Revealing and acting on patient care experiences: exploring the use of Photovoice in practice development work through case study methodology

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Abstract
Traditional efforts in healthcare to evaluate patient satisfaction with care, an outcome expected from effective person-centered practices, rely heavily on survey methodology. At West Park Healthcare Centre, a rehabilitation and complex continuing care facility in Ontario, Canada, data from patient satisfaction surveys were proving insufficient on their own to inform and ultimately motivate those in a position to bring about improvement in person-centered practices. Additional and more effective strategies were therefore sought as part of a larger practice development initiative to evaluate our progress in accomplishing person-centered outcomes for our patients and to guide the planning of continuous improvement strategies. Photovoice was selected and evaluated through qualitative within-site, multiple case study design as a method to reveal the care experiences of patients living in complex continuing care and facilitate change based on expressed needs and concerns. The findings suggest Photovoice improves understanding of:

- The factors that influence patient satisfaction with care
- The practice changes required to enhance the person-centeredness of that care

However, Photovoice did not result in consistent shifts in care practices based on the improved understanding. Going forward, these findings suggest more work is needed to help the organisation move beyond an understanding of what matters to patients to acting on that knowing.

Keywords: Practice development, person-centered practice, patient satisfaction, Photovoice

Introduction
West Park Healthcare Centre (the centre), a rehabilitation and complex continuing care setting in Ontario, Canada, has implemented practice development as one means of facilitating person-centred, evidence-informed practices. Practice development is an internationally tested change model involving a systematic emancipatory process of facilitation towards care and workplace cultures that are person-centred (Manley et al., 2008). Practice development facilitators within the centre – specially trained nursing and allied health clinicians – have been using collaborative, inclusive, and participatory approaches since 2010 to help flatten hierarchies within the organisation and support those who visit, work and live in the centre to share accountability for quality, become agents of social change and address barriers to person-centred, evidence-informed practices.

The person-centred nursing framework developed by McCormack and McCance (2010) was selected to guide the work. The framework identifies the staff prerequisites and care environment required
to enable person-centred practices, the specific care processes for integrating person-centredness into practice and the expected outcomes of person-centred practices. The latter include patient satisfaction with care. Annual patient satisfaction surveys were used in the early phases of the practice development work as the primary tool for evaluation of our outcome successes. Consistent with the perspective of McCormack and McCance (2010), however, the survey results failed to provide sufficient detail to reveal the full story behind patients’ levels of satisfaction with care and what specifically was needed to enhance the person-centredness of that care. The results were too vague to guide effective quality improvement.

Moving forward with the practice development work, additional strategies were sought to supplement the survey data for evaluation of patient satisfaction. Photovoice was selected as a strategy to investigate as, according to Palibroda and colleagues (2009), ‘photographs offer powerful concrete evidence of a reality... that words simply cannot capture’ (p 10). Furthermore, as suggested by Findholt and colleagues (2010), ‘images teach’ (p 187). It was anticipated that Photovoice would teach us something about the patient care experience in complex continuing care beyond what results from surveys revealed and ultimately, lead to action in respect of person-centred practices.

Literature review
The process of Photovoice involves equipping individuals with cameras so they can take pictures that symbolically represent their world. The images are meant to ‘tell stories’ that highlight concerns, relay struggles or show a particular view of a community. Those who take the pictures discuss and critically reflect on the images as individuals and subsequently as a group. Participant-informed narratives about the photographs are written to accompany the images. The process culminates in a gallery showing of all or selected photographs by the group to ‘influential advocates’ – persons perceived as having power to act on community concerns and facilitate action for change (Hergenrather et al., 2009). Those who view the pictures are afforded an opportunity to see the world through the eyes of the photographers, who, in turn, are empowered to reveal their reality from behind the lens, offer insight and teach others about their experiences (Palibroda et al., 2009). It has been suggested that Photovoice is able to uncover rich descriptive information (Catalani and Minkler, 2010) as well as arouse strong emotional reactions and challenge assumptions embedded in cultural norms, leading to significant changes in how persons think and behave (Carlson et al., 2006).

Photovoice was developed in the 1990s by Wang and colleagues to study rural women in China (Wang and Burris, 1997). The theoretical and practice foundations of Photovoice are derived from Paulo Freire’s theory of critical consciousness, feminist theory, documentary photography, public health promotion, and grassroots social action (Wang and Burris 1994; 1997; Wang 1999). Since the work of Wang and colleagues, Photovoice has been used as an approach to participatory action research in the study of different human experiences across varied community groups, most often marginalised or vulnerable in nature (Baker and Wang, 2006; Frith and Harcourt, 2007; Findholt et al., 2010; Bukowski and Buetow, 2011).

