



Relatives' participation at the time of death: Standardisation in pre and post-mortem care in a palliative medical unit[☆]



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A B S T R A C T

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Purpose: The aim of this study was to illuminate the development of standardisation of relatives' participation at the time of death in the Palliative Medical Unit and to explore if the implementation of standardisation brought palliative care more in line with its ideology.

Methods: A registration form was developed and utilized by the Palliative Medical Unit nurse in charge of the patient and family to register to what extent relatives participated at the time of death. The study consists of two data sets named evaluation 1 and 2. Evaluation 1 includes data collected during the period 01.11.1995–31.12.1999, representing 73% of all deaths ($N = 244$). Evaluation 2 includes data collected during the period 01.01.2003–31.12.2009, representing 71% of all deaths ($N = 400$). The data was analysed in SPSS, covering primarily the frequency of participation and correlation between evaluation 1 and evaluation 2.

Results: Relatives are more often present at the moment of death, while nurses are less present at this moment. Additionally, Palliative Medical Unit nurses use more time to inform and discuss relatives' participation in pre and post-mortem care, as well as making agreements with relatives after death occurs.

Conclusion: Important premises for successful standardisation are fostering Palliative Medical Unit nurses' knowledge about various aspects of pre and post-mortem care through regular evaluation and an educational programme providing staff with necessary time, awareness and skills. In addition nurses also require sufficient amount of time in the clinic.

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Introduction

In this paper we describe the process of implementation of clinical practice guidelines over time in pre and post-mortem care in the oncological Palliative Medical Unit (PMU). The general aim of our paper is to determine if implementation of standardisation brought palliative care more in line with its ideology. Our main focus is relatives' participation at the time of death. In Norway hospital pre and post-mortem care has been criticised for excluding relatives (Wergeland Sørbye, 1994). In the wake of the hospice movement and with greater focus on palliative care in Norway, doors have gradually been opened and relatives invited to

participate. In fact, giving time and space to the family at the time of death of a loved one at Trondheim University Hospital PMU has become a standard procedure (Hadders, 2007, 2009, 2011). Nurses strive to involve the family in leave-taking events such as, 'the moment of death', 'laying out' of the deceased body, dressing, and viewing the deceased.

At the terminal stage and during post mortem care in the PMU, staff, patients and relatives are intrinsically linked to each other. At this time most patients are cognitively impaired, sleeping, in some cases sedated or biologically dead, and thus we are not dealing with patients' experiences, or patients' direct agency here.¹ The social identity, personal integrity and wishes of these patients depend on staff and relatives for safeguarding and maintenance (Hadders, 2011; Bremer et al., 2009; Hallam et al., 1999; Hockey, 2008;

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¹ Deep and continuous palliative sedation, so called terminal sedation, was given to approximately 1% of the patients in the PMU at the Norwegian hospital in question (Førde et al., 2008; Guidelines of the Norwegian Medical Association on Palliative Sedation, 2001).

Horne et al., 2012; Kabel and Roberts, 2003; Lawler, 1991; MacRae, 2010; Mossin and Landmark, 2011; Valentine, 2007, 234).

In Norway *The law on patient rights (Pasientrettighetsloven)* specifies who is to be considered next of kin (§ 1 – 3), and specifies the rights relatives have to obtain information about their relative's treatment in the clinic as follows (§ 3 – 3); 'When patients consent and when conditions vouch for it, the patient's nearest relatives shall receive information about the patient's health and the treatment given' (HOD, 1999a). According to the law patient's nearest relatives are persons defined as such by the patient. Norwegian health care is public and built on equity which entails equal access to services with the same standards and quality for all.

Palliative care and grief support: a brief background

For more than three decades there has been a steady growth of what Tony Walter called a revivalism concerning end-of-life care and death. In *The revival of death* (1994) he discussed the increased interest in death and dying that has emerged in the 'western' world. The application of this kind of revivalism has taken place mainly within the hospice movement and, more broadly within palliative care. The revivalist movement critiqued modernity and what it saw as the overly institutionalized, medicalized, de-humanized and technological way of dying within modern health care, leading to the disengagement of relatives (Illich, 1976; Moller, 1990, 2000; Seale, 1998).

The application of palliative care entails a clinical shift from cure to comfort. Central concerns within the hospice movement and palliative care are to control symptoms and to provide patients with an encompassing care which also includes relatives. Palliative care and medicine is a discipline which emerged as a logical extension and further development of the ideas within the hospice movement (Clark and Seymour, 1999; McNamara, 2001). The ideology of so called 'good death' has served as a central philosophical concern and standard within the hospice movement and palliative care (McNamara, 2001, 45–53). One of the elements of 'good death' in this context is fostering an open acknowledgement of the imminence of death, where the dying person is surrounded by family and friends (Clark, 2002, 907).

