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Vigilant attentiveness in families observing deterioration in the dying intensive care patient: A secondary analysis study

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Summary
Background: Family support in intensive care is often focussed on what information is communicated to families. This is particularly important during treatment withdrawal and end of life care. However, this positions families as passive receivers of information. Less is known about what bereaved family members actually observe at end of life and how this is interpreted.
Aim: Secondary analysis study was conducted in order to explore the concept of vigilant attentiveness in family members of adult patients dying in intensive care.
Method: Secondary analysis of eight interviews sorted from two primary data sets containing 19 interviews with 25 bereaved family members from two intensive care units in England was undertaken. Directed content analysis techniques were adopted.
Findings: Families are observant for physiological deterioration by watching for changes in cardiac monitors as well as paying attention to how their relative looks and sounds. Changes in treatment/interventions were also perceived to indicate deterioration.
Conclusion: Families are vigilant and attentive to deterioration, implying that families are active participants in information gathering. By clarifying what families notice, or do not notice during the dying trajectory in ICU, health care professionals can tailor information, helping to prepare families for the death of their relative.

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Implications for Clinical Practice

- The quality of information given to families and the understanding of families about death and dying impacts on health outcomes of bereaved family members. It is important that families are prepared and informed about death and dying in intensive care.
- The concept of 'vigilant attentiveness' can inform how doctors and nurses assess family understanding and comprehension of deterioration at end of life.
- By asking pertinent questions about what families notice, and do not notice about their relative at end of life, health care professionals can refine their communication style, tailoring the information provided to family members in preparation for death.

Introduction and background

Effective communication between health care professionals and family members of dying intensive care patients is an essential component of high quality end of life care (Treece, 2007). Poor communication with families has been identified as contributing to: family anxiety and depression post death (Scheunemann et al., 2011); lower levels of family satisfaction with care (Wall et al., 2007); low levels of family comprehension regarding the patient's condition (Azoulay et al., 2000; Rodriguez et al., 2008), and conflicts between family members and health care team (Fassier and Azoulay, 2010).

Communication with families is an essential, if frequently under-appreciated aspect of the critical care nurses' role (Lind et al., 2012). Nurses act as information brokers and communication facilitators (Bloomer et al., 2013), and use communication to build relationships with families enable the support of families (Slatore et al., 2012). It is therefore unsurprising that Adams' et al. (2015) call for further work to be conducted on how nurses work with families in order to understand the communication processes used in critical care settings.

This would clearly meet the needs of families as studies report that family members want more frequent and effective communication with nurses and doctors (Pochard et al., 2005) especially in relation to end of life care (Breen et al., 2001); this includes involvement in shared decision-making about treatment decisions at end of life (Arnold and Kellum, 2003; Azoulay, 2005; White et al., 2007). However, literature on the experience and communication needs of family members at end of life focusses on the role of the health care professional in assessing family information needs (Luce, 2010) and providing information whilst managing family expectations (Curtis and White, 2008). This focus may lead to the perceptions that family members are passive receivers of information, largely unaware of the progress of their relative (Azoulay et al., 2000).

However, there is literature suggesting that family members are active seekers of cues or signs as to what is happening to their relative, and that family members in intensive care are in a state of vigilant attentiveness described as ''a focussed, persistent, and diligent watchfulness'' (Bournes and Mitchell, 2002, p:62). Although the concept of vigilant attentiveness was originally developed to describe family members' experiences of being in an Intensive Care waiting room, this concept engaged and stimulated our thinking. This prompted us to consider 'testing' this concept in relation to families' awareness of deterioration in their dying relative.

Study design

A secondary analysis was undertaken to explore the concept of vigilant attentiveness in family members of adult patients dying in intensive care. The dataset for this study was generated from two primary studies that interviewed bereaved family members in the context of family experiences and end of life in the intensive care environment.

Secondary analysis is an approach of generating new knowledge from existing data sources. Whilst secondary analysis of primary data is a familiar concept within the positivist paradigm (Fielding, 2004), it is less common in the naturalistic paradigm. Unlike the re-use of archived data, secondary analysis of data suggests that data has a contemporary relevance and is therefore carried out for specific reasons. Secondary analysis offers many benefits to researchers including the: generation of new knowledge from existing datasets previously analysed (Long-Sutehall et al., 2010); opportunity to apply a new perspective or a new conceptual focus (Heaton, 1998) in preparation for further research; enabling of training and development for novice researchers (Glaser, 1963). Furthermore secondary analysis is of particular ethical and economic value if the topic under investigation is of a sensitive nature (Fielding, 2004), for example, family experience of death and dying.

Study methods

Prior to undertaking data analysis, the original datasets were assessed to determine whether data had potential to address the research aim (Heaton, 2004). A quality assessment was undertaken by sorting data from the two primary studies that had interviewed bereaved family members.

Primary datasets

Study One: Coombs et al. (2012) Challenges in transition from intervention to end of life care in intensive care: a qualitative study.

Study One completed in-depth interviews with 33 health care staff ($n = 26$) and relatives ($n = 7$) of 18 non-survivors in two intensive care settings (general adult ICU, cardiac ICU) in England. The 18-month study (2008—2009), funded by the Research for Patient Benefit Fund, aimed to investigate