

Oral presentation Grief Cube – text - Marjon Verboom - IASSIDD 2019

Slide 1 (title)

Hello everybody,

I am very honoured to be here and present to you a cross-case synthesis on the applicability of the Grief Cube, a tool to facilitate communication about loss, bereavement and grief.

Slide 2 (names)

My name is Marjon Verboom, I work as a researcher at Amerpoort, a care facility for people with intellectual disabilities located in the Netherlands.

For this research project, I worked together with dr. Wim Smeets and prof. Michel Wensing from the Radboud University Nijmegen Medical Centre and with a consulting group consisting of service users, relatives and staff.

Before I tell you more about the research project, I would like to tell you a story. It's about Mustafa.

Mustafa is a 24-year-old young man with a mild intellectual disability. He's known exactly what he wants ever since he turned fifteen: to settle down in his own house. He now lives in a group home where he receives support and can work towards goals such as doing the laundry and household chores. Mustafa is almost always cheerful, except when he has to clean his apartment. Mustafa will say that housekeeping is not 'his thing', and that this time he'll skip it. And sometimes, staff will say: "Mustafa if you're so keen on living on your own, you'll have to show us that you can do the cleaning". And when they tell him that he will do it after all. One day, Mustafa says to Joy, his personal mentor: "Joy, I'm ready, I'm going to live on my own." But Joy has a doubtful face and says: Eh, Mustafa, I don't think you're ready to go live on your own just yet. And, if I'm being honest, I think that you'll probably always need support." And after she's said that Mustafa goes quiet and says no more on the subject. But the next day Mustafa stays in bed and does not go to work, nor the day after and the day after that. When staff tries to make contact with him, he threatens to kick them out if they don't mind their own business. Joy turns to behavioural scientist Greta for advice. Greta says that what Joy has told Mustafa might mean the end of Mustafa's hopes for the future. They agree that Joy will use the Grief Cube to talk to Mustafa.

Slide 3 (the Grief Cube)

When Joy arrives at Mustafa's he gets up out of bed because he's curious about the Cube. In addition to the Cube, Joy has also brought a set of pictograms that she spreads out on Mustafa's table.

Slide 4 (person, event, feelings, behaviour, meaning, support)

Person: Who am I? Joy asks Mustafa who he is and which pictogram would be the right one. Mustafa is a Muslim, and in his culture family is very important. He picks a pictogram representing a family and puts it in the transparent plastic holder on the 'person' side of the cube.

Event: What happened? Joy asks: 'What happened when I said that you wouldn't be able to live on your own?' Mustafa says: "To be honest, I wanted to hit you". They select a pictogram showing a person hitting another and Mustafa puts it on the 'event' side of the Cube.

Feelings: How do I feel? Joy asks: "How did you feel?" and lays down a number of pictograms of emotions. Mustafa picks up a pictogram with an angry face and puts it on the 'feelings' side of the Cube'.

Behaviour: How do I behave? Joy asks: “How do you behave when you feel like that?” Mustafa selects a pictogram of a person who’s asleep because recently he’s kept to his bed most of the time. He puts it on the ‘behaviour’ side.

Meaning: What does this mean for me? Joy asks: ‘What does this mean for you, what is it that you want so much?’ Mustafa chooses a pictogram of a house. He puts it on the ‘meaning’ side of the cube. Joy asks him to tell her more, what his dream house would look like. And Mustafa replies: “When I have my own house ... I would want my own doorbell and a doormat with ‘welcome’ on it, and there would be a cat flap in the door because I want a cat, oh, and this is really important, I would immediately hire a cleaning person and buy a dishwasher. And I want to cook my own meals so my family could come to dinner and, when I’m living on my own ... I could finally go look for a girlfriend ...”

Support: What do I need? Joy says: ‘Mustafa, staff did not explain things to you the right way. I feel bad that it affected you so strongly. Staff do in fact believe that you will always need a certain level of support from others. But when I listen to your dream for the future, there are things that we could discuss further or maybe could even be realized.’ They agree to discuss this further with the rest of the team and with his family. Together, they choose a pictogram of people sitting around a table and put it on the ‘support’ side of the Cube.

Slide 5 (Grief Cube with angry face)

This story is an example of how the Grief Cube can be used.

