

“Talk to me in colors” – remote emotional support in home hospice

Abstract

Palliative and end-of-life care requires respect for patients' final wishes and preferences, including respect for patients' dignity and privacy. As a result such care calls for creative solutions if care and emotional support are to be helpful. This brief paper presents a case report of a young, female patient who chose home hospice service, yet refused to meet the palliative team in person. A creative palliative nurse adapted care to the patient's preferences and wishes, while respecting the patient's dignity and privacy.

Keywords: end-of-life, palliative care, high-quality, suffering, dying

Volume 2 Issue 3 - 2018

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Received: February 25, 2018 | **Published:** May 08, 2018

Introduction

The rise in mortality of chronic conditions¹ poses significant challenges to healthcare services and requires creative service solutions including palliative and end-of-life care for diverse population groups.² High-quality care of incurable conditions and end-of-life states is a sensitive, demanding practice in which a balance is sought between the conflicting goals of prolonging life versus relief of suffering. In 2005, the Dying Patient Law was enacted in Israel to regulate end-of-life treatment and care. As a result of the new law, public awareness of this issue increased.³ This law determined that the only consideration in treating a dying patient should be the individual's wishes and suffering. Implementing this law, Maccabi HealthCare Services (MHS; the second largest HMO in Israel) offers a range of palliative care programs and end-of-life services to patients, including pre-hospice and hospice services. Pre-hospice care is provided to patients who do not meet the Law's definition of “dying patients.” These patients are provided with follow-up care by an oncological nurse and consultations with a palliative specialist regarding a care plan, either in a hospital or home setting.

Hospice services are provided to patients who meet the legal definition of “dying patients” (i.e., incurable medical condition with life expectancy of not more than 6 months). Hospice services are available at a hospital or at home. Home hospice patients are weekly visited by a multi-disciplinary team (physician, nurse and social worker) that assists in symptom management and pain relief, based on the patient's preferences and wishes. In 2017, over 1,300 Maccabi patients (52% women) received at home hospice care. This brief paper presents a case report of a young, female patient who chose home hospice service.

Case report

A female patient was diagnosed with tongue neoplasm in May 2015. On the date of the diagnosis, she was a healthy, attractive, 42 years old, employed as a lecturer, and in a relationship. Immediately after the diagnosis, she moved to live with her parents. A radical operation and tongue prosthesis was proposed by her physician, but after several

medical consultations, she decided not to treat her cancer in any way, and she signed her last wishes. As the untreated cancer progressed very rapidly, her tongue rendering her unable to speak, eat, or drink. She refused hospice care in a hospital setting as she was adamant to prevent anyone from seeing her. She refused to leave her room until her death, avoiding even her father. The only person she permitted to see her was her mother. As she refused to see the oncologic nurse or hospice team, the oncologic nurse contacted her via cellular phone messaging. The patient responded positively to the nurse, and over the three months until her death, the patient shared her feelings and her physical pain with the nurse in her daily text messages. The nurse also gave her a mandala coloring book, and asked the patient to express her feelings through the colors. The patient was very excited by this idea, and sent the nurse a weekly picture that she had colored together with her mother. The mandala coloring and cellular messaging with the oncologic nurse were the patient's major sources of spiritual support until her death. The nurse also played a role in helping the mother prepare for her daughter's death. In line with her daughter's wish to die at home, the mother asked the nurse to teach her how to recognize the last signs of life.

Discussion

This case report describes a challenging case in which the patient refused hospice treatment by the palliative care team. This is not surprising as body image is a critical issue that concerns patients with oral cavity cancer, due to their face disfigurement.⁴ Negative reactions to appearance changes and the discrepancy with one's body image ideals may result in negative emotions (e.g., distress, depression) and behaviors (e.g., social isolation, avoiding care).⁵ In this case, the patient specifically refused to have anyone visit or see her other than her mother, including the palliative care team. The team's professional and ethical dilemma was how to provide support treatment and at the same time respect the patient's wishes and dignity, which included respecting the patient's privacy while providing emotional support.⁶ The oncologic nurse creatively employed text messaging and a mandala coloring book as a mode of communication that respected the patient's dignity and privacy. She established tele-communication

with this very isolated patient, making it possible for the patient to share her thoughts, fears and pain, knowing that she was being heard.

Telehealth approaches to palliative care are seen mainly in rural settings.⁷ Although many mobile cancer-focused interventions have been reported, evidence of their utility, effectiveness and safety is lacking.⁸ A recent systematic review of eHealth interventions in palliative care found limited evidence of the effectiveness of eHealth interventions for palliative care.⁹ Nonetheless, this descriptive case report illustrates how telecommunicating pain and feelings is potentially effective in providing remote emotional to patients under their own terms.

Conclusion

This case illustrates that palliative care provided in hospice settings can and should be adapted to patient's preferences (hospital/home) and wishes. Moreover, this case highlights the need for creative care solutions that align with patients' preferences and respect their wishes.

Acknowledgements

None.

Conflict of interest

The author declares no conflict of interest.

References

1. Bakitas MA, Elk R, Astin M, et al. Systematic review of palliative care in the rural setting. *Cancer Control*. 2015;22(4):450–464.
2. Bender JL, Yue RY, To MJ, et al. A lot of action, but not in the right direction: systematic review and content analysis of smartphone applications for the prevention, detection, and management of cancer. *Med Internet Res*. 2013;15(12):e287.
3. Capurro D, Ganzinger M, Perez-Lu J, et al. Effectiveness of eHealth interventions and information needs in palliative care: a systematic literature review. *J Med Internet Res*. 2014;16(3):e72.
4. Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*. 2017;15:102.
5. Fingeret MC, Teo I, Epner DE. Managing body image difficulties of adult cancer patients: lessons from available research. *Cancer*. 2014;120(5):633–641.
6. Lee J, Fingeret MC, Bovik AC, et al. Eigen-disfigurement model for simulating plausible facial disfigurement after reconstructive surgery. *BMC Medical Imaging*. 2015;15(1):12.
7. Lin YP, Tsai YF. Maintaining patients' dignity during clinical care: a qualitative interview study. *J Adv Nurs*. 2011;67(2):340–348.
8. Steinberg A, Sprung CL. The dying patient act, 2005: Israeli Innovative Legislation. *Isr Med Assoc J*. 2007;9(7):550–552.
9. http://www.who.int/healthinfo/global_burden_disease/projections/en/