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Communication of the death of a patient in hospices and nursing homes: A qualitative study

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ABSTRACT

Purpose of the research: Announcing the death of a patient to another in hospices and nursing homes (NH) requires special skills, especially when the recipient is another resident. The aim of this study is to describe how hospice and NH staff deal with the communication regarding a patient's death, if this communication is perceived as a problem, and strategies implemented.

Methods and sample: The 55 health care workers (HCWs, 26 nurses and 29 auxiliary nurses) of two NHs and two hospices in Turin (Italy) were interviewed with a semi-structured interview exploring the residents' perception of need to receiving information on another patient's death, the experiences of having given this information in the last 6 months, and the strategies implemented. The interviews were analyzed using Colaizzi's method and researchers looked for the main themes and related subthemes.

Key results: Six themes were identified and grouped into 2 main themes: a. the choice to tell the truth or not, which may be influenced by: the patients' request for confirmation of the fate of the other resident, by patients' fear of death ("I will be next"), the relationships among the guests, and personal and group experiences; b. the need to share own feelings and the burden of deciding whether or not to inform the other residents and how to go about this.

Conclusions: If a structured discussion of experiences and reflection on cases is not implemented, HCWs may limit communication to bare information, lies, and adopt behaviors of avoidance and concealment.

Introduction

Since the concept of "awareness" was introduced to describe the nature of communication between patients at the end of life and their caregivers, radical changes as to hospital policies and medical practice have occurred and in most cases the diagnosis and less frequently the prognosis is communicated to cancer patients (Mack et al., 2012). Among the places of care where people live the final stages of their disease, hospices and nursing homes (NH) are becoming increasingly relevant (Carlson, 2007; Hall et al., 2011). According to the Italian Survey of the Dying of Cancer (ISDOC) study 0.7% of these deaths occur in hospices, 6.5% in NHs and in Piedmont (Italy) the percentage rises to 16% (Beccaro et al., 2006). In places such as NHs and hospices the contact with death cannot be avoided, and since most residents are old or in advanced stages of illness, they are inevitably confronted with the thoughts regarding their own death (Payne et al., 1996), or with intense and emotionally charged situations such as the death of a roommate or resident in the next room (Shelvington, 2007).

Even if the palliative care model has contributed to improving communication on the death issue, resistance to talk about death is still hard to overcome (Bryan, 2007) and people, including HCWs, are not prepared to face this issue (Carlson, 2007).

The communication of bad news, including the death of another patient is very awkward because both patients and HCWs are faced with an event which is likely to occur in the near future. This is why some HCWs adopted avoidance strategies, which eventually distanced them from the patient (Costello, 2001, 2006; Shelvington, 2007). The attempt to describe how the information of death of a patient to another is dealt with may be the first step to improving this communication. While the communication of bad news, such as the diagnosis of cancer, the worsening of clinical conditions and non responsiveness to treatments have been widely addressed in the literature, (Balaban, 2000; Buckman, 1992; Griffie et al., 2004)

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the communication of another patient's death was explored only indirectly in studies on the impact of patients' deaths. The impact of witnessing the death of a roommate in a hospice was assessed (Honeybun et al., 1992); although only exploratively, due to the limited sample size (20 patients), the study highlighted that witnessing death was not necessarily a stressful and anguishing experience: five of the eleven patients that experienced this event considered it stressful, but the others reassuring. In a similar study conducted in a palliative care unit (67 patients) it was concluded that patients were aware of the death of others, and those who witnessed a death in the same palliative care unit were significantly less depressed than those who did not experience such an event, even though conflicting feelings (stress and reassurance) were reported (Payne et al., 1996). However, the sample was very limited, one third of those contacted refused to participate in the survey, and having collected the data in only one palliative care unit further limited the results. More recently Shelvington (2007) suggested some implications for nurses managing patients who had witnessed the death of another patient, focusing also on the importance of the environment, the choice of the room (single or double), respecting the patient's wishes and protecting caregivers.