The Grief Cube is a tool to help people talk about loss, bereavement and grief. And to find out what somebody needs.

-It can be used in a personal conversation but also during a team meeting.

-You can discuss the sides one at a time or select them in a playful way by throwing the cube like a dice.

-You can use it in case of a grieving service user, but also as a staff member or relative to look at yourself: who am I, how do I cope with grief? The point being that how you cope with grief affects your ability to support other persons in dealing with theirs.

Slide 6 (staff member and service user with Grief Cube)

The Grief Cube looks like a Rubik’s Cube, the puzzle game where you have to rotate the coloured faces. This is because grief can feel like a puzzle: you really want to help someone and solve ones problems, or maybe you’re eager to solve your own issues. The Grief Cube, however, is a puzzle that does not need to be solved. It actually helps when mourning and grief are simply allowed to be. When they are looked at and considered from all sides so that a person feels heard and seen. The Grief Cube is a tool to help people talk about loss, bereavement and grief. And to find out what somebody needs.

That is the Grief Cube. And now, I’m going to tell you two more things. First off, how the idea for the Grief Cube came about and, secondly, how we tested this idea and further developed it in practice.

Slide 7 (the first cardboard version of the Grief Cube)

The idea for the Grief Cube came about four years ago. It was sparked by a clearly felt need among staff for tools to facilitate grief support that was apparent both from practice and from publications in this field. The initial concept of the Grief Cube was based on theories pertaining to grief and

communication. The first version was this homemade version. At Amerpoort, we conducted an initial test involving two staff focus groups. It was clear that staff appreciated being able to discuss this subject and that the cube gave them an approach to do this. It was, however, also clear that the cube needed further development to make it suitable for actual practice.

Slide 8 (research question)

That is the reason we launched a study into the cube's use. Its main question: *How can the Grief Cube help staff provide grief support to service users?*

We conducted our study on the basis of three case studies. To this end, we looked for three staff members who were eager to get help in their support of a service user. We selected situations that were as different as possible. The participating service users were facing losses brought about by moving house, physical decline or the passing of a loved one. Two of these service users have a moderate intellectual disability and one has a profound intellectual and multiple disability. The service users and staff members were offered a supervision trajectory of several months based on the Grief Cube. During the trajectory, we assessed if, and in what way, the Grief Cube could be of use to them.

Slide 9 (sources of evidence)

For our study, the following sources were used: interviews, observations, team meetings, staff reports, questionnaires and meetings with the consulting group.

The data analysis was based on grounded theory. First, each case study was analysed separately, and then a cross-case synthesis between the cases was conducted.

During our research, the Grief Cube was adjusted again and again; its design and the words on the various sides were made more suitable for practical use and we wrote a manual for it.

Slide 10 (research question)

Coming back to the main question of our study: *How can the Grief Cube help staff provide grief support to service users?* We found an answer to this question, namely this Grief Cube and its manual.

During our study, we noticed that despite the fact that the Cube was not completely finished, positive changes were apparent among staff who were using it. I will mention the three most notable changes. First off, staff indicated that the Grief Cube facilitates a more focussed approach, enabling them to form a complete picture of the person more quickly. Or, in the words of one staff member:

Slide 11 (quote staff member)

"As staff, we often look at the here and now, but usually don't go any deeper. The Grief Cube makes you do just that."

Secondly, staff indicated they derived increased self-confidence and confirmation from working with the Cube. One staff member's thoughts on the subject were:

Slide 12 (quote staff member)

"I feel that now I'm able to support a service user because I can use the Grief Cube. I never have to do it on my own."

A third change we noticed was that staff became more aware of the issue of loss, bereavement and grief. In the words of a manager:

Slide 13 (quote manager)

'You see the issue coming alive, there is more discussion among staff on what loss can mean.'

Slide 14 (Grief Cube and website)

The Grief Cube thus seems to be a suitable tool to help people talk about loss, bereavement and grief, as well as to support others facing these issues. The Grief Cube has since been integrated in the Loss and Grief training course, and we are currently investigating whether staff who followed the course have increased self-confidence in providing grief support.

This was my presentation for today, you can find more information and download the Grief Cube manual for free at this website (powerpoint)

Are there any questions?