

Virtual Clown Care:

A case study using technology to provide social and emotional palliative care

Natalie Bradford^{*1,2,3}, Nigel R. Armfield^{1,3}, Andrew Hallahan^{2,3}, Anthony Herbert^{4,5}, Anthony C. Smith^{1,3}, Jeanine Young^{3,6}

* Corresponding author

¹ Centre for Online Health, The University of Queensland, Brisbane, Australia

² Queensland Children's Cancer Centre, Royal Children's Hospital, Brisbane, Australia

³ Queensland Children's Medical Research Institute, The University of Queensland, Brisbane, Australia

⁴ Paediatric Palliative Care Service, Royal Children's Hospital, Brisbane, Australia

⁵ Disciplines of Paediatrics and Child Health, School of Medicine, The University of Queensland, Brisbane, Australia

⁶ Nursing Research, Royal Children's Hospital, Brisbane, Australia

Introduction

Caring for a child receiving palliative care at home can be a daunting and socially isolating experience for the child and family, particularly during a protracted palliative phase. In this case study we present our experiences with using Internet based video calls to provide both clinical care and therapeutic 'clown care' for a child receiving palliative care at home.

The system

The University of Queensland's Centre for Online Health has been working with the Queensland Children's Cancer Centre since 2003 to investigate how technology can be used to support children and their families with cancer. Internet based video calls require only a laptop, iPad or personal computer, a web camera and an Internet connection. While protocols must be followed to ensure patient and clinician confidentiality and privacy, the use of Internet based video calls can be as easy as making a standard telephone call for clinicians and families.

Case Study "Sophie"

Sophie, a seven year old girl, was referred to the Paediatric Palliative Care Service (PPCS) with a hepato-pulmonary syndrome post stem cell transplantation. At the time of referral to the PPCS, it was unknown how long Sophie had to live, but it was estimated to be months rather than years. Sophie was bed bound and moving her was difficult. She required oxygen continually and around the clock cares. Sophie's condition had however reached a plateau and it became evident that she was stable at this new level of functioning.

While telephone contact with Sophie's treating physician and liaison nurse had been maintained, Sophie had not returned to the hospital for several months. Visits for ongoing medical review had proved extremely challenging and the alternative of support by Internet video calls was welcomed by both the family and health care team.

Sophie and her mother were excited to see the team that had looked after them for so long in the hospital during their first video call. Discussions of Sophie's conditions focused on her current symptoms and their management. The video call consults continued each fortnight and gave Sophie's mother easy access to the specialist doctors and nurses at the hospital she had come to rely upon throughout Sophie's treatment.

However, it was the hospital Clown Doctors™ provided by the Humour Foundation, a national

charity that were able to offer Sophie the emotional and social support she was in need of. The Clown Doctor™ links became the highlight of Sophie's week as songs were sung and jokes told while the Clown Doctors™ performed their antics and were 'streamed' into Sophie's bedroom. Sophie enjoyed interacting with them, requesting favourite stories and songs.

Over a twenty-four month period, 72 video calls were conducted between Sophie's home and the hospital. Clinical care, including management of symptoms, anticipated changes in the Sophie's condition and emotional support were able to be provided to Sophie's caregiver through video calls. However, the majority of the video calls (54, 75%) were not for clinical purposes, but made with Clown Doctors™, who formed a unique relationship with Sophie through song, dance and shared laughter. The power and strength of this relationship, forged through video calls, was realised as Sophie's condition deteriorated and the Clown Doctors™ played an integral role at the end of life. The Clown Doctors™ sensitively modified their interactions, moving to gentle versions of favourite songs, story telling and shortened their video visits. Sophie's mother believed it was the Clown Doctors™ who best knew her girl, they knew the joy and cheekiness, and so it was the Clown Doctors™ who were asked to carry Sophie's casket and sing at her funeral, ensuring it was a celebration of life that Sophie would have enjoyed.

Conclusion

Paediatric palliative care includes the physical, emotional, social, and spiritual care of the child and their family. This case study illustrates the importance of the emotional and social aspects of care, and provides an example of how these can be facilitated at a distance using telehealth.