While no studies were found that related directly to this study’s focus on patient satisfaction in the specific context of complex continuing care, Photovoice has been used with populations similar to the study’s patient population: patients living with chronic illness (Fritz and Lysack, 2014; Hermanns et al., 2015), people with intellectual disabilities (Povee et al., 2014), and older adults living in assisted living facilities (Lewinson et al., 2012). Photovoice has also been studied in relation to a concept similar to this study’s central concern of person-centred care: that of patient-centred care (Lorenz and Chilingerian, 2011).

The outcomes of Photovoice have been comprehensively summarised in two reviews of the methodology (Hergenrather et al., 2009; Catalini and Minkler, 2010). The outcomes overall reflected:

- Increased individual empowerment as well as community engagement in advocacy for change
• Improved understanding of community needs and assets within a community itself as well as among influential advocates
• Development of plans of action based on community concerns

Eventual change in programme and policy stemming from the plans of action has been reported in some studies but the length of time taken to realise community change has exceeded the lifetime of many studies, limiting the identification of Photovoice as a contributing factor.

Patients in complex continuing care are vulnerable due to their dependency on others brought about by chronic illness and institutionalisation. They can also be defined as marginalised due to the disabilities that accompany their disease trajectories and their consequent risk of being relegated to the outer edges of mainstream society. There was therefore a perceived fit between this patient population and the theoretical target population of Photovoice (Wang and Burris, 1997). This study aimed to explore this perceived fit by answering the following research questions:

1. How is Photovoice experienced as a process for facilitating patients’ expression of care experiences and for promoting action for service improvement from the perspective of:
   a) patients in complex continuing care?
   b) influential advocates within a healthcare organisation?
2. How effective is Photovoice in facilitating action for service improvement based on patients’ care experiences?

Methodological approach
A qualitative, within-site, multiple case study design was used. For purposes of this study, a case with clear boundaries for inclusion was defined as an individual patient living on one of the centre’s complex continuing care units who was involved in the Photovoice strategy from the start of photographing to six months following the gallery exhibit of photographs (see Table 1 for Photovoice phases). Purposeful sampling was used to recruit eight patients living on any one of the four units. Through personal face-to-face invitations, the staff co-researchers invited patients who spoke and understood English, independently or with assisted communication, and were:

• Willing to learn photography skills
• Willing and interested in working towards long-term practice change
• Enthusiastic about working in a group
• Willing to share their care experiences openly with other participants and eventually stakeholder groups

Inviting participation from patients across the centre’s complex continuing care units reflected maximum variation as a sampling strategy, allowing for inclusion of diverse cases and multiple perspectives on the experience and impact of Photovoice (Creswell, 2007).
Table 1: Photovoice phases

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description</th>
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<tr>
<td>1: Group training on photography skills, Photovoice ethics, and safety</td>
<td>The patient co-researchers met with the staff co-researchers to learn about photography and decide on the parameters for their photo assignment (for example, how many pictures each person would take or whether or not to include people in the pictures). The team established group rules for the project around issues of respect, listening, sharing, and confidentiality. The workshop helped promote feelings of safety and belonging within the group.</td>
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| 2: Photo assignment | The patient co-researchers worked with a staff co-researcher (PD), who helped them take pictures to represent their care experiences in complex continuing care. The patients made all decisions about what and how they wanted to photograph. They then met with another staff researcher (KB) to create the narratives to go with their photographs. The narrative writing was loosely guided by the acronym PHOTO (Hergenrather et al., 2009):  
  - Describe your Picture  
  - What is Happening in your picture?  
  - Why did you take a picture Of this?  
  - What does this picture Tell us about your care experiences?  
  - How can this picture provide Opportunities for us to improve your care experiences? |
| 3: Critical group discussions | The research team met on five separate occasions to discuss all the photographs and the narratives. This process was facilitated by NJ. She first facilitated the patient co-researchers’ identification of the themes reflected in the photographs. Then, the patient co-researchers identified which themes were reflective of their collective experience and therefore appropriate for the gallery exhibits. Finally, the patients picked which photographs would be exhibited to represent the collective themes. |
| 4: Gallery exhibits | The 10 exhibit(s) of the selected photographs and accompanying narratives were scheduled by the patient co-researchers, who decided which ‘influential advocates’ to invite. All invitees received an email invitation to the gallery. The photographs and narratives were enlarged and mounted on easels. During the exhibit, patient co-researchers discussed the project and photographs with attendees. The exhibits provided an opportunity for patient co-researchers to communicate directly with influential people, to express their concerns creatively, and to become further engaged in efforts to address these concerns. |
| 5: Action as outcome | This phase involved monitoring by the staff co-researchers of any measurable action stemming from the gallery exhibits as perceived by the patient co-researchers and verbalised through formal and informal discussions. This phase also involved working with patient co-researchers to create methods of disseminating the Photovoice work that led to the creation of a soft-covered book and an Uberflip web-based book. |

Consistent with Creswell’s (2007) inception of case study design, the researchers explored multiple cases over time (throughout the duration of the Photovoice strategy) through detailed, in-depth data collection involving multiple sources of information including:  
  - A total of 102 field notes from participant and non-participant observations of the five staff co-researchers  
  - A total of 30 written transcripts of 1:1 interviews with patient co-researchers following each phase of the Photovoice strategy  
  - Results from 75 returned questionnaires administered to influential advocates who attended the gallery viewings of the photographs
Inductive, within-case data analysis identified process and outcome themes for each of the eight individual cases. This was followed by an analysis for themes that crossed cases. Process and outcome themes reflecting the Photovoice experience of influential advocates was revealed through a parallel thematic analysis.

