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#### CRITICAL REFLECTION ON PRACTICE DEVELOPMENT

Facilitating person-centred after-death care: unearthing assumptions, tradition and values through practice development

### **Barbara Anderson**

West Park Healthcare Centre, Ontario, Canada Email: <a href="mailto:Barbara.Anderson@westpark.org">Barbara.Anderson@westpark.org</a>

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### **Abstract**

*Background:* West Park Healthcare Centre, a complex continuing care and rehabilitation setting in Ontario, Canada has implemented practice development as one method of facilitating person-centred, evidence-informed practices. West Park is planning the construction of a new hospital, with a target construction timeline of 2018-21. Practice development is an internationally established transformation model (Manley et al., 2008) that can breathe life into the necessary but often burdensome process of policy revision in healthcare settings.

Aims: The aim of this article is to share how practice development was used to review and revise West Park's after-death care policy. The process entailed an integration of a broad span of evidence and intentional challenge of 'habit-based' ways. Such an approach to policy revision is needed if practice leaders are to use evidence to help achieve transformative changes in practice.

Conclusions: Our after death-care policy involved processes that were antithetical to our shared vision for person-centred practices. Unquestioned, longstanding traditional approaches to after-death care needed to be questioned. Through the transformative journey at personal and organisational levels of applying practice development principles to this process, we were successful in bringing forward a policy that supports end-of-life plans of care, choice and person-centred after-death care practices and language.

#### *Implications for practice:*

- Healthcare organisations can review after-death care by exploring different sources of evidence, including research, clinical experience, local audit and patient experience, to challenge takenfor-granted practices
- Consultation with funeral professionals will be valuable in terms of establishing what they do and do not need from a healthcare organisation
- Fellow patients do not need to be 'protected' from the after-death care process and appreciate having a voice on how it is carried out
- Respect for language, religious and cultural issues is part of offering a 'sympathetic presence' in after-death care practices

**Keywords**: Practice development, person-centred practice, after-death care, language, culture change, policy

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#### Introduction

The person-centred framework developed by McCormack and McCance (2010) was used to examine the care of persons who die in the West Park Healthcare Centre, including related policies and processes. The prerequisite traits of nursing staff and characteristics of the care environment were explored to identify factors that were either facilitating or impeding person-centred after-death care. Factors were revealed through a series of activities to raise consciousness and critically examine the experiences of staff who have cared for persons who died. These experiences were integrated with evidence from research, patient experiences and local audit to underpin revisions to the treatment of the body of someone who has died at the centre (Rycroft-Malone et al., 2004).

West Park's traditional approach to policy work may have historically involved limited stakeholder engagement and the application of a narrow range of evidence, resulting in taken-for-granted practices and traditions going unchallenged. The approach to policy work is task oriented. On the other hand, a practice development approach to policy work involves broad stakeholder engagement that is inclusive, participative and collaborative – all key principles (Manley et al., 2008). It also involves consideration of the nature of the evidence in terms of breadth and comprehensiveness, including research, clinical experience, local audit and patient experience.

Using this approach to policy revision enabled us to identify the values, beliefs, ideologies and interests that are facilitating or inhibiting person-centred after-death care practices. It made us step back from what appeared to be acceptable after-death care practices (for example, shrouding and toe tagging) and to ask how these practices evolved. This helped us to identify and address the diverse factors that influence person-centred after-death care at individual and organisational levels.

### Exploring 'evidence' differently

As a starting point to our policy revision, we reviewed the literature to locate 'best' practices in after-death care based on research. In their research Quested and Rudge (2001, 2003) examined the use of language in after-death care policies. They found that the language used can depersonalise the deceased person with references to 'the body' and/or 'the remains'. They also noted that discussion of preferences for care after death and the need for an end-of-life plan of care are not addressed in policy (Quested and Rudge, 2003). The procedures in after-death care policies are often specified and reinforce unquestioning compliance and conformity on the part of the nurse, and of the patient and his/her family or significant others.

Furthermore, Quested and Rudge (2001) analysed how the perspectives of the healthcare system, including concerns regarding medicine, infection control and law, as well as wider societal views of death are reflected in policy. They contend that:

'Tension arises from the differing pulls between the medico-legal milieu of death in an acute care institution and the social and emotional context of the death of a person for their family and nursing staff' (p 264).

The stance of Quested and Rudge (2001, 2003) is that nurses, consciously or unconsciously, have their care shaped and constrained by after-death care policies. The routinisation of after-death care practices may result in a lack of emotional reactivity on the part of nurses. Nurses practice in a subordinate position to medicine, infection control and law, as well as to organisational power structures that define their work; they have to deal with the effects of decisions largely made by others (Traynor, 2014). A lack of person-centred nursing care after death may be due to oppressive professional dominance (Johns, 2010). This led us to seek to understand nurses' experiences and feelings about after-death care.

