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#### ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

Transforming end of life care using practice development: an arts-informed approach in residential aged care

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## Abstract

*Purpose*: To demonstrate that practice development is an effective strategy to enable an aged care team to embed a palliative approach to care of dying people into practice culture.

Method: Practice development methodology was integrated with an action research evaluation framework, as a systematic and reflexive process of inquiry aimed at achieving innovative and transformative end of life care. Drawing on multiple sources of observational, group and interview data, evidence-based guidelines and the use of arts-informed active learning methods, a multidisciplinary aged care team explored personal and professional values and beliefs about principles of care delivery. These were creatively translated into meaningful expressions of evidence-informed end of life care and embedded into daily clinical practice.

Results: Reflexive analysis of multiple sources of data, alongside the use of evidence-based guidelines, supported the collaborative development of a 'palliative care chest of drawers' (PCCOD). As an artefact and one outcome of using practice development in the implementation of a palliative approach to care, the PCCOD brought visible, shared meanings and new ways of working to support care of people who are dying, their families, other facility residents and staff. The PCCOD enabled the aged care team to embed practice innovations into normative patterns of care.

Conclusion: Practice development strategies are effective in enabling practitioner-led innovation in clinical practice through integrated inquiry and transformative processes.

Implications for practice:

The use of a practice development, arts-informed approach:

- Enables the creation of space for workbased learning and innovation, such as the development and use of the PCCOD to support the process of implementation of changes in practice
- Makes visible changes to practice, based on shared meanings of a palliative approach to end of life care that reflects the culture of the workplace
- Provides a creative strategic tool to engage others in the processes of transformation and collaboration, which takes initiatives from a small active learning group into the workplace
- Enables what was previously a 'hidden' part of care to be a distinctive care package that engages residents, families and all members of the aged care team

**Keywords**: Practice development, end of life care, palliative care, innovation, residential aged care, collaboration, transformation

#### Introduction

This paper describes the process and one outcome of the implementation of a palliative approach in residential aged care, using a practice development methodology that enabled participants to engage members of the multidisciplinary aged care team in a collaborative project. This was the development of a 'palliative care chest of drawers' (PCCOD), a five drawer portable cabinet designed by staff as a practical tool to contain items used in practice to support holistic, evidence-informed care for residents who were dying. The outcome of the project enabled the team to embed changes within the normative pattern of care by using an artefact of end of life care to make visible innovations to practice — innovations that clarified the shared meaning of the physical, spiritual, psychological and social needs of residents and their families. Creating space to identify and articulate shared meaning achieved a sound theoretical structure for engaging all members of the care team in the development of the PCCOD. The PCCOD improved the care experience for dying persons, not least by having a positive impact on relationships between the person, their family and the care team.

The project showed how it is possible to achieve innovative practice that is clinically practical, integrated with evidence-informed practice and in line with guidelines for a palliative approach to care (Australian Government Department of Health, 2006). Through facilitated use of practice development methods and transformative change processes, introduced by the researcher as 'external' facilitator, critically informed new ways of working, acceptable within the culture of aged care, were made visible. This paper provides evidence of how an effective practice development strategy can support practice innovation.

#### Study background

## A palliative approach to end of life care

With the integration of palliative care into mainstream healthcare, professional management of terminal care has become highly organised around care pathways (Ellershaw and Wilkinson, 2003) and successfully implemented in care homes (Hockley et al., 2004) in the UK. In Australia, Reymond et al., (2011) reported that pathways for end of life care implemented in residential aged care facilities had successfully achieved improved outcomes and reduced unnecessary transfers to hospital, consistent with best practice guidelines. Horey et al. (2012) indicated that acceptability by managers, staff and GPs was critical to the successful implementation of a palliative approach and that more strategies were needed to ensure their use by all staff in Australian residential facilities. Transformational frameworks to support the use of evidence-based principles in health services suggest the need to create workbased learning conditions. In this way, practitioners can take into account the local social, organisational and cultural factors that influence successful implementation of evidence-based innovation in daily clinical practice (McCormack et al., 2002; Rycroft-Malone, 2004).

