

PALLIATIVE CARE CASE OF THE MONTH

"Where is God?"



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Case: JP is a 60 year old woman with a past history including alcohol and tobacco abuse. Records show that she is estranged from some family members. Her husband, though, is very supportive. She has a history of extensive left facial squamous cell carcinoma and has had multiple surgeries including reconstructive attempts – four flaps, all of which have failed. The first time I saw this patient was prior to the fourth flap attempt. Before visiting her, I was warned that much of her face was missing.

Others who had seen her commented on her good spirits and joking, in spite of her condition. The consensus seemed to be that she was handling her situation well. On my first visit with her, I got a completely different picture. She was visibly distraught, crying. Her husband hadn't called. She was upset that the Catholic priest didn't spend more time with her. She told me, "He prayed and left." She asked the question, "where is God?" Her comments and question suggested that she was feeling alone or abandoned. Further, she indicated that she was upset with her appearance. She seemed to be crying out for attention and acceptance. I spent a fair amount of time with her, trying to see past her physical appearance and to find a point of connection with her beyond her emotional and spiritual distress. I told her that God is always with us and, in response to her distress over her appearance and condition, doesn't see us as we see ourselves. He sees us as beloved children.

In subsequent visits with this patient, she exhibited the jovial bravado I had expected to see in the first visit (based on others' experience with her). A nurse told me she was on anti-depressants, and that seemed to help. A psychologist on the palliative care team mentioned that this patient has a labile personality and mood swings are to be expected.

Discussion: How does one relate to a patient with such a physically disfiguring illness? How does her appearance affect others and how they relate to her? Although this may not be the patient's concern, I could not help but think that when she transfers to a nursing home, which was in the discharge plan, she may be shunned or avoided by some employees, as her appearance is very disconcerting. She was offered a mask, but apparently did not want that. Was JP putting up a barrier by refusing a mask? I did not ask her that question, but noted that she did exhibit behavior that effectively put up barriers between her and others. By not following medical advice in allowing her reconstructive surgeries to heal, her appearance was perhaps worse than it would have been if she had been more cooperative. Research suggests that cancer patients often experience anxiety and depression related to constant uncertainty about the future. The ensuing stresses may lead to self-harming behaviors, such as non-participation in treatment regimens (Holland).

What effect does her illness have on her spiritual well-being? One of my chaplain colleagues commented that Jesus' suffering on the cross was short lived and that the suffering of patients like JP is prolonged, and perhaps more devastating. The Christian perspective is that Jesus knows our suffering. God took human form and walked among us.

The "Good News" in Christianity is that Jesus conquered the ultimate consequence of suffering, death itself, to offer us new life. So often, the words of comfort from a Christian perspective are that God is with us in our suffering, knows our suffering, and has experienced the ultimate suffering and death on a cross. Is this of comfort to patients experiencing cruel and extended suffering? God promises that we will not be tested beyond our endurance. Are there limits?

Interventions: As a chaplain on the palliative care team, my aim was to provide acceptance of the patient on her terms, to offer prayer and to help her see herself as a beloved child of God. This was a challenge, in part due to the fact that her physical appearance created a barrier between her and others. That barrier could prevent her from seeing and feeling love from others, which is one way that God's love for us is manifested.

When a patient is in despair, as JP was in my first visit with her, I remind the patient of the Psalmist, who honestly and openly cries out to God with no censoring of feelings. It is OK to cry out to God and to express anger, hatred....all of those dark feelings. God can handle it. The Psalms of lament in Scripture do not end in despair, though. They show transformation — moving from despair to reintegration. I shared my understanding of the Psalms with JP. They give hope. They are a resource, like medications and surgery, to allow healing. My hope is that JP will accept these resources and find wholeness. Measuring the effectiveness of spiritual interventions is difficult, as results are not often immediate and/or measurable. Pastoral care is one component in the complex mix of offerings to aid in the mystery of healing.

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