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# **Clinical experience**

Claims, concerns and issues (CCIs) groups, using a fourth-generation evaluation approach (Guba and Lincoln, 1989) were facilitated in complex continuing care with registered nurses and personal support workers to identify factors that were either facilitating or impeding person-centred after-death care within the context and culture of the care setting (see Table 1). In reflection on the CCI evaluation from an emancipatory practice development perspective, it could have been beneficial to have included the service managers, unit clerks and housekeeping staff in the CCI groups, recognising the significant role they have in patient care.

Claims are favourable assertions about the topic under evaluation, concerns are any unfavourable assertions about the topic, and issues are questions that might be asked about the topic, which usually arise from concerns. When identifying the issues, the approach is to ask 'how' and 'what' questions. CCIs are used as a systematic approach to evaluation to guide the development of an action plan for quality improvement work. Koch (1994) describes the process of fourth-generation evaluation as one that does not result in conclusions or a set of recommendations, but rather facilitates the identification of an action plan for issues that have not been resolved.

Factors identified that facilitate person-centred after-death care included a 'sympathetic presence' (McCormack and McCance, 2010) with the patient and family, and attentive care of the body of the person who is deceased. Staff spoke about shifting practices, with the use of the person's own or chosen clothing, and having funeral professionals come to the unit. The CCI process helped staff begin to reframe what constitutes acceptable after-death care practices.

Factors identified that hinder person-centred after death care included: moral distress with shrouding; a negative morgue experience; the use of language; religious and cultural differences; and the experience of other patients. A number of responses reflected emotions evoked by the use of a shroud. A picture of a negative morgue experience was evident through responses, depicting a cold, frightening and impersonal space. Staff were also aware of the use of language, holding a preference to hear and use the person's name instead of 'the body'.

Nurses identified the need for staff education to support compassionate person-centred care for the person who is dying, including after-death practices. They spoke about not being clear how to address various religious and cultural preferences. Issues were identified in the form of 'what' or 'how' questions to help staff focus on needed improvement work.

The staff also spoke about the impact on other patients on the unit when one of their 'friends' dies. There is no openness about the person's death – it is treated with secrecy, starting from curtains being drawn around the bed. The other patients are left to suffer in silence and grieve the loss. This led us to seek to understand the patient experience with after-death care.

# Table 1: Claims, concerns and issues

#### **Claims**

#### A sympathetic presence

- We provide gentle care of the body
- We wash the body with dignity
- We respect the body, ensuring a tidy, natural position and use of clothing or gown
- We still say the name of the person
- We sit with the family and explain what is happening
- We comfort the family by staying with the family, use of words, giving something to drink
- Staff are gracious and attentive to the family and their needs
- We spend time with the family and give them time to process the information
- Longstanding relationship that the staff have with the family

#### Shifting practices

- · We have dressed the deceased person in special clothes/own clothes when arrangements are known
- We have arranged for funeral home staff to come directly to the unit

#### **Concerns**

#### Moral distress with shrouding

- It is difficult to put them in a piece of plastic; it's a human being, it's really scary, it's an emotional hit and very sad
- I have goosebumps with shrouding
- Discomfort with placing the deceased person naked into the shroud
- The shroud is opened to identify the deceased person when they are naked, it is disrespectful
- · Alternatives to shrouding

#### Negative morgue experience

- Staff have dealt with the patient for a long time, knowing the patient taking the patient away to the morgue causes sadness for the staff. You close the door to the morgue fridge and feel the emotion, say goodbye the patient is family to you
- The morgue is scary, ice-cold, dark
- Darkness I feel afraid even going into the corridor
- No attractiveness in the morgue it should be warm a better feeling

### The use of language

• We have known the patient for years – discomfort with hearing 'the body'

#### Religious/cultural preferences

- We are not clear how to meet religious needs
- There are different faiths we don't know what to do
- Not knowing cultural differences

#### **Experience of patients**

- Wellbeing and emotional response of patients
- Impact on other patients in the room
- Fearful for other patients seeing the transport of the body
- Journey to the morgue is frightening to other patients they know
- Patient expires and is in the room for hours with the curtain drawn there is silence other patients are given
  permission to leave the room patients need to come to their room

#### **Issues**

- How can we better understand patient and family preferences for after-death care?
- How can we better understand religious and cultural preferences?
- How can the teams be supported in developing end-of-life plans of care?
- What are the alternatives to shrouding?
- What alternatives exist to the morgue experience?
- How can the morgue space be made more aesthetically supportive?
- How can we meet the educational needs of staff related to end-of-life care?
- How can other patients be better supported?
- What would support look like for staff in dealing with their own emotions related to after-death care?