O'Connor and Aranda (2003) explained that care of the dying person is based on a philosophy of care that demands a holistic, person-centred and multidisciplinary approach. Interventions are dependent on the level of care required by each patient and their family, at different stages and times in the illness trajectory, an approach that is consistent with the broader goals of aged care services (Australian Government Department of Health, 2001). Gerontological nursing emphasises the promotion of wellbeing and quality of life when working with older people and those with chronic and life-limiting conditions (Chenoweth and Kilstoff, 2002; Cheek et al., 2003; Nolan et al., 2004; McCormack, 2004; Kristjanson et al., 2005). In the current study, the multidisciplinary aged care team had achieved high standards of quality care, benchmarked statewide with similar facilities. Quality was gauged mainly by quarterly measures of outcomes using indicators such as skin integrity, weight change and the incidence of falls (Victorian State Government, 2007). However, at the heart of palliative care is the notion of a 'good death' experience for the dying person and their family (McNamara, 2001). Part of the vision of the aged care team was to provide care according to the wishes of the resident, a core value underpinning their ongoing projects in developing a palliative approach to care at the facility.

## A 'good death'

Abbey (2004, p 260) said that, in aged care, a 'good death' is a 'managed process'. The meaning of a 'good death' is largely bound by the context in which it is defined. Kring (2006) reported transcendent meanings across medicine, nursing, sociology and Christian theology, including: 'making adequate preparations, experiencing no unpleasant symptoms, having someone by one's side and being spiritually whole' (Kring, 2006, E12). These components are underwritten by evidence-informed principles for a palliative approach such as:

- · Advance care planning
- Pain and symptom management
- Family and social care
- Spiritual care
- End of life care (terminal care)
- Bereavement support (Australian Government Department of Health, 2006)

Attention is given to care that enhances not just physical but social and spiritual comfort (Seymour, 2004) in accordance with the wishes of the dying person (Hudson and Richmond, 2002). This implies prior engagement of the person and their family in decisions about preferred care options, and the creation of the necessary advance care plans (Detering et al., 2010) with the aim of avoiding an unnecessary transfer to acute care at a time when the dying person is at their most vulnerable (Caplan et al., 2006; Hudson and O'Connor, 2007).

The relational nature of personhood that underpins person-centred care frameworks emphasises relationships between self and others, and self and the care environment (Nolan et al., 2004; McCormack and McCance, 2006). Working with a person-centred framework helps guide practitioners to take into consideration the needs of the dying person and of those who provide formal care and informal support (Yalden and McCormack, 2010). Where these relationship oriented frameworks converge with subjective and contextual elements of holistic and dignity enhancing end of life care (Chochinov et al., 2002), they have potential to guide care delivery that supports the dying person and therefore contributes to a good death experience (deRaeve, 1996).

#### Person-centredness in end of life care

Achieving a 'good death' experience within a person-centred philosophy will not happen through the introduction of new policies and guidelines alone. Instead it is argued that the context of care needs to be transformed (McCormack and McCance, 2006). The context of care includes professional and organisational prerequisites that support person-centred processes such as engagement and having a sympathetic presence (McCormack and McCance, 2006). The values, beliefs and attitudes of nurses are vital features of a caring culture because they can be profoundly influential in shaping approaches to care delivery (Phillips et al., 2007). Hanson et al. (2002, p 121) found that personalised care was associated with meeting the spiritual and emotional needs of residents who were dying and provided a 'counterbalance' to their sense of isolation and psychological suffering. In the current study there was a need, therefore, to bring together and make more explicit within the pattern of end of life care, innovations that went beyond physical care.

#### Aim

Part of a larger study of the implementation of a palliative approach, this paper aims to describe the creation of a space within which a multidisciplinary team with varying values, beliefs and knowledge was able to engage collaboratively in transforming end of life care.

#### Methodology

The study methodology was derived from transformational practice development (Manley et al., 2008) with an integrated action research evaluation strategy (Reason and Bradbury, 2001; Denzin and Lincoln, 2008). Transformation is a pragmatic process that is not just rhetoric about translating new ideas or

evidence-based guidelines into practice (McCormack et al., 2002; Grimshaw et al., 2004; Bucknall et al., 2008). According to change theorists, ideas need to be transformed into innovations that can support ongoing development and be embedded as acceptable changes within an organisation's context and culture (Lewin, 1951; Kotter, 1990). From an emancipatory practice development perspective, the intent of transformation (Fay, 1987) is to enable practitioner-led, critically informed action. Practice development strategies used in this study to facilitate transformative action included:

- Raising awareness of the challenges and possibilities for improvement
- · Developing shared meaning and creating conditions to support learning
- Innovation
- The development of person-centred cultures

