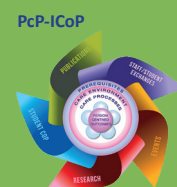


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ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

Reaching for the rainbow: person-centred practice in palliative care

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Abstract

Background: Person-centred practice is inherently integrated in palliative care. However, it cannot be assumed that its underpinning values are lived out in day-to-day practice in a hospice. At St Columba's Hospice, Edinburgh, the five-year strategy demonstrated commitment to person-centredness and this prompted an 18-month project focusing on the evaluation and development of a person-centred culture, taking a practice development approach.

Aim: To implement a person-centred practice development research project to assess, evaluate and enhance person-centred culture within St Columba's Hospice.

Methods: The theoretical underpinnings of the programme were based on the Person-centred Practice Framework. A transformative practice development approach was employed to bring about change in individuals and teams. Twelve multidisciplinary team members from different departments across the hospice formed a core research project group, which was allocated 10 protected learning and development days over the 18-month period. To assess the existing culture, data were collected at the beginning of the practice development programme, including observation in practice and real-time interviews with patients and staff. The data were analysed using a participatory approach, with group members mapping the data collected against the Person-centred Practice Framework and undertaking creative hermeneutic analysis.

Discussion: The project created and sustained a space to explore and expose person-centredness within the hospice and raised awareness of what person-centred culture means in day-to-day practice. Fourth-generation evaluation highlighted further areas for action, with teams developing their own action plans aimed at enhancing person-centred culture.

Conclusion and implications for practice: The context of day-to-day practice in a hospice setting is complex, and developing person-centred culture is an ongoing process. Hospices can help their staff to flourish by providing the necessary space to reflect and for critical awareness of own practices to be heightened. This could encourage staff to embrace the contradictions inherent in the work they undertake and to learn from it in order to improve their own wellbeing.

Keywords: Person-centred culture, person-centred practice, palliative care, practice development, end-of-life care, hospice, facilitation

Introduction

This article describes an 18-month person-centred practice development research project focusing on the evaluation of the existing culture and development of a person-centred culture at St Columba's Hospice, Edinburgh. The background to the project is described, along with its aims, objectives, theoretical underpinning and methodology, as well as key findings and outcomes. Practice development has been defined as a continuous process of developing person-centred cultures through authentic engagement combined with creative imagination to transform individuals and teams (Manley et al., 2013). Such a process is not always linear in nature and although this article presents the project in a linear fashion with key findings and outcomes, its transformative impact was experienced even though staff members participated at different points.

Background

The provision of palliative and end-of-life care calls for a multidisciplinary, holistic and person-centred approach (O'Connor and Aranda, 2003). Research evidence has described how person-centred care in this setting offers direct benefits for patients and their carers. It enables people to feel valued for who they are, rather than being defined by their illness, and fosters relationships through honest information sharing and open communication (van der Eerden et al., 2014). The care environment is central to the Person-centred Practice Framework (McCormack and McCance, 2017, 2019 amendment) in highlighting the need for person-centredness not only for those nearing the end of life but also for those caring for them. An essential aspect of the framework is to embed the philosophy into the care context and environment within the organisation and pay attention to the culture (Yalden and McCormack, 2010; McCormack and McCance, 2017, 2019 amendment). This broadens the reach of the philosophy of person-centredness beyond the provision of clinical care. For example, Boomer and colleagues (2019) describe how enhanced working relationships between staff led to an improved workplace culture, resulting in better person-centred end-of-life care for patients.

