Case Report

Collusion: The Facade and its Implications on Total Pain Management in Palliative Care

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Abstract

Collusion is an unharmonious bond between the doctor and a patient or between patients and caregivers. This case report exemplifies one such experience and highlights the hurdles we face when dealing with collusion. A 31-year-old woman was diagnosed with rectal carcinoma during her pregnancy and underwent diversion colostomy (for intestinal obstruction) followed by neoadjuvant chemoradiation after delivery. Later, she was diagnosed with metastatic disease and was under palliative care. The family always had a negative association with cancer and chose to withhold information from the patient throughout the treatment trajectory. Collusion and lack of information can be a factor for persisting total pain. While caregivers desire to protect the patient from the distress of a life-limiting diagnosis, invariably it causes more anguish than comfort. Oncology professionals need to consider collusion as part of our sociocultural fabric and develop a strategy to negotiate and improve the care.

Keywords: Collusion, palliative care, psychological distress, psycho-oncology, total pain

Introduction

Cancer pain is a total pain and it has four dimensions: physical, psychological, social, and spiritual, as described by Dame Cicely Saunders.[1] Addressing the total pain holistically enhances the quality of life and death of cancer patients and their primary caregivers.[1] However, this becomes a challenge in countries like India where collective ownership is a part of social culture, and often, the decision-maker is not the patient themselves but the primary caregiver.[2] Family caregivers extend a protective response coming from an intent of love on the face of a health crisis. There is a tendency to withhold information and keep the patient in the dark. Collusion is this practice of secret agreement or cooperation between two or more people who are trying to deceive.[3] It is a common issue that interferes with the treatment trajectory and remains a significant health-care challenge in the context of the Indian sociocultural scenario. This case report exemplifies one such experience and highlights the hurdles health-care professionals face when dealing with collusion.

Case Description

A 31-year-old young woman, hailing from a village in Odisha, came to Delhi for better treatment. During her pregnancy, she developed bleeding per rectum. She got herself evaluated 2 months after child delivery and was diagnosed to have rectal carcinoma (locally extensive disease) with pelvic and para-aortic lymphadenopathy. She underwent diversion stoma surgery and then received chemoradiotherapy for tumor downstaging. Unfortunately, before she could undergo definitive surgery, she developed breast metastases. She received palliative chemotherapy and was enrolled under the palliative care services.

She was under palliative care for the last 6 months of her life. At this point, she always had complaints of pain. She was initially managed with weaker opioids and nonsteroidal analgesics and was eventually started on oral morphine tablet as per the WHO ladder. The site and distribution of pain changed during this time, starting from the pelvis, later developing new-onset pain in the low back and neck, and then eventually over the entire body. She developed blindness in one eye due to brain metastases. Throughout the last 3 months of treatment, she also developed

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fatigue, colostomy prolapse, and decreased sleep. During this entire period, her pain score ranged between 3 and 10 despite the optimal titration of opioids and adjuvant pain medication.

This recently married woman with a newborn child, hailing from a lower-middle-class family, was looked after by her five brothers settled in Delhi. While she was undergoing treatment in Delhi, her husband stayed back in the village looking after the newborn and the business. The patient had already lost her parents to cancer leaving them with a strong negative association about cancer. Despite trying multiple times, the health-care team did not have consent from the family to discuss the diagnosis and prognosis with the patient. Acknowledging the circumstances and empathizing with them, the health-care team used the SPIKES model (S – setting up the interview, P – assessing the patient's perception, I – obtaining the patient's invitation, K – giving knowledge and information to the patient, and S – strategy and summary) to convince the family first before breaking the bad news to the patient.[4] However, the family members always remained reluctant to the idea of having transparent communication with the patient. The patient was worried about her son and her inabilities to meet the roles and responsibilities that are expected as a mother. During the counseling session, the patient was advised to do mantra meditation, positive affirmations, and visualization in order to enhance the emotional well-being. The patient was accompanied to the hospital by a different family member each time despite the therapist's advice to keep one point of contact for all follow-ups. This posed additional challenges to the palliative care team.