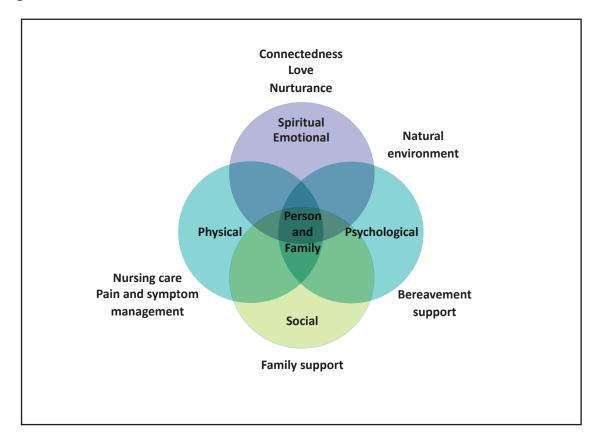
#### Practice development and active learning in the workplace

Practice development involves 'a continuous process of developing person-centred cultures' (Manley et al., 2008, p 9). A central feature of this process is facilitated active learning that is informed by a range of education and other theories (Dewing, 2008). In this study, active learning was informed by education theorist Rogers (1961) and other theories and frameworks to guide facilitation (Heron, 1989; Titchen, 2001) and reflective practice (Schon,1983; Johns, 2001). A model of active learning was developed, which included structured education and methods to enable participants to engage in critical and creative reflection interlinked with the systematic inquiry process of practice development (Yalden, 2010). It resulted in several projects that developed innovations in practice from the point of admission of a resident (rather than for the last hours or days of life) to support improved end of life care. One of these projects, the PCCOD, is reported here because it was collaborative and highlights a creative strategy that helped to integrate palliative care interventions that went beyond physical care within the normative pattern of care for residents.

The methodological approach aimed to create conditions for innovation by enabling space for new learning and creative engagement in the workplace. It involved the use of imagination and freedom to explore constructions of holistic end of life care (Figure 1) developed through previous interviews and workshops with participants and then translated into practical interventions (Yalden, 2010). Critical space as a method for stimulating new learning conditions also facilitated the negotiation of resources and the rolling out of ideas through collaborative engagement of the whole aged care team. This was achieved through:

- Discussions with nursing and allied health staff at handover periods
- Formal meetings with nurse managers
- Informal networking with activity staff and workshops with nursing staff, residents and personal service attendants
- Structured education sessions and interactive seminars for all staff
- Formal palliative care symposia on research and practice development in collaboration with a university palliative care research unit and the healthcare organisation where the study was located

Figure 1: Constructions of end of life care



#### Method

#### Engaging the aged care team in collaborative development

The study included two main active learning groups organised to accommodate full time and part time staff, including clinical staff on all shifts, as well as the education needs of participants in the various study projects. There was a clinical group (consisting of registered and enrolled nurses, a physiotherapist, an occupational therapist, a dietitian, activity staff and personal service attendants) and a management group (nurse managers, organisation nurse manager and director, educator, GPs and a clinical nurse consultant in palliative care). Members of the latter group regularly joined the clinical group according to the needs of the projects and progress of the inquiry. The researcher acted as the 'external' and main facilitator of both groups, which represented a variety of values, beliefs and knowledge. A key function of this role involved maintaining a flow of information between the groups through validated notes of groupwork and/or verbal reports and sustained interaction over the extended period of the study. This paper reports from the perspective of the clinical group, where the idea of creating a PCCOD originated as an outcome of structured education and active learning activities related to developing meanings of end of life care.

#### Arts-informed method to support innovation

Members of each group had participated in a series of creative and reflective workshops lasting between 60 and 90 minutes. The workshops enabled the groups to draw on experiential knowledge and other forms of evidence that had emerged from the action research inquiry to co-construct themes and shared meanings about key elements of care that reflected the values and beliefs of residents, families and staff (Figure 1). The first of a series of three workshops dedicated to end of life care with the clinical group was entitled 'Creating a space for dying'. Using the media of paint and collage, participants engaged with the aim of identifying interventions to enhance comfort, dignity and supportive relationships between the dying person, their loved ones and others within the residential facility in the final days or hours of life. The data and ideas from the initial creative/reflective workshop

provided the focus for subsequent developmental workshops and the stimulus for engaging other groups within the unit in collaborative design and development.

