

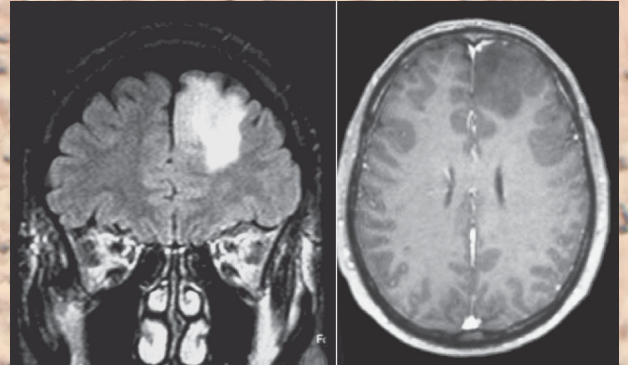
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Grief, Bereavement, and Mourning

Zwinkels H

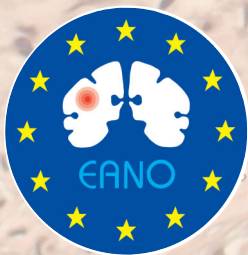
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Grief, Bereavement, and Mourning

Hanneke Zwinkels

In the years working as a nurse practitioner in neuro-oncology I have spoken with many patients and their carers about grief, bereavement, and mourning. In these conversations, they all talked about a period of grief after having heard the diagnosis, after recurrence of the tumour, after reaching the point when there are no treatment options left. Patients feel sorrow over the loss of future perspective, over their loss of ability to be independent, over the loss of functions. What touches me very often is grief over loss of communication ability.

During consultation hours I have been meeting Mrs M and her husband for 3 years now. When I first met her, we spoke about the operation the following day because of a suspected high-grade glioma in her left frontotemporal lobe. She had complained about loss of sense in her right hand and experienced an episode of speech arrest. She was full of hope of recovering after the operation and returning to everyday life, and at some point during our conversation she understood the seriousness of her illness. Several weeks later she told me she had been crying the whole evening before the operation, being aware of her changed future perspective.

During treatment with radiotherapy and chemotherapy according to the Stupp scheme, we got to know each other quite well and I was able to support Mrs M in her emotion-oriented coping. Because she participated in a clinical trial, we kept seeing each other on a regular basis. After every MRI, we discussed the results (after she and her husband had spoken the doctor) in relation to possible future treatment options and how she and her family – she has 2 teenage children – were doing.

She did quite well, with subtle speech disturbances when she was tired, as well as some lessened sensory feelings in her right hand.

“My life is of good quality, but when I am thinking of the fact it will not last long enough to see my children grow older, to see them go to university and graduate, start a relationship, marry, to see them become parents, to become a grandmother ... then I become very upset, very sad, very angry and I regret the fact this disease is my fate ... and the fact I am empty-handed ...”

By giving Mrs M and her husband the opportunity to talk about their loss of future perspective, by listening to their grief of lost health, their bereavement on powerlessness, about their mourning over the inescapable outcome, they were able to adjust to the situation and the results of that specific moment. Receiving reassurance and support was essential to Mrs M and her husband to help them to cope with the illness, and allowed them to hope for a next episode of stable disease. But the balance between realistic hope and their bereavement was fragile. Each time a new MRI was performed

and results had been discussed, they again asked for support in regaining this balance.

Mourning of a patient about loss of future perspective can be very comprehensive: loss of functions, loss of working satisfaction, loss of support by the partner, loss of communication with colleagues, loss of social interaction, loss of income, and by that an increasing social isolation, a feeling of uselessness, without the ability to perform daily tasks. During the disease progress psychological adjustment to the new situation is a dynamic process, in which the nurse practitioner can play an important role, in providing the supportive tools and guidance to facilitate adjustment. Patients faced with life-altering news and a loss of future perspective experience distress and need honest, personalized information to promote hope and adaptive coping. A discongruent coping style within a couple of which one is affected by a glioma could be an extra source of tension and distress, which could imply referral of the patient and his or her partner to the psychologist.

Mrs M was employed in her husband's company as a secretarial administrator but because of her language problems she was no longer able to work one year after her initial treatment. The children went to college and left the house, Mrs M and her husband regained a sort of balance but then the tumour recurred. It took a little while, but she realized she had no other choice than to participate in another trial. Every 6 weeks an MRI was performed, and every 6 weeks we spoke about the tension and fear of tumour recurrence, the MRI results, future treatment options, and her bereavement of future time. Every next step was a step closer to losing the ability of taking any step, as she said.

Several studies have investigated the supportive care needs of carers, focusing on the end-of-life phase. They concluded that information on end-of-life issues is of importance and state that when health care professionals are open and sensitive on these issues, they will be able to guide patients and carers and fine-tune communication. Psychosocial care and guidance aim at the patient being able to take control in the end-of-life phase, supported by his or her partner and relatives, regaining a balance in saying what has to be said, in experiencing coping on psychosocial and spiritual aspects of a completed life.

The last time I met Mr and Mrs M, she was wheelchair-bound because of a hemiparesis and not able to speak. We discussed the diagnosed tumour recurrence and the subsequent focal deficits, Mr M told me how he and his wife were doing at home. She needed help with daily activities, could speak a few words like yes and no, but most of the time could not find the right words, needed to rest more and more, was up for about 4 hours per day, but did not suffer from headache or nausea. A hospital bed had been arranged for, help from friends was available, the general practitioner was informed, and home care would soon be coming.

Mrs M tried to understand what we were talking about, but it was difficult for her to respond to questions. I asked them if they would agree to listen to what could be expected for the last phase, and Mrs M looked into the eyes of her husband with a question in her eyes. After some seconds, he told me, he would be glad to hear about that, she agreed by nodding her head and I carefully talked about what was expected to happen. Tears fell, not only from the eyes of Mr and Mrs M, and after ending our conversation we said goodbye. I wished her a valuable comfortable time, with a lot of love, care, understanding, and hope for a good and beautiful completion of her life.

Suggested Reading:

1. Cavers D, Hacking B, Erridge SE, et al. Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *CMAJ* 2012; 184: E373–E382.
2. Sizoo EM, Braam L, Postma TJ, et al. Symptoms and problems in the end-of-life phase of high-grade glioma patients. *Neuro Oncol* 2010; 12: 1162–6.
3. Khalili Y. Ongoing transitions: the impact of a malignant brain tumour on patient and family. *Axone* 2007; 28: 5–13.

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