The five brothers thought, revealing the diagnosis would completely shatter their sister's willpower to even fight. After each session with the therapist, the caregivers agreed to reconsider the advice of breaking the bad news and discuss the same with the other family members. The choice remains with the primary caregivers to decide between revealing and hiding the diagnosis and prognosis with the patient and other extended members of their social circle. Even after knowing her condition, they borrowed >3 million Indian rupees to meet the medical care expenses over a period of 1 year. Moreover, the patient never inquired about anything about the disease status and treatment approaches. Her brothers took all the decisions for her. The collusion had made this case complex at multiple levels, affecting not only the treatment but also the patient's psychological well-being [Figure 1]. During the multiple hospital visits, the therapist performed following psychological assessments; National Comprehensive Cancer Network (NCCN) Distress Thermometer,[5] Mini-mental status examination,[6] Numerical Rating Scale,[7] Patient Health Questionnaire 9[8] and General Anxiety Questionnaire[8] [Table 1]. She was already carrying a lot of guilt and burden within. As time passed by, she started fearing about abandoning her child, just like her parents did. Toward the end, such intense emotional turmoil mixed with pervasive sadness, anger, fear, restlessness, adjustmental issues, anhedonia, fatigue, sleep deprivation, and crying spells led to having both symptoms of anxiety and depression mixed with unrelieved physical pain.

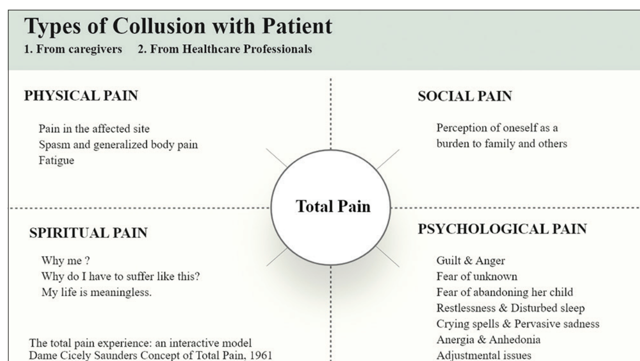

Figure 1: Based on the model of dame cicely Saunders

Finally, the brothers broke the news themselves to the patient. During that time, there was no health-care team, and the brothers sat with the patient and revealed the diagnosis and prognosis to the patient. The next time when we met the patient, there was a lot of hesitation from her side. The prolonged breach of trust between the patient and the health-care team had been acknowledged. The team recognized her feelings and provided comfort. When the therapist asked her reaction after learning the diagnosis, she said that she had been expecting ominous news for some time now. There were mixed feelings of grief, guilt, and relief to some extent, and that all she wanted now was a little more time, as it was her son's first birthday in a week's time. It almost sounded like her last wish. After the celebration, she got readmitted to the hospital, but this time around, she was not complaining of any pain. She was now more interested in narrating the son's birthday celebration. To conclude, she spent good quality time with her son and had closure to a lot of unanswered questions within her.

Discussion

Cancer pain is a total pain, and it is vital to address the four dimensions of total pain in order to provide optimal relief.[1] The physical aspects of total pain are more perceptible and are managed medically as per predesigned protocols and guidelines already in place.[9] However, the other three dimensions are intangible in nature, being affected by innumerable factors. This might mean we cannot remove the causes directly without addressing its symptoms. Effective communication is often the first step toward managing social, spiritual, and psychological pain.[10] Having said that, the health-care providers face hurdles when an effective communication is made impossible due to various reasons. Collusion is an unharmonious bond between health-care professionals and patients or between patients and caregivers or health-care professionals and caregivers. Collusion is prevalent all over the world, more so in a country like ours.[2] Nearly one-half of the cancer patients on treatment from India are unaware of their diagnosis and prognosis or the treatment modalities.[10] However, a recent study from India stated that the cancer patients prefer full disclosure of their diagnosis and prognosis, while the caregivers prefer nondisclosure of the same to the patient.[11]

Table 1: Psychological assessments done for the patient

Test administered and its objective	Score and interpretation (November 2018)	Score and interpretation (April 2019)*
NCCN Distress Thermometer Objective: To understand the level of psychological distress	9/10 - Severe distress (due to pain)	10/10 - Severe distress (pain, worried about child, fear, financial concern)
Mini-Mental Status Examination Objective: To rule out cognitive dysfunctions	27 - No cognitive impairment	-**
Numerical Rating Scale Objective: To assess the level of pain	10/10 - Severe pain in the affected site	10/10 - Severe pain in the affected site and generalized body pain
Patient Health Questionnaire-9 Objective: To quantify the level of depression	9 - Mild depression	14 - Moderate depression
General Anxiety Questionnaire Objective: To assess the level of anxiety	4 - None	11 - Moderate anxiety

