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CARING ABOUT COMPLEX TRAUMA

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Case-Based Learning

CARING ABOUT COMPLEX TRAUMA

When I first meet Mia, she is leading a rather isolated existence. She lives in a group home, but is not by any means an active member of the group. She stays in her bedroom. It's where she sleeps, and eats, and enjoys of her hobbies/relaxing activities. Her *window of tolerance* (that is, what she is able to deal with and handle) is minimal. The home's carers visit her in her room at set times. And the same holds true for the day activities centre. Mia has her activities in a separate room.

Mia is lonely and sad. She is unable to communicate what is wrong. She has little emotional control and her tension and anxiety levels can rapidly spike. Then, she often becomes verbally and physically aggressive. She attacks her carers: hitting, pinching, pulling their hair, spitting in their faces, cursing. After these explosions, Mia is very sad and very sorry.

Mia is the subject of a great deal of discussion during team meetings. On the one hand, carers feel sympathy for her; but on the other, they are at times, afraid of her. They've been doing their best to help Mia as much as they possibly can. But despite all their efforts, Mia is very unhappy, and displays a lot of challenging behaviour.

During my conversations with Mia, she is very sad about her lonely situation and her painful memories of the past. Mia led a difficult life before she came to live at SOVAK fifteen years ago. She was raised in a large family with many children. Both of her parents had intellectual disabilities, as did several of her brothers. Sadly, her parents weren't really capable of taking care of such a large family.

Mia often talks about her life experiences. She tells about her harsh history of full on neglect and abuse. When she talks about this, she has flashbacks, and relives her horrific experiences. She doesn't sleep well and is plagued by nightmares. Her suffering is great, and her quality of life is extremely low.

I am very struck by Mia's situation. I keep thinking: she's still a relatively young woman, she can't go on like this for another forty years. I believe we should do everything in our power to see if we can improve her situation. At the same time, I know that this situation is a complex one, and it's a daunting task for everyone involved to change things. Working together with the CCE, we embark on an intensive project.

IDEOGRAPHIC THEORY

Factors from Mia's past play a huge role in her current situation. Her parents were unable to meet her and her siblings' emotional and physical needs. The family system was neglectful, resulting in an insecure attachment with her parents.

Mia is also a survivor of sexual abuse, perpetrated by one of her brothers. The sexual abuse was continued by a boyfriend she subsequently lived with, and via this boyfriend and his family, by other men as well. The boyfriend was also violent and physically abusive.

Because of her history of long-term abuse and neglect, Mia is diagnosed with complex trauma. The term 'complex trauma' refers to the fact that she was exposed to multiple traumatic incidents, and that she is suffering from the far-reaching consequences this has had and will continue to have on her development and the rest of her life. Aafke Scharloo, a trauma specialist, discusses the term 'complex trauma'.

VIDEO interview with Aafke Scharloo

In addition to complex trauma, Mia also has an intellectual disability. She may have been genetically predisposed to this condition, but her traumatic experiences have also had a negative impact on her intellectual development. Because of her intellectual disability, Mia does not have many coping skills. And because of her lack of coping skills, she is less able to deal with the many problems she faces.

This combination of complex trauma and a lack of coping skills results in several symptoms for Mia. First of all, she always feels stressed, unsafe and afraid. Moreover, she displays characteristic post-traumatic stress symptoms such as nightmares, flashbacks reliving events, dissociative responses, and hearing voices. And finally, she also has symptoms of depression as a result of her many traumatic experiences.

Mia's stress, and feeling unsafe and afraid, cause her to lash out with physical aggression and destructive behaviour. She hits and kicks carers, spits at them and pulls their hair. She often curses at them. Sometimes, she destroys her own possessions. She also steals other residents' belongings. These are often found in her room, sometimes in bits. Although she doesn't have much contact with the other residents, there are many negative interactions. Because of her high stress levels, Mia reacts to even minor incidents much more intensely than is usually expected.

After a physical outburst, Mia often starts crying and she desperately wants to make it right with the carer involved. The tension and anxiety that had been building up in her has now been released, and she then seeks comfort and closeness with that carer. Most of her carers are able to give her the comfort and closeness she needs. When this process can be completed successfully, there is a temporary reduction in her levels of stress, insecurity, and fear.