#### Action research evaluation in transformational practice development

In this study, action research was used as an integrated evaluation strategy, with data collection and analyses occurring continuously and as an integrative part of the transformational practice development methods. This integrated approach guided the systematic and iterative processes of review, planning and action (Hart and Bond, 1995; Denzin and Lincoln, 2008). Figure 2 illustrates how emergent data from one process of the inquiry guided the decisions that subsequently unfolded through connections between the practice development and action research cycles. Figure 2 follows the systematic and reflexive processes of inquiry and creative processes of active learning, to tap into:

- Personal and experiential knowledge
- Multiple sources of study data such as observations of practice and culture
- Themes from earlier interviews and workshops with staff and residents/family members
- Material data from previous workshops, such as paintings, collage or photographs
- Evidence-based guidelines
- Theoretical frameworks for end of life care (Yalden, 2010)

Figure 2: Translating meanings through iterative inquiry and transformational processes

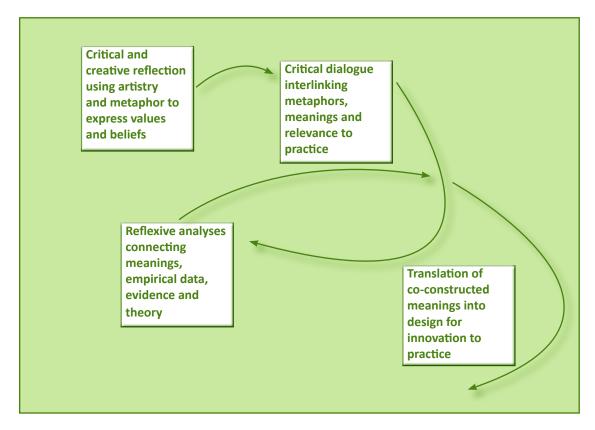


Figure 2 shows how the transformational processes enabled participants to move from creative imagination and expression of values and beliefs to co-constructing a practical model of care that converged with evidence and theory. Reflexive methods supported communication of the meaning of holistic, person-centred care and guided the ongoing collaborative development of interventions that were appropriate within the culture of residential aged care facilities. Outcomes were embedded as practice innovations and overall transformation in the culture of end of life care. They included interventions developed concurrently within both active learning groups — an integrated palliative approach pathway with evidence-based ways to support advance care planning and management of care within the normative pattern of care from the point of admission.

#### **Ethical approval**

This project was part of a larger action research doctoral study of the implementation of a palliative approach in residential aged care approved by the Research and Ethics Committees of the participating healthcare organisation and the accrediting university.

#### **Findings**

#### Turning shared meaning into symbolic action

The findings from the integrative transformational practice development and evaluation strategies resulted in the aged care team being able to turn a shared understanding of end of life care (espoused values) into actions that would transform the delivery of care.

## Creating shared meaning of end of life care

Workshops and active learning groupwork enabled co-construction of shared meanings about care for the dying person, remaining consistent with the philosophy of palliative care and what was realistic in the context of residential aged care. In the processes of analyses (Figure 2), new understandings emerged, as participants began to make connections between their own beliefs, what was important to residents, what was appropriate within the culture and the ways in which each of these were consistent with best practice theory and palliative care principles.

The following extracts from active learning groupwork reflections (Table 1) provide examples of emergent metaphors and meanings from the paintings/collages created by participants. These meanings formed the foundation for a subsequent model of care using the PCCOD as a symbol of the interconnected elements of care and associated palliative care interventions, taking into consideration not just the place, but the space in which care was provided.

In summary, the intent of care delivery in practice translated as:

- A space of human warmth, physical comfort and connectedness to others and to natural and social environments
- Recognition of a resident's needs for closeness, emotional comfort and nurturance
- Respect for family needs their own space, mutual comfort and support, interaction and communication with staff in coping with the anguish of impending death
- Space that acknowledges and supports the psychological needs of residents for self-integrity, self-identity, reassurance, sexuality (giving and receiving love), nurturance of family relationships and giving as hospitality
- A welcoming place that attempts to normalise the physical, social and spiritual/emotional
  aspects of care and caregiving involvement of the family, and the inclusiveness of the support of
  pastoral care, personal service attendants and volunteers as appropriate