*A day before collusion has broken, **The test did not administer due to patients' worsened condition. NCCN: National Comprehensive Cancer Network

Table 2: Case formulation based on biopsychosocial model

	Biological	Psychological	Social
Predisposing factors	Introvert and shy personality Strong family history of cancer Current cancer diagnosis and associated severe pain	Parents died due to cancer when she was young and strong fear of cancer with death Enmeshed family system	Lower socioeconomic background Poor access to health care in their village Poor knowledge and negative attitude toward the cancer among the caregivers
Precipitating factors	Medical and surgical interventions Treatment related side effects Issues associated with the colostomy bag	Since she lost her parents when she was young, she has this fear of abandoning her child and repeating the history Trauma associated with medical and surgical procedure Guilt and fear of young mother who us not caring her child due to her medical condition Guilt associated with being a burden to family members Fear associated with word "cancer" Fear of unknown Fear of pain and suffering Fear of loss of control Feeling confined and loss of hope Adjustmental issues with the colostomy bag	Staying away from the husband and child due to the treatment Missing her home town and her neighbors Thirty lakh rupees' debts associated with her treatment Intense sense of helplessness in her brothers
Perpetuating factors	Continuous generalized body pain Fatigue Aggravated disease condition	Feeling of helplessness Limited insight Vulnerable, feeling of burden to her family Overly attached to the family which leads to feel guilty	Unable to see her child and husband/lack of husband's presence in Delhi Inability to perform social roles and responsibilities
Protective factors	Resilience	Coping mechanism (prayer)	Religious belief Good support from the health-care team

The patient was a newly married female from Odisha, an Indian state in the eastern coastal region. Her treatment was in Delhi and was overlooked by her brothers while her husband stayed back in the village taking care of the business and their newborn baby. From day 1, her brothers were adamant about not revealing the diagnosis and prognosis to the patient. Their collusion had a direct relationship owing to their negative association of cancer as they lost both their parents to cancer. Such stigma associated with cancer is widespread in the country, including metro cities like Delhi.[12] The patient rarely asks about the diagnosis or the prognosis. This aspect has its sociocultural influence of gender, females removed from decision making, especially when there are financial implications, while men enjoy an active role.[2,11] The present narrative fits into this context and the therapist tried to conceptualize the case based on the Bio-psycho-social model[13] [Table 2].

The collusion between the patient and the family led to the collusions between the patient and the health-care providers, which then got interwoven with the medical interventions to make the case more complex. The invisible layers

of miscommunication over the clinical trajectory led to unresolved physical pain and severe psychological distress despite the drug prescriptions. The lack of communication and the barriers created due to collusion were the reasons for the patient's unrelieved suffering.[1,10] Toward her end stage, psychological counseling and open communication brought in the closure.

This case throws light into hurdles faced by the health-care professionals due to collusion by the caregivers. The team tried to impart the importance of revealing the diagnosis and the consequences of not doing so to the caregivers. Despite these efforts, they chose to hide information and made the patient to believe "it was an intestinal obstruction." She remained highly optimistic about coming out of it eventually. The conspiracy of silence and the failure of transparent communication mixed with sociocultural sensibilities had resulted in ethical dilemma and made the task of the palliative and psychosocial care a real difficult one.

As health-care professionals we believe, breaking the bad news is something that must be dealt with careful negotiations involving the patient and the caregivers. The communication skills of the team play an absolute key role here. A qualitative study in palliative care has identified, (a) morality to have a relationship with a patient and (b) to comprehend moral dimensions in communication and to negotiate individual conflicts.[14] Under many circumstances, this becomes challenging to a medical team in a country like India where the patients from various sociocultural backgrounds migrate to cities seeking tertiary treatment. Collusion is a recognized phenomenon in clinics making it a major challenge for health-care professionals and hinders all aspects of cancer care.[15] An early integration of psycho-oncology services would benefit the patient and the caregivers.

Conclusion

Collusion is an important factor for persisting total pain. The caregivers often wish to protect the patient from the distress of a life-limiting diagnosis, but invariably and quite ironically, this results in more anguish than comfort. Oncology professionals in Indian settings need to understand collusions as an inevitable part of the sociocultural fabric of the country. We must take active measures to develop strategies to negotiate such unarticulated needs of the patients for improving their much deserving care and quality of life.

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Conflicts of interest

There are no conflicts of interest.

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