



Being there for a dying person in their final hours is often very important for their relatives. During the pandemic, however, this is often not possible.

Photo: Chinnapong/shutterstock

Dying without saying “Goodbye”

During the pandemic, social distancing applies for the sick and dying too

By Anke Sauter

Losing a loved one is difficult. Losing them without being there for them at the end is for many people almost unbearable. The contact restrictions during the pandemic are demanding a lot from all of us, but especially when dealing with serious illnesses, dying and death. This is not without consequences for the grieving process.

A fall at home, a broken bone with a foreseeably protracted healing process – these were the start of a tale of woe that ended with death. Because of the risk of infection, the patient, we can call her Ms M., was not allowed any visitors for weeks. The coronavirus found its way into the hospital nonetheless: It was probably a physiotherapist who brought it in. Several patients fell ill, including Ms M. It was only when her health took a severe turn for the worse that her children were allowed to visit her. After many weeks, they saw their mother for the first time again – on her deathbed. To know how much she had suffered from loneliness was almost as painful as her death itself.

An example from the second wave of the coronavirus – and there are presumably many others. In times of the pandemic, falling seriously ill is particularly hard, not just as far as the coronavirus is concerned. No wonder many people are shying away from going to the doctor for fear of having to go to hospital and being separated from their relatives. This is how illnesses are protracted that could actually still have been cured. Those who are seriously ill and do end up in hospital have to forego all contact with their loved ones because of the risk of infection. That is the one side of the coin. The

other side is that of the relatives, and it is no less difficult. Although hospital staff do their best to reassure patients and keep families informed, they are themselves often overworked and at the end of their tether. And being told by nurses is not the same as a visit. Especially COVID-19 patients are often without their relatives even in their final hours because of the high risk of infection.

Anger, guilt and longing as a normal grief reaction

Sandra Zulauf, a young psychologist working on the PROGRID project, which aims to help people with prolonged grief, has observed: “This helplessness, the feeling of not being there for someone, that is very bad for people.” The loss of control often leads to anger towards staff, but also to a sense of guilt, she says. Thoughts go round and round in circles: Should I have been more insistent about being allowed in to see my mother? Anger, sense of guilt, overwhelming longing – all these are normal reactions when a person close to us dies. Sometimes, however, time does not seem to heal all wounds – on the contrary: Everything just gets worse and worse.

We speak of “prolonged grief” when people are still filled with extreme longing many months after a relative’s death and refuse to accept that it was “Goodbye” forever. “Some widows set a place for their husband at the table every day, parents who have lost their child keep everything in their dead son’s room exactly the same for years,” says Regina Steil, professor of psychology at Goethe University and head of the Frankfurt study centre within the PROGRID project. Other possible symptoms are the feeling of loneliness, self-reproach, but also suppressing memories of the deceased. Many affected people still have difficulties coping with everyday life long after the person’s death. Regina Steil is glad that “prolonged grief disorder” (PGD) has now been acknowledged as a mental disorder by the WHO and included in the International Statistical Classification of Diseases and Related Health Problems. “It’s not about stigmatising those in mourning. It’s quite normal for people to suffer very badly from losing a relative. But if this suffering doesn’t diminish, then it can have serious consequences. These people can now be helped,” says Steil.

Risk factors for prolonged grief disorder

About 4 per cent of all people in mourning develop such a grief disorder. Are there risk factors that encourage it? “Various studies show: If the death is unforeseen, if it occurs in the ‘wrong order’ within the generations, if it was a violent death at the hands of a third party – or the rela-

tive died in intensive care, these are aspects that increase the probability of prolonged grief disorder,” says Regina Steil. The dramatic scenes in an ICU also foster a problematic development. “When an elderly father, advanced in years, dies in his bed after a long period needing care, then that’s rather an event which is to be expected,” says Steil. And yet even in such apparently undramatic circumstances there are cases where a person’s grief threatens to be all-consuming. “This is often connected with the deceased person, with the relationship,” she explains.

