

# How Prepared are We to Address Sexuality in Palliative Care?

## Quão Preparados Estamos para Abordar a Sexualidade nos Cuidados Paliativos?



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Sexuality, as one of the determinants of quality of life, includes different subjective dimensions related to identity, communication and intimacy.<sup>1</sup> According to the World Health Organization (WHO), sexuality “is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.” In this sense, WHO considers intimacy as an important element of the expression of sexuality. This includes individual satisfaction with his/her affective, loving, and sexual relationships. Moreover, in concordance with WHO, and distinct from sexuality and intimacy, sex “refers to the biological characteristics that define humans as female or male”. However, in general use, the term sex is often used to mean ‘sexual activity’.<sup>2</sup>

For many patients, sexual health (SH) is an essential component of their quality of life, providing a sense of normality and closeness within the couple.<sup>3,4</sup> Studies show that terminally ill patients continue to crave intimacy, although the type of intimate relationship may change along with their illness. At this stage, patients’ intimacy reinforces their emotional bond.<sup>5</sup>

Advanced illness, such as oncological diseases, can create significant disruptions in sexual functioning. Changes such as immobilization, alopecia, weight variations, surgical scars, immunosuppression, uncontrolled symptoms (pain, depression, etc.) can be disruptive and change the couple’s dynamics. Major problems can arise from an integrative model which includes biological, psychological, social and interpersonal issues.<sup>6,7</sup>

Despite the high levels of sexual dysfunction (decreased libido, vaginal atrophy, dyspareunia and erectile dysfunction) related to patients’ diseases or prior treatments, the lack of communication between patients and their healthcare professionals (HCP) prevent their needs from being totally satisfied, causing more suffering.<sup>8</sup>

Patients and their partners who are admitted to a Palliative Care (PC) unit struggle to express their sexuality due to the lack of privacy, the existence of small

accommodations and the constant presence of HCP. These obstacles can contribute to the weakening of the relationship.<sup>6,9</sup> There may even be an inherent fear of causing pain, risk of infection or even death during sexual activity; all of these lead patients to avoid physical intimacy.<sup>10</sup> Sometimes it is the partner who expresses and feels ashamed to sleep close to another patient, despite being willing to do so. Feeling guilty can arise from these obstacles.

### Assessment models of sexuality and intimacy

Some studies have shown that in PC there is a superficial approach to SH.<sup>11</sup> In order to fill this gap, and within the patient’s initial assessment, the Brief Sexual Symptom Checklist is recommended, which assesses patients’ dissatisfaction with their sexual function, type of sexual dysfunction and the willingness to talk about it.<sup>12</sup>

Some institutions have adopted other tools that provide HCP with skills to address intimacy and SH. To name a few: PLISSIT (Permission, Limited Information, Specific Suggestion and Intensive Therapy); BETTER (Bring up the topic, Explaining, Telling patients about resources, Timing of SH services, Education on specific topics and Recording the interactions); 5A’s (Ask, Advise, Assess, Assist, Arrange) and ALARM (Activity, Libido, Arousal, Resolution and Medical Information).<sup>11</sup>

Furthermore, the Stepped Skills model is an approach in which complementary functions are assigned to different team members, preventing the same member from controlling the issue of palliative and sexual aspects simultaneously. This is a more realistic and practical way to deal with sexuality and intimacy by the team.<sup>13</sup>

Complementarily, Kubler-Ross’s theory provides a better understanding of the difficulties that patients and their partners face at the end of life. Despite the lack of empirical validation, this model continues to be a gateway in conducting discussions with patients about sexuality and its interdisciplinary complexity.<sup>14</sup>

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Additionally, Bronfenbrenner's theory of ecological systems consists of a holistic structure applicable to the understanding of multiple levels of influence on sexuality in the end of life. It is all about the integration of the individual (mental and physical health, knowledge), the microsystem (family, partners and caregivers), the mesosystem (interaction between elements of the microsystem), the exosystem (laws and politics), the macrosystem (attitudes and ideologies) and the chronosystem.<sup>9</sup>