Table 1: Evidence from creative workshop: translating meanings of paintings		
Image	Meaning/theme	Relevance to practice
Sunshine and window (or virtual electronic window with variable views of natural environment, e.g. mountains)	<ul> <li>Place of brightness,         warmth</li> <li>Connectedness to nature</li> </ul>	<ul> <li>Creating a calm, soothing, relaxing space</li> <li>Supporting spiritual needs</li> </ul>
Portable bed with trundle and push-button mechanism	<ul> <li>'Feather' bed and soft pillows</li> <li>Portable to outside patio/garden area</li> <li>Trundle for use by spouse/family overnight</li> </ul>	<ul> <li>Change of scene promoting wellbeing, enjoyment</li> <li>Supports relationship and connectedness to loved ones</li> </ul>
Medication cupboard in room	<ul> <li>For easy and ready access</li> <li>Promoting good pain and symptom management</li> <li>Individualised, responsive care</li> </ul>	Timely, synchronised and coordinated pain and symptom management with physical needs and care such as sponging and turning the resident
Animals (pet) companion if required	Supporting emotional wellbeing by connection with those who are loved or familiar and close	Comforting, relaxing, reassuring
Crystal vase with fresh flowers Chocolate, alcohol, beer	<ul> <li>Luxury items for special time and life event</li> <li>Best nightgown, soft towels, good linen in different colours</li> </ul>	<ul> <li>Providing luxuries as a token of love and respect</li> <li>Promoting a sense of comfort and wellbeing</li> </ul>
Bible, other favourite reading material	Opportunities for family or pastoral care/religious communication with the resident	Supporting spiritual needs, psychological and emotional comfort and peacefulness
Space for family and children	<ul> <li>Spare room/garden area</li> <li>Take-away menu and wine list</li> <li>Providing facilities for food and drink</li> </ul>	<ul> <li>Enabling family coping and maintaining relationships</li> <li>Space for family to relax together while being with the dying person</li> </ul>
Chest of drawers	<ul> <li>Symbol of holistic care of the dying as 'special'</li> <li>Contains articles that help to remember and celebrate a life lived and dying as a life event</li> <li>Articles to support relationships between the resident and children within the extended family</li> <li>Acknowledges anticipatory sense of loss and grief reactions</li> </ul>	<ul> <li>Recognition of dying by the aged care team and family</li> <li>Promoting self-esteem, self-image, identity control, personal wellbeing, giving and receiving love</li> <li>Creating opportunity for reminiscing with resident and family</li> <li>Meeting needs of children (for activity and information)</li> </ul>

Additional sources of data from creative engagement with residents in this study are described elsewhere in more detail (Yalden, 2010). Combined, they represent the knowledge, values and aspirations of the participating staff, residents and family members. As metaphors, they express initial ideas that subsequently inspired a plan to develop holistic and integrated approaches to care for the dying person by the care team.

## From shared meaning to symbolic action

Clough (1994) argues that images move thinking from the personal to the political. As the care team members started to translate shared ideas into practice changes, their skills in negotiation, communication and networking were demanded over several months. They opened up discussions outside the active learning group to engage other members of the team and gain management approval and funding for innovations to practice. A renewed vision and aim for the team was to provide care that promoted the comfort of the resident, enabling them to die with dignity in the presence of their family and in a space that enhanced connectedness with loved ones (and others), with nature and with human nurturance.

Inspired by one of the paintings from the reflective workshops, the idea of a palliative care chest of drawers (PCCOD) was explored, to use as an item of furniture in practice, with five drawers to accommodate contents associated with the care of the dying person. The paintings (see Table 1) included images of a chest of drawers containing specific items that supported not only the physical but spiritual, psychological and social aspects of care for the resident and their family. Other images included metaphors for the dynamics of relationships between resident, family and caregivers. They stimulated ideas about how better to structure the 'place' of care (the resident's room and surrounding areas within the facility) to enhance privacy for the family as a unit. They generated ideas about creating greater openness to the significant life event that was occurring in the 'space for dying' and to acknowledging the effect on the family, staff and other residents. As a simple visual cue to the aged care team, the PCCOD provided a timely reminder and creative space to enable care of the dying to be initiated and integrated within the normative pattern of care. These interventions were interlinked with concurrent projects for developing a team approach to communication, and care planning and management associated with a palliative approach.