# **Patient experience**

Patient focus groups were held to understand the patient experience of after-death practices and to engage them in the policy revision work. Patient feedback included that:

- They would like to be told when a fellow patient is dying or has died
- They would like the opportunity to say goodbye to a friend
- They were distressed by overhearing staff conversations about the death and references to 'the body'
- They would prefer that staff use the person's name after death
- They asked that respect be shown by staff when packing a deceased person's belongings

Staff may feel it is their duty to protect patients from being upset by the knowledge of a fellow patient's end-of-life period or actual death, whereas patients want to know and to have the opportunity to respond and to be acknowledged. Furthermore, the patients who participated in the focus groups stated that they were comfortable with the topic and pleased to provide their views. It is extremely important to consider that in many circumstances, especially in complex continuing care, patients are aware of the possibility of death and may be disturbed that the lack of respect they witness for others may occur upon their own death. Offering the chance to voice their opinion could ease such concerns.

#### Local audit

Building on staff and patient experience, a local audit was conducted. This consisted of a visit to our morgue space, consultation with funeral professionals and consultation with the long-term care sector. It was important for West Park staff to have personal experience of the morgue space.

The descriptions of a negative morgue experience in the CCI exercise raised our curiosity and a visit to the morgue was incorporated into the local audit as a source of evidence. It was a shock to see the vestibule to the morgue. It was used as a storage place for old lamps, computers and cabinet upon cabinet of pathology slides dating from the 1970s. The fact that part of the morgue space was used for storage in this way was not explicitly noted or singled out by the staff participating in the CCI exercise. The condition of our morgue space was brought to the attention of the senior administrator responsible for the space and the aesthetics of the space were addressed. Feedback was provided for consideration of the morgue space and its vestibule in the design of the centre's new building.

Figure 1: The morgue vestibule, before and after





Consultation with funeral professionals was a key aspect of local audit. The president of the Toronto Association of Funeral Homes and the programme co-ordinator of the funeral service education programme at nearby Humber College were interviewed. They welcomed the conversation and the exchange of ideas about hospital after-death care practices. We were told that the procedures imposed by hospitals for the transport of a person who is deceased were not consistent with preferred practices of funeral professionals (see Table 2).

# Table 2: Local audit – funeral professionals

# Quotes from personal communication from Michelle Clarke, programme coordinator, funeral service education programme, Humber College, Toronto

'We are appalled by many hospital practices, but to my knowledge no one from the hospital sector has ever come to us to ask us what we think. We respect there are policies at various facilities and although we may not agree with all of them, we adhere to them.'

'The reality is that most families would rather avoid their loved one being taken to a morgue, but most have no idea that there is an option to avoid this and some are afraid to ask.'

'So many funeral professionals are bothered by many of the practices we see in hospitals. For example, exiting the building with a deceased person only to pass garbage dumpsters because we are expected to enter and exit through the delivery doors. It appears that the deceased person receives the same respect as the facility's garbage.'

There is a clear need for open dialogue between healthcare professionals and funeral professionals. In terms of language, funeral professionals have a preference to say the person's name or to refer to the deceased person, rather than refer to 'the body' or 'the remains'. In terms of specific procedures, funeral professionals told us what they do and do not need from us (see Table 3).

Table 3: Funeral professionals specific requirements of hospitals	
Issue	Requirements
Shrouding	They do need body fluids to be contained, but not necessarily by shrouding; incontinence containment products are adequate
Clothing	They are agreeable to the use of clothing to dress the person who is deceased, as long as it is easy for them to remove
Identification	<ul> <li>They require one identifier; the hospital identification band is sufficient</li> <li>There is no requirement for a toe tag, a taken-for-granted and unquestioned tradition</li> </ul>
Tying	They do not want us to tie the deceased person's jaw or wrists. This practice causes marks that cannot be easy made inconspicuous for the viewing of the person's body later
Morgue	<ul> <li>There is no absolute requirement for placement of the body of the person who is deceased into the morgue</li> <li>Funeral professionals have a preference to come to the unit to transport the person who is deceased, thus avoiding a morgue experience</li> <li>Placement in the morgue is necessary if the timeframe for transport will be more than four hours</li> </ul>

Another component of local audit was a conversation with West Park's long-term care facility to understand its after-death care practices. The facility rarely uses a shroud or the morgue. The deceased person is dressed in clothing and funeral professionals come directly to the unit. Residents have an after-death plan of care that can include their wishes to allow resident friends to say goodbye to them at the time of their death. Residents are brought to the bedside to say goodbye.