Person-centredness is inherently integrated into the core values of palliative care (Saunders, 2006). However, having developed from a grassroots movement into an established organisational structure, the culture of palliative care has become increasingly influenced by routine and the need for standardised practice, thus pulling it away from its founding principles (Haraldsdottir, 2011). McCance and McCormack (2017) draw attention to how task-oriented ways of working with hierarchical thinking can become the norm unless organisations make a commitment to a person-centred approach. Additionally, hospices have changed significantly over the years in terms of the patients that they provide care for, and are being increasingly regarded as specialist palliative care units for people with complex care needs. The added demands on the workforce that such changes in care provision involve have been recognised by Hospice UK, which published a framework that reinforced the importance of promoting resilience in hospice staff in order for them to flourish even in stressful times (Hospice UK, 2015). The increasingly complex work environment adds to pressure on staff and can significantly affect their wellbeing and ultimately impact on patient care. This is outlined by Maben et al. (2012), who describe how the experiences of healthcare staff have a direct impact on those of patients. Hospice UK's resilience framework challenges hospices to find ways of supporting staff in the valuable work that they do, while maintaining their reputation as 'exemplary places, where ordinary people do extraordinary work' (Hospice UK, 2015, p 2). It is vital that hospices don't assume that they are person-centred but acknowledge their complexity as workplaces and the impact this can have on staff's wellbeing and capacity to deliver care.

However, as person-centred practice is synonymous with person-centred outcomes and human flourishing (Dewing and McCormack, 2017), it is vital that hospices keep person-centredness at their core. While many policy documents make mention of person-centred care, it is not always clear what this term means and how it can translate into practice. Person-centred practice is only truly achievable where there is a person-centred culture within the organisation that enables staff themselves to experience person-centredness (McCance and McCormack, 2017). Hospices need to pay attention

to how person-centred values and beliefs can be lived out and embedded in day-to-day practice, staying true to the original philosophy of palliative care in the ever-changing context of care provision. In line with current healthcare policy, St Columba's Hospice has demonstrated a commitment to person-centred palliative and end-of-life care in its five-year strategy 'Care and Compassion Matters' (St Columba's Hospice, 2015). It therefore decided to undertake a project exploring and developing person-centred practice within the organisation.

Project aim and objectives

The aim was to explore and develop person-centred practice within St Columba's Hospice through the implementation of a practice development programme.

The objectives were to:

1. Raise awareness of person-centredness and what it means in practice through enabling staff, volunteers and managers to recognise and appreciate the attributes of person-centredness
2. Evaluate existing practice against a theoretical framework of person-centred practice and raise a critical awareness of the concept across the hospice
3. Enhance person-centred practice across the hospice through action planning and mini projects based on findings from objective 2

Setting and participants

St Columba's Hospice is an independent hospice that provides holistic care for people living with and dying from life-threatening illness, and their families. It has a 30-bed inpatient unit and also provides day therapies, community services and outpatients services. The hospice also has a committed education and research department. Overall, it employs more than 200 staff and in excess of 600 people volunteer their time and skills in a range of positions.

The project group established at the beginning of the project included people from a variety of disciplines. These included registered nurses, auxiliary nurses, a doctor, a chaplain, a receptionist, fundraising staff, volunteers and a service-development facilitator. Over time, the group membership changed for a variety of reasons, such as retirement, staff turnover and sick leave.