But sadly, her behaviour can also lead to different results. The team has very little knowledge about trauma. This means they often don't recognise

when Mia is having a flashback. For the team, it's as if her aggression and destructive actions simply erupt out of the blue. For them, she's simply unpredictable, and they have become fearful of her. Because Mia is highly sensitive to signals in her surroundings, she picks up on their fear. Moreover, the carers are unsure of what to do when Mia's levels of tension and anxiety begin to rise, and they unintentionally make demands of her she is unable to meet. They in turn are then unable to meet her underlying needs. Some carers engage in confrontation, while others distance themselves from her. But at these times, what Mia actually needs is closeness with a peaceful and calming carer. A lack of calming care simply worsens her stress and anxiety.

But it isn't only the carers who do not meet Mia's needs. The residence itself and the day activities centre aren't really suited to her. Both places are full of so-called trauma triggers for Mia. For example, she gets triggered by altercations between other residents. She takes it all very personally. These incidents always remind her of conflicts she faced in the past. Mia's ingrained old fears are triggered by this kind of event. Her stress and feelings of insecurity then spike, which further exacerbates her challenging behaviour.

Because the team believes that her challenging behaviour is caused by overstimulation, they decide to isolate her from the group. She no longer frequents the common areas in the home but is restricted to her bedroom and receives her care there. In the day activities centre, she is given a separate workroom. But Mia is becoming more and more isolated, increasing her symptoms of depression. Mia is lonely. When she is alone, the memories of past trauma rise easily to the surface of her consciousness. And this is precisely when she needs support and closeness with others.

Mia is also very sad about the fact that her family members don't give her any credit for the efforts she made to try and care for them. When living at home, she performed many tasks and had many responsibilities. A few

family members accuse her of not taking good care of the family. Her good intentions are unacknowledged and unappreciated, and Mia feels abandoned by them. This plays a major role in the development and continuation of her depression.

INTERVENTIONS

INTERVENTION 1: STRESS REDUCTION: NEW ENVIRONMENT

For people with complex trauma, it is important to lead as stress-free a life as is possible. Therefore, Mia is moved to a peaceful, rather dull group of older residents. Here, there are few situations or events that will activate her triggers. It is unfortunate that the move also means that she will no longer have her most trusted personal carer. In light of her attachment issues, this is not optimal. So, during the beginning of her time in her new group, this carer will be working there as well. Mia can get used to her new situation with her carer's help. The carer will also be transferring her knowledge and experience to the new team. And she is still, as a volunteer, involved in Mia's life. Mia's trust has not been broken.

About one year after moving to a new group, Mia is also sent to a different day activities centre. This one is intended for people with severe intellectual disabilities. Most of them cannot speak and some are wheelchair bound. The trauma triggers are therefore minimal.

INTERVENTION 2: BOOSTING MIA'S SELF-ESTEEM

Mia still has her own programme of day activities, but she is no longer in a separate room. She now helps the carers with preparing and distributing beverages to the other participants. This is boosting her self-esteem, because in her eyes she is now 'working in healthcare'. This provides a bit of counterweight to her symptoms of depression. She feels important and needed. It fits well with her old role in her family of origin. There, she based most of her identity on being a carer for her family members. Now, she can

resume this foundation of her identity in a positive manner that is suited to her capabilities.

INTERVENTION 3: ADJUSTING TO COMPLEX TRAUMA

A better knowledge of complex trauma and its impact on Mia was crucial to understand what she was going through and what she needed. The people who work with Mia are given a training course on dealing with traumatised individuals with intellectual disabilities. The course is customised to suit Mia's situation. An important aspect of this was recognising and dealing with trauma triggers.

VIDEO interview with Aafke Scharloo

Mia has several traumas and triggers. One of them relates to the Dutch celebration of St. Nicholas. (In December, people give each other presents wrapped in colourful wrapping paper decorated with images associated with St. Nicholas.) Mia enjoys giving and receiving presents, but the St. Nicholas-style wrapping paper is a trigger for her. She wants to have her gifts wrapped in 'normal' wrapping paper. Now that we are aware of this, we can ensure that Mia can enjoy celebrating St. Nicholas.