The idea of creating a PCCOD for common use assimilated:

- Review and revision of care plans by the aged care team
- Acknowledgement that the resident was dying
- Anticipatory care management arrangements
- A shared understanding of the meaning of holistic care for the dying person
- Involvement of the family (if possible) and ongoing information and support
- A team approach to care
- Availability of nursing expertise, equipment and funding resources

All the above were consistent with palliative care principles (Australian Government Department of Health, 2006, Guidelines 2, 4, 5, 15, 16, 56, 59, 74, 75, 79). A prototype PCCOD was created and subsequently developed in collaboration with clinical and management staff. A modest chest of drawers was purchased in accordance with workplace criteria for safety and portability. It was personalised and stocked with special equipment in response to comments, advice and feedback from staff regarding design and articles to be included to support the delivery of care for the dying person and relationships with the family. It reflected where participants were on their creative journey, their tentative beginning in moving from an abstract idea to designing a practical tool for developing end of life care.

#### The palliative care chest of drawers (PCCOD)

The PCCOD is a simple practical item, with one located in each of the two main buildings of the facility. It is easy to maintain and manoeuvre on wheels within the resident's room and facility, and includes

prompts to support the resident and family as a unit. As an object, it has no meaning in itself. But, to members of the aged care team who observe and use it, the meaning is in the contents, interventions and ways of working associated with it. The presence of the PCCOD indicates to staff that palliative care is something other than just 'ordinary' care. Each of the five drawers holds specific items that represent aspects of the interconnected physical, spiritual, psychological and social dimensions of care provided by the nursing and aged care team. The contents of the drawers and examples of supplementary items are described and illustrated. Assessment charts (for example, pain, fluid balance and physical observation charts) can be hung on the side rail.

#### Top drawer: spiritual care

The top drawer holds a memory booklet (Figure 3) that includes biographical notes for each dying resident's life, and sections for photographs, personal messages and notes from family, other residents and members of staff. A template of the booklet, first designed by the management and administrative staff, is compiled and completed by family, staff and invited others. Additional items in this drawer are a bible, rosary beads and other significant items, such as a music player, each helping to identify how best to support the spiritual needs of the person. This drawer also includes contact details of the local pastor, priest and other spiritual support persons who regularly visit residents.





## Second and third drawers: physical care

These two middle drawers contain nursing care equipment, for example, for mouth and skin care, any special creams, disposable sponges and aromatic oil. They also hold any special items of clothing that are preferred by the resident, such as a nightgown or jacket, plus any 'luxury' or personal bed linen. The top of the chest of drawers is often used as a working surface for documentation of care.

## Fourth drawer: psychosocial care

This drawer includes music CDs, with annotated notes on the preferences of the resident. Personal habits, for example, 'likes to have a drink of beer with family when they visit' or 'always has a gin and tonic at 5pm' are also identified here. These are things that the resident (and their family) are familiar with during their life when needing to cope with difficult situations, celebrate or just relax at the end of the day. It also houses items for the support of the family such as 'frequently asked questions', which include requests for information about the resident's condition, treatment plan and management of care, plus useful telephone numbers such as local restaurants/takeaway food outlets and taxi services.

This drawer is also stocked with other items for the family, such as fresh coffee and glasses.

#### Fifth drawer: social care

The final drawer contains activity packs for grandchildren purchased from the specialist palliative care unit. The contents of this drawer were later extended by the nursing staff with supplementary items to help create a space for children and family within the facility (Figure 4), which are listed below.

## Supplementary items

Additional items not included in the drawers but stored nearby include:

- A special patchwork quilt, made by volunteers, for the bed of the resident, if desired
- Child-sized table and chairs for children to play or eat on
- Specialist children's books about saying goodbye forever, to support the family in the bereavement process
- Decorated, personalised boxes for the family to take the belongings of the deceased residents, to replace black plastic bags (Figure 5)
- A china teaset for exclusive use by the family

Figure 4: Space for children within the facility



Figure 5: Examples of special personalised boxes



All these practical innovations provide triggers for opening up and implementing new approaches to ongoing care following death. Examples of these are:

- Managing the ritual of escorting the deceased person from the residence
- Communicating expectations for funeral services arrangements
- A memorial service back at the residence

These and further innovations for bereavement support of the family, other residents and staff, became an ongoing component of practice development.