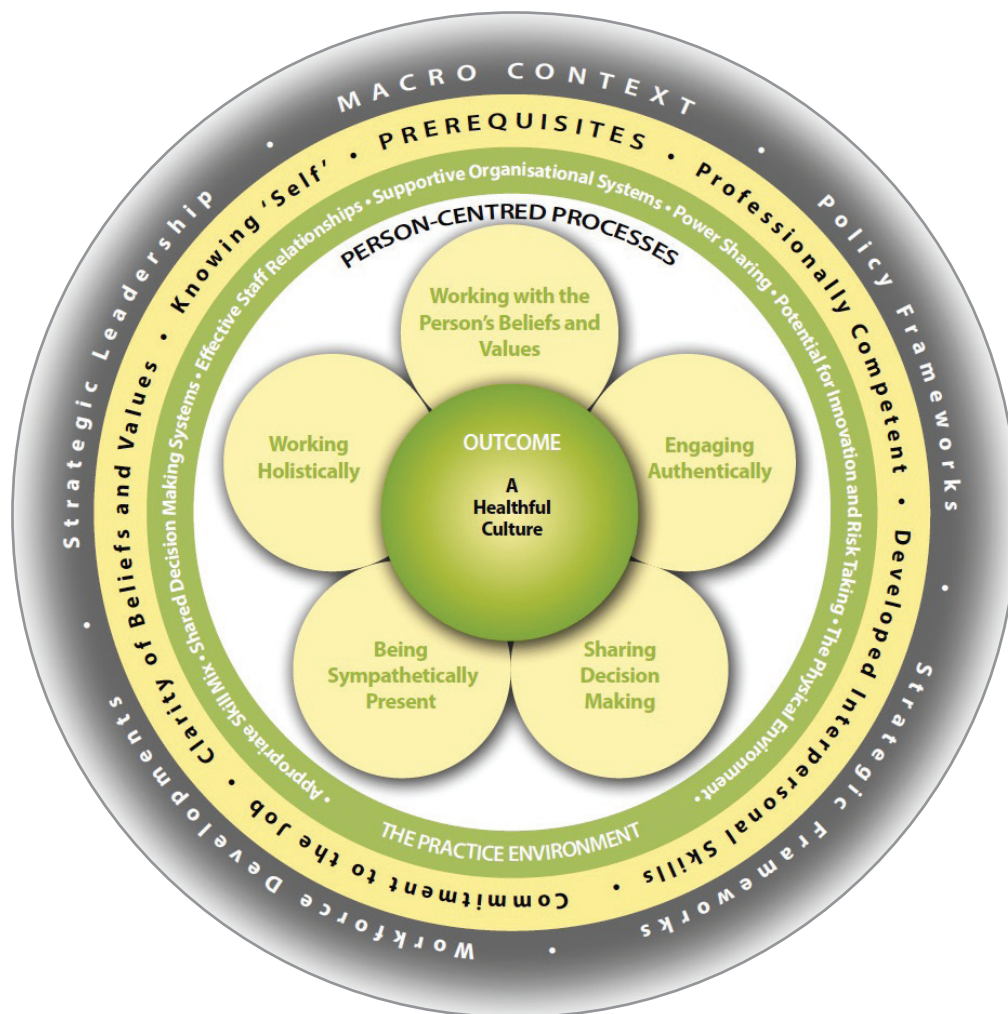
Methodology

Theoretical framework

The project was theoretically informed by the Person-centred Practice Framework (McCormack and McCance, 2017, 2019 amendment). The framework comprises four domains that are essential for developing and sustaining a healthful person-centred organisational culture. These are: prerequisites, which focus on the attributes of the healthcare professional; the care environment, which addresses the context in which care is delivered; person-centred processes, which focus on delivery of person-centred care; and finally a healthful culture, which is the overall outcome (see Figure 1).

This project's use of the framework encouraged an enhanced understanding of how the concept of person-centred care can be translated into practice and provided a shared understanding and a common language for exploring and discussing person-centredness. The framework was also used when analysing data, to generate insights and understanding of person-centred practice as it was lived out within the hospice.

Figure 1: Person-centred Practice Framework (McCormack and McCance, 2019)



Practice development methodology

To operationalise this theoretical perspective, practice development methodology was applied with the key aim of transforming the context and culture within the hospice (Manley et al., 2013). This methodology includes processes such as: developing shared values among team members; having a shared vision for ideal practice; developing team relationships; using workbased reflective learning strategies; engagement in critical questioning; and adopting a systematic approach to changing everyday practice (Manley et al., 2013). The key aim is to direct attention to the micro-level of practice, where healthcare is experienced and provided. The principles of participation, collaboration and inclusivity always underpin evaluation activities in practice development (McCormack and McCance, 2006). The focus is on engaging practitioners, through creative learning methods and skilled facilitation, in critical questioning about their own practice and enable them to answer their own questions.

In order to achieve this, the multidisciplinary project group carried out the project over a period of 18 months across 10 dedicated eight-hour facilitated learning and development days. The structure and design of each day were informed by the principles of practice development (Dewing et al., 2014). See Table 1 for details of each day's themes and activities.