With greater focus on palliative care in Norway, relatives of the deceased are more often invited to participate at the time of death. In contemporary Norwegian society approximately 80% of the population die in hospitals or in some other type of health care institution. In 2012, 32.5% died in hospitals and 47.5% in some form of nursing home or other geriatric institution. 14.5% died at home and 5.5% died at other places (Statistics Norway, 2013). Mossin and Landmark report that 50% of cancer patients in Norway die in a hospital. The authors highlight the importance of relatives' presence when a patient is dying in the hospital (Mossin and Landmark, 2011).

At Trondheim University Hospital it has become standard practice to provide time and space for relatives at the time of their loved one's demise and the immediate aftermath of death. The procedure manual concerning the management of patient death on all wards at Trondheim University Hospital regulates the post-mortem care at the PMU (Hadders, 2009). In accordance with these guidelines, nurses generally attempt to include and accommodate relatives at the death watch of their beloved ones, at the time of death and at the subsequent viewing of the deceased. One of the driving forces for this practice standard, the wish to include relatives in leave-taking events, is to help relatives face the reality of death and assist them in their bereavement, in order for them to be able to accept the reality of death on their own terms. The tenet of grief support, anchored in palliative care ideology, is included in the general procedure

manual for death at Trondheim University Hospital (Hegvik et al., 2010; Mossin and Landmark, 2011; Walter, 1999; Worden, 1991). It is also included in a small information folder published by the Norwegian Directorate of Health, routinely distributed to all bereaved relatives by the nurses at the Trondheim University Hospital (Bergh, 2004:4). Furthermore, involving relatives at this time is also an outcome of the late-modern trend to celebrate the social identity of the deceased (Eschenbruch, 2007, 105; Hallam et al., 1999; Seale, 1998).

The aspiration to assist the relatives in their 'grief process' often hinges on a modernist understanding of a normal and proper universal grief pattern, which the mourners have to 'work through.' Since Sigmund Freud wrote *Mourning and Melancholia* (Freud, 1917), such 'grief work' has typically been understood to result in 'leaving the deceased behind', terminating the relationship with the deceased person. However, in recent decades the value of continuing the bond with the deceased has been increasingly documented and acknowledged by academics as well as in the clinic (Wortman and Silver, 1989; Walter, 1994, 1999). Several authors have underlined that the variety of rituals and actions following the death of a family member may contain aspects of separation as well as aspects of continuation of the social relationship with the deceased (Danbolt, 2002; Walter, 1999; Valentine, 2008; Hadders, 2011).

There is a growing body of research exploring relatives' experiences of being present at the time of death in the hospital setting. This research suggests that accommodative staff behaviour, emotional support and communication are fundamental to the experience and facilitates bereavement (Kwan Wai Man, 2002; Eriksson et al., 2006; Masson 2002; Donnelly and Battley 2010). Williams et al. underscore that family presence at the time of death of a loved one is a quality marker of end-of-life care. Among other things, they highlight keeping the family informed, providing reassuring attentiveness, being a compassionate presence, facilitating final acts of leave-taking and honouring the dignity of the deceased (Williams et al., 2012).

Theoretical approach to standardisation

Discussing standardisation in health-care, sociologists Timmermans and Berg point out that the etymological root of the word *standard* implies power; 'Originally a standard referred to a conspicuous object (such as a banner) carried at the top of a pole and used as a rallying point, especially in battle, or as an emblem' (Timmermans and Berg, 2003, 24). In other words, standards are ideals enforced in practice by legitimate agents. Generally Timmermans and Berg define standardisation as the process of making things uniform with various tools and policies. In their discussion they deal with the means as well as the outcome of standardisation. Standardisation in health care involves personnel with a legitimate mandate to implement certain clinical standards with the help of standardisation tools. Such standards are based on fixed criteria which safeguard a certain quality level of services rendered. However, it is important to underscore that the process of standardisation is not necessarily one-way and top-down. The dynamics of standardisation in process are complex. Timmermans and Berg argue that 'the generative power of procedural standards thrives on the local expertise the nurses and doctors develop in their interaction with these tools – and vice versa.' Standardization does not necessarily result in an obedient workforce, accomplishing their tasks in a rigid fashion (Timmermans and Berg, 2003, 78). Late-modern Norwegian standardisation of hospital death is embedded in material, social, legal, ethical, aesthetical and economical practices – at collective as well as individual levels.

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