INTERVENTION 4: STRESS REDUCTION: ADJUSTING TO TENSION/ANXIETY

It is decided to draw up a checklist of warning signs to help carers recognise when Mia's stress levels are beginning to rise, and what to do when this happens. When Mia gets very tense, for example, she gets red spots on her neck, she starts asking carers a lot of questions, and involving herself in anything that is happening around her. The plan details the interventions the carers can take to help Mia when her tension rises to a certain level. These interventions are often related to adjusting Mia's activities. At the day activities centre she may be asked to stop helping to

pass out beverages, for example, because this can be too challenging for her when her stress level is high.

Mia knows all about the plan, and she also knows what can help her. The carers and Mia work together to help her to relax. She is now capable of realising when she is getting tense, and she feels secure enough to communicate this to her carers. And then she sees that everyone can respond effectively.

INTERVENTION 5:STRESS REDUCTION: SHANTALA MASSAGE

To help Mia relax physically, she is given Shantala massages by a designated carer. Beforehand, Mia is consulted about which parts of her body she is willing to have massaged, and which she is not. This is key, because in the past, others violated her physical boundaries. Mia must feel that she is in charge of her own body. No-one is allowed to touch her without her permission.

The Shantala massage technique impacts hormone production levels. It results in a reduction of stress hormones such as adrenalin and cortisol. In addition, it boosts production of the oxytocin hormone. This hormone is part of the system which promotes rest, recovery, and balance. The effects can last for days, if the Shantala massage is performed regularly. Oxytocin is also the hormone that influences the development of emotions such as affection and connection for and trust of others.

INTERVENTION 6: EMDR

Mia was suffering from nightmares, flashbacks, and intrusive memories of traumatic events. These intrusions would take her by surprise and pained her considerably. They are primarily responsible for the amount of suffering Mia experienced. Using EMDR -- Eye Movement Desensitization and Reprocessing – these intrusions are being addressed and reduced.

RESULTS

Now that her environment has become more peaceful, Mia is experiencing fewer triggers. Her 'window of tolerance', what she is able to handle, has become larger. She takes part in the group more often. She has more social contacts, performs more activities, and experiences more closeness with her carers.

Mia is now better able to communicate exactly what it is she is having trouble with. Carers listen to her attentively, and by asking questions, try to find out what Mia needs. There is a mutual trust that together, we will always find an answer.

Mia is also better able to take part in group activities, be they indoors or outdoors, and to enjoy them. And she herself decides when she does this. Carers are now better able to aid her because of their new knowledge of trauma and attachment. For example, they make sure they are physically present and available to Mia when she needs them. When things are going well for Mia, she can perform many tasks unaided. But when she is stressed, carers know that they must stay close to Mia and take over some her tasks. They can also use the plan to help them recognise Mia's stress level signals and perform interventions in a timely manner. Thanks to this plan, Mia's life is now far less isolated.

Mia is not displaying any externalised behaviour at all anymore, and her symptoms of depression have decreased.

Mia is currently receiving EMDR treatment. She is highly motivated and has reported that thanks to EMDR she is much more at peace. Before EMDR, when she thought about her traumatic experiences, she could get emotionally overwhelmed. Now she is much calmer.

Mia believes that she is now 'working in healthcare sector'. She beams with pride and happiness when she goes to day activities centre, and it is a joy to behold.

LESSONS LEARNED

Everyone involved in this case has learned a great deal. We are better able to look past Mia's behaviour and see the function of it in the context of her complex trauma. And when we can see that function, we can adjust our responses to suit it. Step by step, we are mapping out Mia's triggers. We can tailor our behaviour and our approach to minimise them by taking them into consideration, such as what we now do during St. Nicholas celebrations. Sometimes, a situation calls for an unorthodox solution. For example, Mia was afraid of opening the windows, because she feared intruders. Outfitting the windows with screens allowed her to feel safer.

We also learned to be brave about instituting changes which seemed risky. Mia can handle a great deal more than we originally supposed, as long as we ensure that certain conditions are right for her. We must ensure that she feels safe and secure. The team has learned to trust in their own capabilities. The team used to sigh when Mia was discussed, now she is regarded as a pleasant and extraordinary woman with a great deal of potential. We are not yet finished; this is an ongoing process. As Mia's current personal carer strikingly says: "Mia is like a layer cake -- and you keep finding beautiful new cherries on top".

CONCLUSION

This was the case Mia Works on Complex Trauma. We hope that this case description will add to the knowledge of complex trauma in people with intellectual disabilities. Thank you for listening.

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