Table 1: Themes and activities of the 10 programme days

Project programme days		
Day	Theme	Focus/learning activities/PD activities
1	Getting to know each other and understanding practice development and person-centred care. Starting to learn about observation in practice	<ul style="list-style-type: none"> • Introductions through ‘how you got here today’ exercise • Exploring practice development – looking at the PD journey • Exploring own values and beliefs around person-centred culture and palliative care using envision cards • Reflective walkabouts in pairs: <ul style="list-style-type: none"> – Starting three to five minutes away from the hospice and walking towards and into reception – Walking into reception and into key area – pausing, sitting and observing
2	Values and beliefs around person-centred care	<ul style="list-style-type: none"> • Facilitated reflection on previous session and thoughts • Values and beliefs clarification exercise on person-centred culture in the working group
3	Preparation to engage wider hospice in values and beliefs clarification exercise on person-centred culture	<ul style="list-style-type: none"> • Facilitated reflection on the values and beliefs exercise from the previous session • Discussion, planning and creating materials to engage wider hospice in values and beliefs clarification exercise: patients/families/staff/volunteers and visitors
4	Creating shared vision statement	<ul style="list-style-type: none"> • Analysing data from the wider hospice values and beliefs clarification exercise • Creating shared vision statement • Discussion and preparing materials for feedback to wider hospice
5	Getting ready for workplace culture assessment and deepening understanding of the role of observation in evaluating practice	<ul style="list-style-type: none"> • Reflection on learning so far • Creative culture workshop • Exploring the Workplace Culture Critical Analysis Tool (WCCAT)
6	Developing evaluation tools	<ul style="list-style-type: none"> • Using the WCCAT to design observation and interview tools (real-time interviews) • Devising a plan to evaluate using the above
7	Evaluating	<ul style="list-style-type: none"> • Undertaking observation in practice and real-time interviews
8	Understanding and undertaking analysis	<ul style="list-style-type: none"> • Hermeneutic analysis of workplace evaluation data
9	Findings	<ul style="list-style-type: none"> • Preparation for creative feedback session for the senior management team and wider hospice
10	Feedback	<ul style="list-style-type: none"> • Reflections on feedback session for senior management team • Preparing feedback for wider hospice

The project days enabled participants to consider their own values and beliefs and to come to a shared understanding of current practice through exploring what person-centred culture means in the hospice context. The days also gave staff the chance to become familiar with each other – this was vital for the group as it allowed exploration of sometimes-challenging and emotional areas of practice as well as developing a climate where success could be shared and congratulated. McCormack and Dewing (2013) discuss the importance of this type of learning for individuals to develop and transform by moving out of their comfort zone to actively engage in evidence-based and sustainable change processes. Participating in the workshop activities and reflecting on practice allowed individuals within the group to experience emancipatory and transformational approaches to practice development (Shaw, 2013). These approaches were used to shine a light on our ways of working and to highlight the current culture in order to understand it and ultimately to bring about a change in individuals and teams.

Getting inside and developing current culture

Having established a shared understanding and vision for person-centredness within the hospice, the project group sought to gain a deeper insight into current practice. This was done through observations and real-time interviews informed by the Workplace Culture Critical Analysis Tool (WCCAT; McCormack et al., 2009). The tool was developed to enable engagement throughout the process of undertaking an observational study, analysing the data, feeding back to clinical teams and developing action plans. The tool adopts five phases:

- Pre-observation
- Observation
- Consciousness raising and problematisation
- Reflection and critique
- Participatory analysis and action planning

Observation

As part of the pre-observation phase, staff and managers were informed about the observation to clarify the process and reduce potential anxiety. Ethical principles underpinning the process were also clarified and ethical approval was gained from Queen Margaret University. Following on from this, 41 sets of observations, each lasting up to one hour, of day-to-day practice were conducted during the day time. These were undertaken in the inpatient wards, multidisciplinary workrooms, reception and corridors in staff areas.