In the pandemic, the probability of prolonged grief disorder increases as a result, for example, of relatives becoming ensnared in a sense of guilt because they could not accompany the dying person to the end, and this is additionally intensified by the environment in the ICU. “I should have insisted on being with him. I didn’t understand what a bad state he was in and let them send me away too easily” – people’s thoughts revolve around such self-reproaches. Being with a dying person until their last breath gives us a good feeling, says Steil. Because being close especially to COVID-19 patients is only possible under very strict regulations for reasons of protection and due to the risk of infection, saying “Goodbye” in a dignified manner is almost impossible.

As a consequence, the person’s death often remains abstract. And the subsequent rituals for coping with it also remain abstract – however different they may be in different cultures. “All over the world, mourning means closing ranks with other people, also physically. But that is also only possible to a very limited degree during the pandemic,” says Steil. The funeral ser-

ABOUT REGINA STEIL



Regina Steil, born in 1965, is professor in the Department of Clinical Psychology and Psychotherapy of the Institute of Psychology at Goethe University. She studied psychology at the universities of Marburg and Jena, completed her doctorate in Göttingen and Oxford and was senior psychologist in the Department of Psychosomatic Medicine and Psychotherapy at the Central Institute of Mental Health in Mannheim from 2004 to 2008. She has been scientific director of the Centre for Psychotherapy at Goethe University since 2008. She also heads, among others, the Frankfurt study centre within the PROGRID project on the treatment of prolonged grief disorder, which is funded by the German Research Foundation.

steil@psych.uni-frankfurt.de



In mourning and lonely: People who have lost a close relative during the pandemic often suffer additionally from the contact restrictions in place.

vice at the cemetery, insofar as guests are permitted at all, is subject to social distancing rules, closest family members sit two metres apart in the chapel without being able to lean on each other. A wake afterwards with coffee and cake and chatting about shared memories are out of the question, and so relatives often feel lonelier than they would in “normal” times, left alone with their sorrow and their thoughts going round in circles.

PROGRID study on behavioural therapy approaches

Most people will somehow overcome the loss, even in times of the pandemic. Yet what about those whose grief does not disappear by itself, but instead becomes chronic, as psychologists say? “Possible consequences are substance dependence, that is, addiction, psychosomatic disorders such as autoimmune diseases, but also depression leading to suicide,” Steil says. That is why it is so important to recognise the problem in good time and to help. The PROGRID project funded by the German Research Foundation, in which Goethe University is collaborating with the universities of Eichstätt-Ingolstadt, Leipzig and Marburg, is comparing two different behavioural therapy approaches. One approach focuses on the practical side of life and tries to find solutions for everyday problems together with the patient. The other approach centres on the relationship with the deceased, the sense of guilt, the anger, the longing. Both approaches have proven successful for various problems, says Steil, adding that the aim now is for them to benefit people with prolonged grief disorder as well. Treatment includes a detailed anamnesis, around 20 weekly personal therapy sessions as well as short- and medium-term check-ups. Treatment within the PROGRID project is financed by the health insurers.

Were the contact restrictions during the pandemic too harsh, especially for old people’s homes and hospitals, because they led to irre-

versible damage on both sides? “I wouldn’t put it like that. It was always a question of weighing up the health risks,” says Steil. However, she adds, this aspect of COVID reality needs to be looked at in more detail: Were there more people with depression? More suicides? And the situation of hospital staff also needs to be examined more closely, she says, as it is intrinsically related to relatives’ suffering. ●



The author

Dr Anke Sauter, 52, is a science editor at Goethe University.

sauter@pww.uni-frankfurt.de

IN A NUTSHELL

- The contact restrictions during the pandemic demand a lot especially from the relatives of the dying. Because they cannot be with their loved ones in their most difficult hour, many people are haunted by a sense of guilt.
- The comfort that comes from mourning together is also more or less lost: Keeping a distance is the order of the day, even at funerals and during the time afterwards.
- If the grief still does not diminish even after months have passed, it could be a case of “prolonged grief disorder”, a medical condition that has only recently been acknowledged as a diagnosis. Typical symptoms are physical or mental problems, suppressing memories, problems coping with everyday life as usual.
- The PROGRID project at Goethe University funded by the German Research Foundation offers help to affected persons. Two different behavioural therapy approaches are used – one focuses on the grief itself, the other on the everyday problems it causes.