## The PCCOD: a symbol of 'special care' and a cue to action

The PCCOD in action is not only a practical part of care delivery for the dying person, but also provides a symbol for the different or 'special' care being given as a planned intervention to support and respect the idiosyncrasies and comforts of the resident and their loved ones. It signals to staff and other residents that the dying resident's room and surroundings are for now, a place devoted to enabling a resident to die well, in the presence of family or significant others. It acts as a reminder that dying is a time for respectful presence of those who wish to be with the resident, for privacy and avoidance of unnecessary interference, for example, by daily clinical 'traffic' and its associated noises.

## Embedding practice change in an improved culture of care

The PCCOD is an artefact of care that has become embedded in the culture of end of life care delivery. It has endured as a highly visible piece of evidence translation, from evidence-based principles into practice. It has embedded by association, the philosophy and set of practices that characterise holistic dimensions of care of the dying person (Figure 1 and Table 1). Combined with the transformational leadership of the practice development groups, the use of the PCCOD constitutes a form of modelling that has influenced the perceptions and actions of others within and between groups in the workplace, enabling them to make associations with the meaning of end of life care and their contributions to different aspects of it.

## **Evaluation of impact**

There were many follow-on effects that contributed to ongoing transformation of end of life care. Practice-led innovations, such as the PCCOD, have contributed to meaningful teamwork and effective care delivery that is not limited to a particular episode, because repeated use and continuing

development of its special features involve the whole team, including volunteers. Using thematic content analysis within an action research inquiry process, data was collected by the main researcher (first author) through 17 recorded and transcribed interviews towards the end of the study. The following are selected, short extracts from subthemes of care of the dying person that relate to changes in practice culture in the planning and management of end of life care. They include engaging with the family, raising the status of end of life care and an end to back door exits.

## Improved end of life care: engaging with the family

The impact of the practice development approach and innovations to practice include direct and indirect influences on work as a nursing and caregiving team involving the resident and family. For example, staff recognise the need to:

- Remain available, and more open and willing to communicate and engage with the family
- Adopt positive attitudes and proactive practices around end of life care
- · Offer care after death and bereavement support beyond the routine of daily care

'I have thought more about their family – preparing the families for changes... yes, there is more involvement of the family... excellent care is more common now' (clinical group).

'Yes, I do like to be a part of that care... Oh yes, especially in the last two weeks, X has gone rapidly downhill...' (family of dying resident).

'Yes, because we have more knowledge now... a lot of people are now communicating [and as a result] residents are receiving better care' (management group).

'Talking about it – death is the natural end – it is not something we interfere with unnecessarily... it is no longer a taboo subject that you have to wait until almost the last breath... it is much more open now' (registered nurse).

The inclusion of the family and their contribution to caring for the resident can help the family members to cope with the anticipated loss of their loved one and can positively influence family functioning in the bereavement period (Kristjanson et al., 2005; Australian Government Department of Health, 2006, p 133).

#### Raising the status of end of life care

The work of the active learning groups in implementing the PCCOD helped raise the status of end of life care within the daily clinical workplace culture; making it transparent, opening up opportunities for communication, encompassing all members of the aged care team and involving the family before, during and after the death of the person. This is significant in residential aged care where death is more acceptable, perceived as a natural end to an often long life or an illness (Komaromy and Hockey, 2001; O'Connor, 2009). It is, nevertheless, a unique experience for any family. The status of dying and 'special' characteristics of holistic care, as represented in the PCCOD developed in this study, go some way towards contributing to a 'good death' experience for those involved. Saunders and Baines (1989, p 392) asserted: 'How people die remains in the memories of those who live on.'

To be actively 'doing everything for the dying resident' (Australian Government Department of Health 2006, p 171) was interlinked not just with physical care but now with attentiveness to the perceived value of space and time for psychosocial and spiritual care. The following extracts from interviews with nurses crystallised more informed care leadership, which supported the need of both resident and family for closure.

'Sometimes it's about what they [the family] need as well... sometimes the resident has journeyed on and settled their life and things... but the family still needs to... the one thing I have really

learned is... that time the family is sitting there... it is valuable because... they get time to finish off their story' (Nurse 1).

'As staff we need to provide an atmosphere that is conducive to [the family being together]... so it can happen... without families feeling pressured or over-emotional... or silly, you know... so important they feel they can go through this process in their own way... and if that means drinking a bottle of old red wine or watching a video, then that's fine... Yes... other people and the family want the priest in there for a few hours' (Nurse 2).