The long-term care facility experienced a period when the front exit was used for the deceased person. Feedback from residents was that the resultant visibility caused angst, so a decision was made to revert to using a back exit. On the other hand, long-term care facilities in another jurisdiction that provided feedback reported positive experiences using the front door: in one case, a quilt was purchased to drape the transport container and family, residents and staff formed a guard of honour. Such stories highlight a diversity of views, preferences and patterns. A practice development approach suggests we welcome this diversity because it can create insight and ultimately lead to change.

#### Discussion

The completed evidence review led to the key learning that much of what we were doing was based on habit and unchallenged assumptions about what was 'best' or 'required'. Furthermore, these unquestioned practices were being experienced as uncomfortable and antithetical to the personcentred approach of our espoused organisational vision. The practice development approach to policy revision work then progressed to a phase of problematisation (Titchen, 2001), which involved raising awareness of those after-death care practices that were going unchallenged and making explicit their conflict with our vision for person-centred practices. This was achieved through a series of conversations with stakeholders representing medicine, infection prevention and control, and organisational leadership.

The policy review was experienced as a values-driven process. It is important to be cognisant of the impact of both the prevailing paradigm and the role that power plays in taken-for-granted customs and practices, illustrated by the response from one of the centre's administrative leaders about alternative exit options. The leader expressed concerns about offering transfer of the deceased person through the lobby to a waiting hearse; such a transfer was seen as problematic for reasons of visibility, sensitivity and privacy. The leader expected that such a transfer in full view of patients and others would not be well received. The comments made explicit the world view that the leader brings to what constitutes an 'appropriate' exit. The majority of funeral homes now use a minivan to bring the deceased person into their care in order not to attract undue attention, reserving the use of a hearse, or funeral coach, for driving in a procession to a place of worship or place of final disposition.

Seeing the deceased person leaving through the front exit might be upsetting to some; for others, though, it could give comfort. A decision was made not to seek consensus about use of the front exit, but to allow for the flexibility to determine the preferred point of exit on an individual basis.

This work, using practice development processes, unearthed traditional and unquestioned practices. We set out to see what effect end-of-life care plans and person-centred after-death care would have on such practices – for example, the use of language, applying a toe tag, wrapping a naked body in plastic and mandatory transport to the morgue. We provided a series of education sessions on the units as a component of the implementation of the new policy. Nursing staff in continuing complex care embraced the changes in patterns of care, including the importance of respecting the family's wishes and cultural traditions (see Box 1). We continue to experience resistance from administrators to the use of alternative exits from the building. It is anticipated that we will experience a gradual shift in practice and culture with further evaluation and discussion.

# Box 1: Experiencing a shift in practice. A case scenario

A patient from a particular religious tradition died in the months following the implementation of the transformed after-death care policy. It was important that staff sought to understand this religious tradition and the perspectives on death and dying, at least enough to appreciate what the patient and family needed from us. There were specific death rituals important to the family, which required that the transfer to the funeral home be delayed for several hours.

The service manager consulted with the funeral home involved about this delay and it was agreed to transport the deceased person after eight hours, thereby honouring the family's wishes. A private room was provided for the family to carry out the death rituals. The following morning, the funeral professionals came directly to the room. The service manager arranged for the deceased person to leave through the front exit. One of the staff had a brief conversation with people who were in the lobby at the time to inform them what was about to happen and to ask them to leave the area for a few minutes if they were uncomfortable. The exit occurred without reaction. The family expressed satisfaction with the care that they received and the staff expressed satisfaction with the personcentred care that they provided – the ultimate outcomes of person-centred practice.

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#### **Conclusions**

A practice development approach is of value because it helps to reveal the ideological nature of takenfor-granted practices. A reflexive approach involves a series of conversations with self and others, critically analysing a situation and leading to the giving and receiving of feedback that challenges that status quo. Such an approach to policy revision led to identifying many problematic aspects of afterdeath care practices. Practice development processes allowed for the possibility of change because an array of larger forces shaping practice were made explicit and then discussed. The process was systematic and the timeframe spanned several months.

Policy work can perpetuate the status quo or it can be transformative. We had the opportunity to step back and take the time required for a reflexive policy revision process, to ask important questions about the social construction of the problem and to shift value-laden practices.

#### Disclaimer

The views expressed in this publication are those of the author and do not necessarily represent those of the West Park Healthcare Centre.

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Barbara Anderson (MN, RN), Clinical Nurse Specialist, West Park Healthcare Centre, Toronto, Canada.