Consciousness raising and problematisation

To gain deeper understanding of the culture, 24 interviews with staff, volunteers and patients were conducted. Key questions in the interviews included:

- What is it like to be a staff member or patient in the hospice?
- Can you give examples of effective or ineffective teamwork you have experienced? (staff and volunteers only)
- In what way do you feel valued/or not as part of this community at St Columba's Hospice?
- Can you describe how the hospice provides a safe environment that allows open and honest communication? (staff and volunteers only)
- How well do you feel your needs are being met? (patients only)

Reflection and critique

The next step in the process was to share the findings from the analysis with the senior management team and the wider organisation. A creative presentation was developed for senior management, and drop-in sessions were held over a one-week period to encourage involvement from the wider organisation. These enabled the management team and staff to engage with the practice development process used throughout the project and the findings of the WCCAT observations. The key purpose of these sessions was to generate dialogue regarding person-centred culture in the hospice, as well as to seek agreement on areas of practice that needed further exploration or development. The findings from the WCCAT led to some discomfort for staff and the management team, and a range of feelings were expressed through the process. Expressions of pride were associated with positive findings, while disappointment and at times disbelief were conveyed in relation to the more negative findings. This was at times challenging but was part of the process of acknowledging and accepting the complexity of achieving person-centred practice within the organisation and identifying where change could happen. It is recognised within the practice development methodology that this is a challenging process as attention is being drawn to differences between values espoused and those observed in practice (McCormack et al., 2009).

Participatory analysis and action planning

Data from the WCCAT were analysed as a participatory process by the project group. This proceeded in four phases.

- Phase 1: collating and reviewing the evidence. The project group read and re-read the data, identifying anything that was striking
- Phase 2: analysis and interpretation of the evidence. The group made sense of the data by reviewing and discussing what had been observed and expressed through the interviews. Entering into dialogue generated deeper engagement with the data and the themes emerging. To get an overall understanding of the data and represent the experience, the project group developed images and metaphors to illustrate what was emerging (Simons and McCormack, 2007)
- Phase 3: data were mapped against the Person-centred Practice Framework (McCormack and McCance 2017, 2019 amendment)
- Phase four: based on the findings, the project group identified, with staff teams, areas that should be considered for action planning

Findings from the WCCAT observation

Mapping the data collected through the WCCAT observation against the Person-centred Practice Framework highlighted issues with how well person-centred care was lived out in practice. While there was evidence of positive person-centred practice outcomes for patients, it was within the care environment construct, or the context where care is delivered, that the project highlighted areas for improvement.

Person-centred outcomes for patients

It was clearly demonstrated that person-centred practice was being experienced by patients and families, and integrated in day-to-day practice within the hospice. Many examples of exemplary person-centred practice for patients were evident in the data and were verbalised by patients when describing how they felt being a patient/family member in the hospice:

‘Being a patient here is lovely, different staff all know what is going on – they clearly talk to each other, just as it should be.’

‘The communication is honest and open, [I] tell everything to the doctors and nurses and they are straight with me about what’s going on.’

‘The stewards showed me the locking [windows and exterior doors] which made me feel safe.’

During the project, staff were able to celebrate these areas of practice. These positive findings were shared among the group and demonstrated how person-centred care was valued and lived out in day-to-day care for patients within the hospice.

Person-centred outcomes for staff

The data that were mapped against the care environment construct of the Person-centred Practice Framework drew attention to the complexity of care delivery in the palliative care setting. It was evident that the person-centred care delivered for patients gave staff a sense of meaning and worth and this was widely expressed.

‘It’s an enjoyable job which offers an opportunity to make a difference with patients and we are all proud of working in the hospice.’

‘You feel you are doing something worthwhile, I feel better in myself for it.’

However, while many staff members described the joy of working in the hospice, they also described how pressure could impact on their feelings of wellbeing at work. The data highlighted the demand, and at times the stress, that staff faced in order to ensure person-centred outcomes for patients and families. Staff described how working in the hospice could be stressful and how their sense of wellbeing tended to be overshadowed when under pressure, as illustrated by the following quotes:

'It is stressful to work here, I get a constant feeling that I can't cope and I don't work hard enough or fast enough.'

