The Use of Social Media in a Palliative Care Research Centre

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Introduction

Online communities are full of discussions about illness, death and dying and these communications are increasingly repositioned within research environments as sources of publically available data. As a palliative care research centre, we have been keen to embrace social media within our research work, however, with no definitive set of ethical or practical guidelines we have been unsure of how best to proceed. The centre thus initiated two consensus days to construct a workable, ethical framework for future research in the field.

Aim(s) and method(s)

Researchers within the centre, and two external experts in online research, met to focus on constructing a set of ethical guidelines. Issues of confidentiality, anonymity and informed consent were all discussed.

Results

A framework for social media research was constructed, the guiding principles include:

- Recruitment of participants should be transparent with adequate opportunity for participants to ask questions.
- Information sheets should be provided and be clear about confidentiality issues that are specific to online research.
- Consent should always be taken from participants for the use of their online communications as research data.
- Potential anonymity issues in dissemination of research must be highlighted to participants.
- The use of historical text is considered problematic and therefore not encouraged.

Closed forums created specifically for research purposes are considered to be the most appropriate way to conduct online research.

Conclusion(s)

Social media has the potential to be of benefit to palliative care research; however, it is important that ethical principles in relation to this medium are fully considered, and guidelines in place, prior to the commencement of research.