At last, and as previously mentioned, the biopsychosocial model describes the relationships between biophysical, psycho-cognitive and social health dimensions. Individual health is affected not only by his/her intrinsic health, but also by the partner's or the couple's health. This model integrates the partner as a determining factor of the patient's SH. The presence of a disease that affects the partner or the caregiver's exhaustion will negatively affect the patient's SH.<sup>15</sup>

### The role of health care professionals

HCP should recognize that during the end of life, physical intimacy and the desire to express oneself sexually are not interrupted by the illness process or its treatment.<sup>3</sup> Nevertheless, the majority of HCP tries to avoid this issue or believes that somebody else will be more skilled in this subject.<sup>16</sup>

Communication about SH should extend not only to the PC team but also to primary care and oncology professionals, as well as others involved with the care of the patient. Thus, the approach to SH is too far from desirable. This is most often related with the lack of adequate clinical training, disregard for the importance of SH, lack of time, priority in treating the disease or symptoms, and even personal discomfort of the HCP regarding the subject.<sup>17</sup> These barriers are emphasized in extreme age groups (adolescents and the elderly) for not being considered sexually active.<sup>18</sup> In truth, the HCP's ageism towards older people's experience of sexuality during the wake of a life-threatening disease is evident, despite the prevalence of cancer in this population.<sup>5</sup> Besides, it is also undeniable that the medicalized behavior towards a life-threatening disease process, puts on hold the impact of sexual and intimate aspects on the patients' life.<sup>19</sup>

One way to solve these problems might be through on-the-job training, making it easier for HCP to review their own sexuality and consequently, their patients' SH.<sup>20</sup> It is the role of the HCP to open and facilitate discussion between couples in order to reduce concerns surrounding SH after

advanced disease.<sup>10</sup> HCP should ask patients openly how they feel about their sexuality. This can open a communication channel and be the first step towards reflection.<sup>11</sup> HCP should ask how patients' illnesses and/or treatments affected them, how they feel about themselves and whether the relationship with their partners has changed.<sup>6</sup>

The introduction of sexuality at the beginning of the patient/HCP relationship shows openness to the patient so that he/she can discuss it at any point in the trajectory of the disease. The inclusion of sexual history in the review of symptoms may be a successful strategy to help and normalize the patient's feelings. Devoting special attention to details about the patient's concerns can lessen the impact of physical and psychological symptoms on SH. For example, in a situation of pain or fatigue, HCP may suggest behavioral measures that imply greater closeness between the couple, such as lying next to the partner and caressing him/her. Sexually active couples have found new ways to maintain their intimacy, such as holding hands, dancing, touching, hugging and kissing.<sup>5</sup>

It is important to approach intimacy and sexuality, but it is also essential to respect and make sure the patients' privacy is upheld by providing appropriate conditions. Even when this happens, the physical aspects of intimacy often overlap with psychosocial aspects, such as affective care and loneliness, which in fact are the ones that most affect the patient.<sup>21</sup>

The positive impact of providing SH to patients in PC should motivate HCP to overcome the difficulties they experience regarding this matter.<sup>11</sup> Communication skills and psychosocial guidance provide HCP with the ability to explore the SH needs identified by the patient or the couple.<sup>22</sup> A better understanding and recognition of SH by HCP can be a significant contribution to an improved and true holistic view in PC.<sup>11</sup>

### CONCLUSION

SH is an essential component in the clinical approach of patients.

In PC, patients report a change of meaning and expression regarding their sexuality. It is the role of HCP to ask patients openly about their feelings and needs regarding SH, and provide them the opportunity to comfortably discuss the impact of the illness on their sexuality.

HCP should give PC patients the possibility to be close to their partners by creating the proper physical and psychological conditions that embody their quality of life.

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