While open communication, not only about disease, but also about death and dying is common in hospices (Payne et al., 1996), information on how it is dealt with in NHs is not available. To our knowledge, so far no studies have explored how HCWs perceive the patient's need of information and how they deal with it.

Aims

The aim of the study was to describe the experience of nursing home and hospice HCWs in delivering information of a patient's death to another patient and comparing the strategies adopted.

Methods

Study design

A qualitative study, using Colaizzi's phenomenological method of data analysis (Streubert Speziale and Carpenter, 2005) was conducted.

Study sample

The study involved all the nurses and auxiliary nurses working in four units (one for each setting) of two nursing homes and two hospices in Turin, who consented to being interviewed, and had cared for at least one dying patient in the last six months. Auxiliary nurses were also involved because in NHs they outnumber the nurses and spend more time than the nurses in helping the patients (in hospices the situation is the opposite), thus they are more likely to receive requests for information. Participation was voluntary, anonymity was guaranteed and authorization was obtained by the medical directors of NHs and Hospices.

Settings

The study was conducted in 2 NHs and 2 hospices (a NH and a hospice are in the same building). Both NHs have 24 bed units, with double rooms, with the same nursing personnel rotating through two units on the same floor. Hospice A (14 beds) was opened in 2000, the first in Turin; hospice B (10 beds) in 2008. Both have only single rooms where a caregiver can be hosted for the night. In NHs and hospices there are spacious common areas such as living and dining rooms. In the first hospice planned meetings such as briefings, handovers and staff supervision are organized and HCWs are selected after a six month trial period, in the latter and in the NHs only handover is a planned time for communication.

Data collection

Data was collected using semi-structured interviews with the entire hospice staff and the two NH units. The units selected were those with less HCWs turnover and with the lowest number of dementia patients. The interview guide was based on the literature. The open ended questions explored the following areas: the residents' perception and need to receive information of the death of another patient, experiences of communication of the death of a patient in the last 6 months, strategies used in dealing with patient's questions, behaviors commonly adopted and the presence or need for protocols to deal with this kind of communication. The study was presented to the team. The interviews were scheduled during working hours, in a quiet environment without interruptions; they were recorded and fully transcribed.

Method of analysis

The interviews were analyzed according to Colaizzi's phenomenological method (Streubert Speziale and Carpenter, 2005): each interview was read several times, the main themes were then identified, and those recurrent extracted and grouped into main areas. Two researchers conducted the analysis independently and disagreements of classification discussed at the end of the analysis. The list of the main themes was identified and agreed upon by both and secondary themes were extracted only if recurring in at least one third of the interviews.

Before analyses, the transcript of the interview was mailed to the participants asking each one to validate the contents and to add further reflections, if deemed necessary. The list of themes was shared and discussed with participants during a meeting and the final document with the main and secondary themes was sent to each participant for additional comments. Three participants added some comments but no new themes were added.

Results

All the 55 nurses and auxiliary nurses accepted the interview. Each interview lasted about 20 min (range 8–30 min). The sociodemographic characteristics of respondents are shown in Table 1

Six themes were identified and grouped into 2 main themes: *to tell the truth or not*, which is influenced by the patient's need to know (*request for confirmation*), his/her fear of death ("*I will be next*"), the acknowledgment of bonds between residents (*the relationship among the residents*) and by personal experience, which shared with colleagues, may modify the attitude towards communication (*hiding and unmasking*). The second main theme is *the need for sharing* the responsibility and burden of the choice of communicating such bad news to a patient.

To tell the truth or not

Two thirds of the participants (38) were convinced of the importance of informing residents of a death if specifically asked, with no differences between nurses and auxiliary nurses. The majority of interviewees (22 auxiliary nurses and 17 nurses) in the previous 6 months had to deal with the request for information of a patient's death, and auxiliary nurses received even more requests from residents. However, the truth needs to be adapted by taking into account the resident's fragility and his/her relationship with the deceased person. For 25 participants the communication should be reassuring or gradual, and delivered in steps (13 NH and 12 hospice staff).