

Case Report

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A case report of a child with autism spectrum disorder grieving after losing her father during covid-19 pandemic

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Abstract

Background: Bereavement is one of the least studied conditions in children, especially among the ones diagnosed with ASD. Lack of enough understanding about what to expect from a grieving child with ASD complicates how to help them and their caregivers.

Case presentation: In this paper, we present a 13-year-old girl with ASD who lost his dad recently due to myocardial infarction during COVID-19 pandemic period while lockdown was implemented, and how that girl reacted to this adverse event. Informed consent is obtained from the mother.

Conclusion: Grief of a child with ASD may be dissimilar to what is used to be seen in other grieving people. However, similar to all bereaving individuals, psychoeducation and counselling should be prioritized for both the grieving children with ASD and their caregivers.

Keywords: ASD; autism; bereavement; COVID; grief; psychoeducation.

Abbreviations: ASD: Autism Spectrum Disorder; PCBD: Persistent Complex Bereavement Disorder; MDD: Major Depressive Disorder; PTSD: Post-Traumatic Stress Disorder; ID: Intellectual Disability; SAD: Separation Anxiety Disorder; CBT: Cognitive-Behavioral Therapy.

Introduction

Autism Spectrum Disorder (ASD) consists multiple, complex neurodevelopmental conditions scaled on a continual severity and functioning levels [1]. Bereavement of a child with ASD is one of the least studied issues. Even in typically developing children, grieving is not well studied as the concept of death changes depending on the age of children. For most of the children the reactions resolve relatively rapid while some children could experience a complicated or prolonged grief similar to seen in adults [2]. Children with an underlying mental disorder, especially depression or bipolar disorder, were found to have prolonged grief more likely, while having prolonged grief itself were

shown to increased risk of functional impairments and mental health problems namely anxiety, depression, Post-Traumatic Stress Disorder (PTSD), somatic symptoms, and personal sensation of loss of control in one's life [3,4].

A review of the latest literature has showed that the number of publications associated with ASD and grief is still insufficient. While there is an assumption that ASD could be related to disturbed emotion regulation, how a person with ASD react to an adverse life event leading grief, and what to do to help people with ASD and their caregivers is still unclear. To investigate the

relevant literature, the search engines PubMed and Google Scholars were used. Majority of the related studies found were about Intellectual Disability (ID) [5,6]. The resources found for children with ASD experiencing grief were mostly books, and suggest these children experienced grief more complicated due to lack of adequate social communication and emotional comprehension [7-10]. Impaired social abilities in ASD could cause difficulty empathizing with grieving others and expressing their own feelings [11]. Having limited coping skills could exacerbate anxiety and depression [11]. It is noted that reactions of students with ASD to death may be more intense if there was a strong attachment to the person or object lost [11]. If the particular loss damage their routines, children with ASD could express rigidity with increased distress [11]. Lastly, using different characters in the videogames is found to facilitate exploration of grief and death in a bereaving children with ASD in a dissertation [12].

Case presentation

Here we present a 13-year-old girl, B.Ö., with ASD diagnosis, who lost her father due to myocardial infarction during COVID-19 pandemic while lockdown was implemented. She currently lives with her mother, and the report given here is based on the interview with her mother.

B.Ö. is the only child of the family, and her parents divorced long ago. She was consulted our psychiatry outpatient clinic in April 2020 for behavior changes after losing her father. She had self-injury, lost personal hygiene, and showed regression in capabilities and emotional imbalance.

For the past 1.5 years B.Ö. and her father talked on phone, or face to face every day, whereas they had seen each other once a year at most beforehand. When they met, they drew, and played together. They regularly gave compliments to each other that she was asking for as “sweetheart”, “I love you”, and “my beauty”. These regular meetings lead B.Ö. to get better at reading and mathematics, eat more regularly, suddenly stop having enuresis, communicate better, and have better personal hygiene.

While he was alone at home during COVID-19 pandemic lockdowns, on April 2020, her father died due to a sudden cardiac event. At the beginning, her mother could not tell B.Ö. that. As the meetings with her father were interrupted suddenly, B.Ö. showed reaction from the first few days of loss, according to her mother. First, she said “father will not come back”, started eating less, had enuresis, and showed regression in reading and mathematics. She was crying and asking where her father was nearly every day. Her mother explained B.Ö. that her father was death because of COVID. B.Ö. hit her head to wall, then threw her red dress, which she wore in the last meeting with her father, out of the window. Other than these, she did not attack to her mother or another people either physically or verbally. There were no other self-injury related acts. Then she was consulted to us. We prepared a booklet guiding what to do with a bereaving child. Following the booklet, her mother talked with B.Ö. about real reason of her father’s death, and she did not show any aggression as in the previous encounter. Her mother got both verbal and written help from us to regulate grief reactions based on B.Ö.’s needs. Severity of her reactions dimin-

ished by time after receiving these supportive psychotherapy and psychoeducation.