'How staff feel is important and this needs addressed to improve care.'

Our analysis highlighted a certain tension and ambiguity, revealing that staff perceived the experience of working in the hospice as very positive, but also very challenging, as summarised in the following quotes.

'To be a nurse in the hospice is challenging, exciting, upsetting, saddening and frustrating.'

'Working here is challenging, demanding but rewarding.'

Hermeneutic analysis of the data highlighted how staff members could, in the same sentence, describe how wonderful it felt to work in the hospice and how incredibly demanding it was. This was further evident in the image chosen by members of the group to reflect their feelings about working in the hospice (Figure 3). What the image brings into focus is the ambiguous space between the positive and the negative – the rain, the sun and the rainbow representing the complexity of the context in which hospice staff work.

Figure 3: The sun and the rain



The data revealed staff generally describing positive relationships with each other and a clear sense of mutual respect.

'Staff laugh, get on well and support each other.'

'I feel valued here.'

'On the whole I think colleagues respect what I do.'

However, there was also evidence that when demands of work increased, some felt that teamwork could be better.

'[There can be] a breakdown in teamwork when we're not working towards the same goals.'

'It feels like there is sometimes lack of team spirit and lack of good teamwork.'

'It feels like we're working in silos.'

Despite such tensions, the drive and desire to support each other and to strengthen cohesion and connections was evident across all areas and teams. The image the group chose to illustrate the findings of the hermeneutic analysis that people wanted to connect better was one depicting hands trying to reach each other but not quite getting there yet.

Figure 4: Good place to work... reaching out to each other.. some closer than others



Action planning

Based on the two images that represented the essence of the whole dataset, the members of the project group ran fourth-generation evaluation workshops with their teams using a claims, concerns and issues exercise (Guba and Lincoln, 1989). This enabled them to critically reflect, in a safe environment, on their own ways of working as a team and on their own sense of wellbeing at work. Teams were able to identify what was currently effective and what their remaining concerns were, and to develop critical questions to improve the context in which care was delivered. All teams that participated developed their own action plans to address the issues raised, based on their own critical questions. Examples of what was included in the action plans are as follows:

- Increase formal forums and opportunities for reflection and debriefing
- Have small breaks together when working, to allow for a 'breather' and for reflection, for example when doing a ward round
- Create better relationships between different teams, set up meetings to discuss structures and processes related to shared tasks and how these are managed between the teams
- Increase opportunities for the ward leadership team to meet together

In addition to working with individual teams, an external organisational development facilitator ran workshops for all hospice staff as part of the hospice's mandatory programme of education. The workshops created an opportunity for staff to connect, get to know each other better and share values and beliefs around the work of the hospice. These sessions proved valuable in providing a safe space where issues could be voiced, shared and heard, as well as in allowing time to be spent with other teams. This was evident in the following quotes:

'I really enjoyed this session. It was really good to consider the impact of the culture within an area and the wider impact it has on the team.'

*'Brilliant opportunity to spend time with colleagues from other departments and hear their views.'
'Really good session. Probably best thing ever for integration of departments.'*

Discussion and implications for practice

In order for hospices to be extraordinary places, it is necessary to pay greater attention to the care environment construct of the Person-centred Practice Framework (McCormack and McCance, 2017, 2019 amendment). Person-centred outcomes are beneficial not only for people who are being cared for in hospices but also for the staff who care for them. The aim of a person-centred organisation is to create a place with the necessary conditions to allow people to flourish and ultimately foster a 'healthful culture' (McCormack and McCance, 2019). Such an environment allows staff to deliver person-centred care and consequently improves job satisfaction and staff retention (The King's Fund, 2010). This relates to human flourishing, which has been described as a situation where individuals are in a continued state of wellbeing, are able to remain at their best for prolonged periods of time and have the resilience to bounce back stronger when challenged (Seligman, 2012). The eight conditions required for a person to flourish have been outlined as: bounding and framing; co-existence; embracing the known and yet to be known; being still; living with conflicting energies; embodying contrasts; harmony; and loving kindness (McCormack and Titchen, 2014).

