

Sexuality and Terminal illness: A Forgotten Topic

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Abstract

This short review shows the preliminary results of a larger ethnographic study with terminally ill patients, their families and the medical team. Sexuality in this last stage of life is put on the back burner even by the sick themselves. Their intimacy is lost, because the family and the health care team put the symptoms of the diseases before the emotional and social needs of the patient. Home care arrangements expose their bodies and their "shame". It is urgent that even palliative care incorporates in the integral care the valuation and attention to the sexuality of each person.

Keywords: Sexuality; Terminal ill; Patients; Cancer; Palliative care

Introduction

Living with a chronic disease means gradually losing almost all social functions, especially forgetting the sensitivity of the body, emotions and feelings. Body image is not a priority and, when patients are in the terminal phase, all their sexuality seems denied. Some studies have explored sexuality in old age and chronic illness, especially in cancer patients, discuss sexuality as a human right and a fundamental part of individual and social health [1]. Medical oncologists often discuss diagnoses and treatments with patients and their families, try to communicate medical information as empathetically as possible, equally excluding patients' emotional needs [2], besides, they also assume that cancer treatment have a major impact on sexual function and libido, and when assessing overall quality of life, including sex life, they expect patients to be the ones to talk about it [3].

Barriers to openly discussing sexuality at this stage of life are created by both physicians and patients. In some cases, patients assume that their condition is the result of their sexual life, and health professionals assume that sexual desire is lost with the disease, and in any case, they conceive it as a merely physical function and do not consider its social, cultural and emotional dimensions [4]. Previous studies indicate that the possibility of addressing sexuality in chronic and terminal illness is difficult even in palliative care, despite the recognition that sexuality is an integral part of the whole of life [5]. Palliative care in Mexico is limited and confusing and uncertainty for health personnel. There is a lack of knowledge regarding which treatments are legal for a terminally ill patient and by protocol of care, only pharmacological and clinical therapy is considered; the physician, due to lack of knowledge, does not consider the social or emotional needs of the patient [6]. The ethical discussion of palliative care in Mexico focuses on medical treatment and the information provided. We are still in our infancy and there is still a long way to go before the patient is analyzed as an integral being.

An ethnographic study with seven terminally ill patients (4 men and 3 women, with an average age of 47.3 years) who were treated in a palliative care unit in the city of Guadalajara,

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Mexico, has revealed that sexuality is a pending subject in medical care and palliative care. All of them was informed in verbal form about the general propose of the study and agree to be recorded our conversations. All of them were verbally informed about the general proposal of the study and, agreed to be recorded in our conversations. We were very careful not to be intrusive, imposing, or use symbolic violence during visits to their homes. We are grateful because they confided their personal stories and their near-death experience [7].

Palliative care involves home care arrangements, what means leaving their bedroom and living their last days in the living room of the home, exposing their bodies and robbing them of any privacy for personal hygiene and expression of emotions or to establish intimate conversations with their partner, if they have one. In addition, they live their last days wearing sleeping clothes and without personal grooming, they feel that their embarrassments are not considered as such. Families may be preoccupied only with health care and symptoms, not imagining the need for affection and contact.

The couple, for their part, leave physical contact behind for fear of hurting the sick person, and neither of them talk about it for fear of hastening the parting. Only one of them spoke to her medical oncologist about it and she felt she was judged as "needing" pleasure, when she should first think about healing. The doctor said he was not prepared to listen to that question because his priority is, the physical health of the patient.

Conclusion

For the terminally ill patients, sexuality was an important part of their lives. They were very able to discuss their needs. For the

others (family and health team), sexuality as a part of the of the lives of their loved ones or their patients in nonexistent. Lack of privacy and other barriers must be assessed by the palliative care and, inform and promote with families the respect and encourage the exercise of sexuality as a right until the end of life. First, the entire healthcare team must be educated from their formative stage to face this challenge.

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