She requested her mother to visit her father was in August 2020. They went to graveyard where she cried a lot. As the time passed, she have started to draw, eat more, socialize with her mother, and take care of personal hygiene by saying “father wanted me to be tidy”. But nearly every day, she has told “I feel sorry, father would have loved me, why had he gone?”

It was thought to be not her first encounter with death of loved one. When she was younger, they had many fish that all died. Her mother brought a chick to home, she assumed it as a bird and tried to release it from the window. Unfortunately, the chick died but together with her mother they buried the chick. Lastly, they had a neighbor, an old lady, who lost her son, deteriorated and died later. After this decease, B.Ö. did not want to go to the house of that lady.

B.Ö. has no thought, or fear of death about herself, but she fears that her mother could also leave, in terms of death or abandonment. Recently, she has started to ask if her mother would also go, and expressed her wishes about her mother to stay with her.

They quarantined at home during pandemic with having no social interaction at all. With the lockdown of schools, B.Ö. could not socialize with her friends as well. On the following days, she asked for TV remaining open to be able to fall into sleep. Whenever her mother closed the TV, she woke up. Her circadian rhythm shifted and most of the time she fell into sleep at 7:00 a.m. Her mother has additional stress recently since she wants to move their house to another place, and she worries what could happen to her child if she dies as well. The hardest thing to correct nowadays is enuresis and her sleep schedule, as her mother reported.

Discussion

Duration of normal bereavement changes from culture to culture, mostly lasting around 6 months. In our case, bereavement has been continuous for 11-month. While the diagnosis Persistent Complex Bereavement Disorder (PCBD) is suitable due to duration of bereavement (6-month for children), it is not a true match for our patient as she does not fulfil other criteria including preoccupations or continuous yearning, refusal of death or holding herself responsible, avoiding reminders, or desire to die. The diagnosis of uncomplicated grief is not likely as well since there are no prominent improvements in her symptoms, and her distress, seen as developmental regression (as enuresis), and anxiety at time of separation from her mother, continues to affect her daily life.

In relation to the reminders of the deceased person, intensity and expression of the grief could be seen in waves, as in our patient [13]. This pattern distinguishes grief from major depressive episodes in which depressed mood is more persistent [13]. Also, our patient does not have self-critical or pessimistic ruminations about the deceased, not feel worthless, and her focus is not herself but the deceased. All these criteria differentiate diagnosis of our case from MDD. While it is not uncommon to have comorbid MDD, this comorbidity typically leads severe deterioration in daily functioning.

Since death of someone could be interpreted as a separation, it is not unusual for bereaved people to be diagnosed with Separation Anxiety Disorder (SAD) [13]. However, in SAD the caregiver is still alive compared to any kind of grief reaction. Thus, our case could not be diagnosed with SAD.

Despite being unexpected, her father's death was not a traumatic one. Despite showing acute reactions to this event, our patient did not have similar reactions in the long term. She has not tried to avoid memories of her father, or anything could reminding the way he died. Contrary to this, she talked about her good memories with her father frequently. There were no flashbacks or nightmares reported. Thus, diagnosis of PTSD is excluded in addition to other aforementioned diagnosis based on the DSM-5.

Psychoeducation and psychotherapy are intervention of choice for grieving children and their caregivers. Unfortunately, our patient could not come psychotherapy due to COVID-19 pandemic, and economic problems. Meantime, we contacted her mother on the phone, and prepared a booklet in Turkish for guidance. The guideline explains that reality should not be hidden as learning the truth later on can lead trust problems, and severe reactions. In our case, our patient showed more severe reactions after learning COVID-19 as the cause of the death compared to the real cause. Guideline also suggests talking about the death even before someone dies to accept and conceptualize the situation, helping children to express their thoughts, showing understanding the way they express grief, and getting together with the child to do activities that child was used to do with the deceased. Caregivers could encourage children to create a memory box for the deceased. These recommendations helped our patient to accept the death, and diminished the frequency of her questions about her father. Cognitive Behavioral Therapy (CBT), peer training, and social skills instruction could also help children with ASD to cope with complex social emotional issues as grief [10]. Art therapy, play therapy and music therapy could be useful for some children even there is no evidence for effectiveness of these therapies [14].

Conclusion

As a conclusion, one should be aware that COVID-19 is deadly disease, which, unfortunately, leads higher likelihood for children to witness loss of someone they are familiar nowadays. The same risk applies to people with ASD. The uttermost important thing for both the grieving children and their supporters is giving psychoeducation and counselling. A guideline could be created for supporters of the children in case they may not be able to visit regularly for psychoeducation. When necessary, a chosen psychotherapy modality could be used based on the needs of the children. Since COVID-19 pandemic most likely will be present in our lives for a while, all mental health workers share responsibility to make this kind of help to be more common, and to provide as early as possible before a case becoming complicated.

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