Student: Claire Whitehead

Project: Measuring a 'good' death in CDHB

Supervisor: Dr Kate Grundy

Sponsor: Canterbury District Health Board

Introduction:
Measuring patient outcomes in death is difficult and usually involves retrospective interviews or questionnaires of health professionals and patients families.

However, there are often discrepancies within and between groups which makes interpretation difficult, as well as bias towards personal experiences with death which may differ from the patient. These personal and varying viewpoints around death mean that there is only really consensus on the broader themes of what constitutes a 'good' death, including; physical, cultural, spiritual and emotional aspects.
When it comes to teasing these out, there is much discussion about what is important. Current literature suggests that a 'good' death is when these physical, spiritual, emotional and cultural aspects of both the patient and their family are considered and observed both during and after death.

Aim:
To test and refine an audit tool developed to capture physical, spiritual, cultural and emotional aspects of patient death, particularly expected death. Once validated, this tool will be used for all deaths within CDHB, with the ultimate goal of being able to measure the quality of death for patients who die in Canterbury.

Method:
In 2015, an audit tool was developed within the oncology department, Christchurch Hospital. Category of death definitions were also developed by the palliative care department, expanded and refined from a tool used by the Royal Brisbane hospital. This tool enables deaths to be classified into eight categories. Both the audit tool and category of death tool were then tested and refined on all deaths in Christchurch Hospital over November/December 2015.

The tool was also tested on a subset of deaths within the Nurse Maude Hospice, Christchurch and two selected Aged Residential Care (ARC) Facilities.

Throughout this process, the tool was refined as additional information was elicited from case notes and non-discriminatory information was removed. This was done by a process of continual review and discussion between the author and two palliative care physicians, with consensus being required before changes were made.

Results:
Three tools have been produced, one each for hospital, hospice and ARC. The hospital tool has 34 items and the hospice and ARC tools have 29 items, in addition to demographic information. Each item is binary (0,1) coded, with 1 indicating a positive outcome. This allows for a higher score to indicate a death that has addressed more of the items identified from the literature that suggest a 'good' death.

The admission is split up into two parts-the first being the 48 hours before death (hospital and hospice tools) or 5 days before death (ARC tool). This difference in timeframe was because information from this section was not being captured in the 48 hour period prior to death in ARC. Aside from this timeframe, the hospice and ARC tools were the same.

The second part of the tool reviews the remainder of the admission to hospital/hospice/ARC. The differences between the hospital and hospice/ARC tools is the removal of some hospital specific information, such as Early Warning Score (EWS), which were not relevant to these settings. Through the refining process, much data was collected. This data was used to decide which items were providing discriminatory value and those which were to be removed or refined. For example, the nausea/vomiting outcome was not coded highly, yet anticipatory prescribing regarding nausea/vomiting was. It was decided that these were likely coding for the same things and so the low scoring nausea/vomiting was removed.

Language also needed to be refined to incorporate all the different language used by both the patients and health professionals recording the information. For example, in the fear or anxiety around death item, patients may have expressed that they had 'no regrets' about dying or felt 'afraid to go' which needed to be included as it is important that this information is able to be captured.

For ease of use and to provide explanation, a user guide was written to accompany each tool expanding on some of the intricacies of items. From collected data, categories of death were generalised into expected and unexpected deaths. Hospice (n=9) and ARC (n=22) information was analysed together as there was considerably less data than the hospital (n=112). Comparisons between expected and unexpected hospital deaths were significantly different (Z=1566, p<0.01) with expected deaths having higher scores. There was no significant difference between the hospital and community expected deaths (Z=1201, p=0.52). The data also indicated that physical aspects of dying are well documented whereas advance care planning, preference of place to die, bereavement care of the family and spiritual needs were not well documented. Documentation error may be the cause for some of these discrepancies and this may need to be addressed in order to make sure that outcomes are being recorded, to avoid artificially low scores.

Conclusion:
This study is different to much of the research on death and dying. While many studies retrospectively interview patients' families and healthcare workers, this study used case notes of deceased patients. This tool, when applied to all deaths, will provide a dataset from which further analysis of subgroups can be undertaken.

This provides the opportunity to focus on aspects which are not as well documented and to evaluate how to improve these outcomes to improve quality of death. Future research could analyse ARC and hospice separately and look at differences between the three settings.

The information gained from this tool will allow improvements to be made in both hospital and community settings so that a 'good' death can be achieved by all.