselling, the mother shows understanding for such behaviour but the girl feels that no one really understands her. The most difficult aspect of the current situation for the girl is the loss of the mother, who – as *she says* - "will never laugh again". The mother is very caring, providing the girl with everything material she needs, hugging her and kissing every day. Yet, the girl misses some of their joint activities and discussions that are not related to the father. The girl discussed the possible death of her father with the therapist, but she could not discuss this subject with her mother, except for one time when they were together with the therapist. The mother was overwhelmed, and the girl found this experience very uncomfortable. The session has been recast with the girl. Few months earlier, the mother and the girl have booked a weekend trip to another country. The mother considered cancelling the trip due to a strong sense of guilt for not spending every moment she had with her husband. But, since the trip was of key importance for the girl and since the father, in a period of lucidity, said that they should go, the mother took the girl to the trip. The trip becalmed the girl, for she understood that "Mum was still there".

4. The father's approaching death

Approximately two weeks before the death of the father, it became clear that he would die within a month, of which the doctors warned the family. The mother wanted to be with him all the time, while for the girl it was important to finish the school year. It was agreed that the girl would go with her mother on a weekend and return to the best friends, whose parents are familiar with the situation. The girl sensed that this might be the last time to see the father. In the session with the therapist she wrote a letter to the

father, which she decided to leave in the therapist's office instead of giving it to either mother or father. Based on a clinical impression, the father was not ready to say good bye or openly discuss the illness with the girl, so the girl in this way symbolically said good bye to him. The letter says: ***"Dear Dad, thank you for everything. You were the best dad in the world and please forgive me for the times when I was a little bit naughty. I love you"***. In the discussion about the letter, she explained that she wrote in the past tense (you were the best Dad) because she was addressing "the old Dad" who was, due to constant recollection and discussions, more strongly etched into her memory than the father from the period of illness. The mother received telephone support twice a week, and the girl attended psychological sessions also twice a week, at her own discretion or as per psychologist assessment. Since the Polyclinic was in the same street where she lived, the girl was coming to the sessions by herself. Following a short account of the current situation, I mostly played with the girl. The girl often stressed that it feels nice to be "allowed to laugh" She had hard time leaving the therapist. An envelope was made for her to write or draw the things she wanted to say to the therapist until the next time they meet.

5. Father's death

The mother called to say that the father has passed. She was provided support. As for the girl, it was suggested that the mother pick her up from home, but prior to that, to call the landlords and ask them to take the girl's mobile phone from her before someone calls to express condolence. However, the mother's psychophysical condition was not fit for travel, so the girl was collected by the members of extended family. She has not asked any questions, although she later explained that she knew what happened. It took a lot of encouragement and practice to help the mother convey the message about the father's death to the girl. Namely, she wanted to convey it using unclear phrases such as "Daddy has left" or "Daddy is no longer with us". She was afraid of hurting the girl "more than needed". She even suggested that the girl should stay in Zagreb and not go to the funeral. As for the funeral, it was agreed that she should ask the girl if she wanted to go and that someone should explain to her what happens there. Also, it was suggested that the girl should go with someone she knows but who is not the close family member who can look after her, and if need be, leave the funeral with the girl. Ultimately, the girl went for a funeral mass, but not to the funeral itself.

In the next session (two weeks following the father's death), the mother and the girl spontaneously entered the therapist's office together. The mother burst into tears, while the girl was silent, watching the mother with interest. She subsequently said that she is not as sad as her Mum, although she too was very sad. After this, they were received separately. The mother felt relieved over the girl's reaction, but she also demonstrated lack of understanding. The girl kept asking whether her reactions were normal, and whether she should be more sad. Few sessions later she admitted that she felt a relief,

which was very important to normalise for both the girl and the mother who, in addition to her husband also lost the “purpose” i.e., “the battle”. The mother quickly returned to work, but she also agreed to receive professional psychiatric support of the Polyclinic, which is provided as part of the parental counselling, mostly because she had hard time falling asleep.

The girl understood mother’s question about whether she wanted to go to the funeral as an instruction not to go, which bothered her and which is why she was angry with her. She was also angry with her mother for crying a lot, especially when they go to the cemetery. She was interested in all the details about the funeral, which she thoroughly discussed and drawn with her therapist. After two sessions dedicated to the funeral she said: ***“we have now buried these funerals too”***.

6. Grieving and adjustment

The mother and the girl are now grieving the death of the husband/father, but they are in different stages of grief, and it has been five months since the father’s death. The mother is predominantly sad (stage 3), while for the girl it took about three months to start mourning the father, as she was in the stage of emotional shock (stage 1). As her mother become more empowered and supportive of the child, the girl began to feel and express her sorrow, thus entering into the stage of experimenting (stage 4) and progressing toward integration. In sessions with the therapist, the relevance of play is emphasised, as well as development of interests and problems appropriate to her age and restoring normal life. When prompted, she brought photos of her father, making a favourite album, and she gladly talks about their shared anecdotes. She is capable of getting sad and cheerful when talking about the father. Her process today appears to be a normal grieving process, without any signs of trauma.

With the assistance of the therapist, the mother hired “a nanny” whose task is to spend 2 hours a day with the girl - while the mother is at work - playing, taking her out, which the girl accepted very well.

Conclusion

The child and the mother went not only through different stages of grieving at different times but they also went through a different experience of reality. While the mother “fought” for the life of the father, the girl was grieving the loss of the father (as she knew him and loved him) and after that, the loss of the mother who was emotionally no longer there for her. The mother began her grieving process only when the father died, but at the time, the girl felt lonely and detached from the mother’s current emotions. The girl’s third grieving was significantly different from the mother’s “first”, which created an additional gap between them due to different object of the loss (partner v. father) and development age of the child.

In this complex situation it is of crucial importance for a therapist not to assume (who, when and what they mourn), but rather to carefully investigate and provide the support needed at a given time. Also, it is a challenge not to lose sight of the ultimate goal, which is not only to support the girl in grieving her father’s loss, but also to provide support to both the mother and the girl as a community to establish a new balance in their family life. Finally, an active engagement and overcoming some of the usual constraints (for example, assistance in seeking a person who would spend time with the child) were in this case positive for the patients - with no adverse effects on the therapeutic relationship, and for the therapist, thanks to the supervision and primarily because of the lack of natural helpers in the mother’s and girl’s life.

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