#### No more back door exits

Respect for the body and the open observation of ritual as part of end of life care contributes to dignified closure, providing an opportunity for other residents and staff to acknowledge the death and say farewell to a friend. A nurse manager (Nurse 3) talked about recent changes that confirmed the researcher's observations and conversations with other members of staff.

'When they go... we escort them out [the body with funeral directors] through the main door.'

'When X died, all the ladies who knew her stood together holding hands and cheered her out the door! And it was so lovely... they celebrated her and it was a really lovely form of respect... I think it's important.'

Other innovations have contributed to be reavement support for the family, other residents and staff:

- The introduction of a twice-yearly memorial service at the facility
- Support from management in allowing time for some members of staff to attend a deceased resident's funeral in the community
- A follow-up telephone call to the family
- A rarely used sitting room has been converted and identified as a quiet place for family, staff reflection and meetings with relatives

## Discussion

The demand in Australia for improved access to palliative care in mainstream and aged care services is acknowledged and supported in healthcare reform (Australian Government National Health and Hospital Reform Commission, 2009; Australian Government Productivity Commission, 2011). It has created opportunities for innovation in practice with supporting literature on models and frameworks for advance care planning (Detering et al., 2010), critical care pathways at end of life in aged care (Ellershaw and Wilkinson, 2003) and evidence-based guidelines for a palliative approach in residential aged care (Australian Government, 2006). However, Gott et al. (2011) have argued for greater emphasis now on how to integrate palliative care interventions within professional roles and sequence of care services at the end of life for older people and their families.

This paper has described a theory-informed practice development strategy that created conditions for innovation. It enabled participants to unravel and reconstruct the meaning of end of life care as a starting point for developing and integrating evidence-based ways of working that were acceptable and practical within a residential aged care facility. The strategy enabled participants to make connections between the predominant emphasis on physical care and the more abstract dimensions of spiritual and psychosocial care, translating the latter into tangible and meaningful objects and associated ways of working that were informed by evidence-based palliative care guidelines (Australian Government Department of Health, 2006) and person-centred care processes (McCormack and McCance, 2006).

The promotion of communication with and involvement of residents and their families supports many of the key components of palliative care, such as the ongoing development and use of advance care planning (Jeong et al., 2010). Key aspects of the role of registered nurses in residential aged care, such

as clinical leadership and management to support quality of life and quality of care (Chenoweth and Kilstoff, 2002; Cheek et al., 2003), are increasingly being defined with reference to the priorities for person-centredness in the context of the environment of care (Hunter and Levett-Jones, 2010). Denzin and Lincoln (2008) have argued that it is becoming more acceptable to use artistry in qualitative research because it draws on imagination, the senses and human values. The critical and creative process and methods described in this paper readily gave way to more liberal expression of different

research because it draws on imagination, the senses and human values. The critical and creative process and methods described in this paper readily gave way to more liberal expression of different ideas that were rapidly synthesised to form a 'whole' picture as a starting point for designing innovations to existing end of life care. Consistent with the principles of practice development (Manley et al., 2008), they also had a practical purpose in reorientating collaborative activities around a collective project for including more members of the aged care team, such as personal service attendants, activity therapists and volunteers in the processes of innovation and change.

The outcomes were specific to residential aged care but the practice development strategy could be used in other healthcare environments to support innovation and transformation.

#### Conclusion

Constructing and communicating the meaning of holistic, person-centred end of life palliative care through integrated inquiry and transformative processes of practice development is a strategy that enables innovations to be embedded in practice. Artefacts, such as the PCCOD, provide practical, visible tools to simplify complex aspects of a palliative approach. New ways of working that correspond with best practice provide a continuing prompt to what is appropriate and acceptable support for the dying person, their family and all those involved in delivering care that, in the words of Dame Cicely Saunders (Saunders, 2001, p 432), enables the person to 'live until they die'.

This paper has outlined the process of embedding and improving the care experience, through facilitated practice development and practitioner-led, action orientated inquiry. The creative co-production of the PCCOD provides a practical tool created, developed and used by care staff to improve the experience of death and dying. Outcomes of this work have led to a more integrated team, through enabling staff to be more fully engaged with family and carers and incorporating evidence-based palliative principles into the work of residential aged care. The importance of a values based, practitioner-led approach to practice innovation is recommended in order to achieve transformation and contribute to holistic, person-centred end of life care delivery.

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