In considering our findings as they relate to the conditions for human flourishing, harmony, loving kindness and being still are reflected in the positive outcomes described for our patients and families and in the evident pleasure and fulfilment of staff that they are able to provide care that leads to this. These are metaphorically reflected in the sun behind the rainbow of our illustrative photo (Figure 3). However, that this photo also contains rain may illustrate concerns relating to the conditions for human flourishing that are more dualistic in nature: embracing the known and yet to be known, living with conflicting energies and embodying contrasts. Finally, the condition of co-existence, which underpins a healthful environment, supports person-centred practice and care and encourages healthful relationships, is demonstrated by the image of 'hands reaching out' (Figure 4). This reflects a desire among staff at the hospice to support and connect with each other as well as with those they care for.

Cameron (2010) suggests that flourishing can take place even in organisations where internal or external challenges exist. Aranda (2008) describes a 'tyranny of niceness' in palliative care, which dominates and limits the capacity to confront or even engage with what does not fit the frame of niceness of hospices and hospice care. She highlights how such a culture suppresses the expression of feelings about more challenging areas of practice, which can lead to a downplaying of the emotional labour involved in providing care in this setting. Emotional labour, initially described by (Hochschild, 1983) and later applied to nursing (Smith, 1992; Smith and Lorentzon, 2008), describes the affective aspect of healthcare work where staff may be required to express or maintain a particular emotion when experiencing another. This is more colloquially understood by nurses as the 'emotional work' that is a vital component of their role (Gray, 2009). Without acknowledging hospices as challenging places to work in, such demands may be downplayed rather than embraced and dealt with. Dealing with the distress of dying patients and of their families and friends brings unique pressures, and complaining or being less than fully selfless could well induce feelings of guilt that compound this pressure. The physical environment of hospices is often aesthetically pleasant and they are frequently seen as nice places to be in for staff. However, the reality is that they will experience pressures and demands, as evident in the findings from this project.

Increasing pressure to be effective, efficient and accountable are being experienced by all areas of healthcare, and hospices are no exception (Hospice UK, 2015). This creates high goals in the face of increasing demand. Such contradictions and competing pressures will exert their toll on the capacity of hospice staff to deliver the best possible care and at the same time take care of themselves and their colleagues. It is the combination of the many positives of hospice work and the more difficult and challenging aspects that can create a dissonance, and this ambiguity should be accepted first of all as a

way to live with contrasts and to embrace the unknown as well as the known. To be healthful places to work in, hospices need to embrace all the experiential dimensions of staff at all levels as well as those of patients. Doing so will foster the mutual respect and understanding that is so important to this aim.

Adopting a person-centred culture that fully extends to the workforce can be facilitated through not just celebrating the inspirational and positive side of hospice work but by acknowledging and embracing the high challenge that hospice care entails. Doing so can develop a transformational, healthful culture and ultimately bring rewards to hospices. The real desire to achieve such an environment and workplace culture in the St Columba's Hospice, through connecting and supporting each other, was clear in the findings from this project.

Conclusion

This paper has highlighted how person-centred practice can be achieved disparately in the same environment. Some preconditions are met yet others are not, which limits the capacity for human flourishing. As highlighted earlier in this article, developing and improving person-centred culture will not be achieved by a one-off project; rather it is a continuing process of raising awareness, asking critical questions and responding, as described here. Ultimately it is hoped that this ongoing process will lead to staff flourishing in their practice. Allowing the necessary space for this to happen is vital for organisations committed to person-centred culture; for St Columba's Hospice, the critical exploration of routine practice has become a transforming change agent within the workforce. The project will continue to inform its strategic direction and focus in various ways as we move forward.

There is black, there is white and there are shades of grey. More poetically put, there is sunshine, there is rain and if both are fully embraced, there can be a rainbow.

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