Rigour was enhanced by hiring an external research assistant, who accompanied participants during the photo assignment phase of the project to assist with the technical aspects of using the camera as required and to provide support and encouragement. The research assistant had no insider preconceptions about patients’ care experiences in complex continuing care, unlike staff at the centre, so was able to refrain from influencing the photographs participants chose to take and the meaning they assigned to their choices. A number of checks and balances were also carried out throughout the qualitative data collection and analysis processes to maintain acceptable standards of scientific inquiry. These were based on the four factors identified by Denzin and Lincoln (1994) to establish the trustworthiness of qualitative findings (credibility, transferability, dependability and confirmability), and included:

- Assigning each component of data analysis to a minimum of two staff co-researchers, changing the dyad combination for different components
- Taking detailed field notes including descriptive and reflective content
- Keeping memos of key analytic decisions
- Holding frequent peer review meetings

Ethics approval was received from the research review board of the participating institution.

Findings
The eight patient co-researchers were aged between 35 and 75 years (median 62.5 years) and there were five women and three men. The patients lived with various chronic conditions, with two being dependent on ventilatory assistance to breathe, seven dependent on a wheelchair for mobility, and four dependent on communication assistance (such as a spelling board) to express themselves. They also had varied needs in terms of additional specialised treatment, such as enteral nutrition, tracheostomy care, and wound prevention and management.

The Photovoice assignment culminated in a set of 20 enlarged photographs with accompanying narratives (see Figure 1 for examples). These represented the collective care experiences and concerns of complex continuing care patients under nine themes:

- Journey
- Opportunity
- Time
- Equipment
- Relationships
- Control
- Safety
- Listen
- Peace

The set of photographs was displayed at gallery exhibits on 10 occasions within the centre. It was also translated into a soft-covered book and a web-based Uberflip book available at westparkhc.uberflip.com/i/318654-photovoice. The reader is encouraged to access the Uberflip book at this point for a virtual gallery exhibit experience. By clicking on the pictures of the patient co-researchers, the reader will hear their perspectives of their care experiences and/or of the Photovoice process. The remainder of the findings section will focus on the experiences of the influential advocates who attended the gallery exhibits and of the patient co-researchers, to reveal the effectiveness of the Photovoice method.
When I think of blankets, I think of my past and what I was able to do with a sewing machine. It’s a happy memory. It was an expression of me and my creativity. Blankets are soft, warm, and comforting and that is what I would like my care experience to be. I want to feel the comforts of being wrapped in a blanket and feel secure.

Blankets

You are chained to scheduling. There has to be scheduling, but it is important to have some control and flexibility over your own schedule. I just want to be free from the clock. I want to be given the chance to be asked for my opinion and for my opinion to be heard.

Tick-Tock

I appreciate the calm and serene atmosphere. Since the move people are more tense. When one person is angry it affects everyone. When I feel like I am surrounded by nature it fills me with hope. Deep down I know I can cope.

Fountain
The experience of influential advocates

A total of 141 influential advocates invited by the patient co-researchers attended one of the 10 Photovoice gallery exhibits scheduled between April and June 2012. Attenders included service and clinical staff, managers at all levels up to senior leaders, board members, patients and families. A questionnaire was distributed at the gallery exhibits and was returned by 75 (53%) of those who attended. These responses led to the following descriptive account of the influential advocate gallery experience (themes in bold).

Influential advocates came to the gallery exhibits with a range of feelings and thoughts about what they were about to experience; these feelings and thoughts sat along a continuum of eagerness through to disinterest. In between were feelings of curiosity, interest and uncertainty. Advocates’ thoughts and feelings about the patient care experiences specifically ranged from uncertainty to a ‘solid’ conviction that the care experience was positive. There were some, however, who described the care experience as negative and others who thought it to be a mix of negative and positive.

The gallery exhibit was experienced by the advocates as an engaging and revealing process. As a result of their experience with the exhibit they highlighted a new understanding of patients as able, and thought the meaning behind the patient co-researchers’ photos to be profound, enlightening and inspiring. With regard to being enlightened, some learned that the patient care experience was better than they had thought and many were surprised by the positivity of the patient co-researchers’ messages. Few of those who attended left the exhibit feeling the care experience was worse than they had assumed or with an affirmation that their original understanding of patients’ care experiences had been accurate.

Attenders described being emotional and reflective after their exhibit visit. They described the Photovoice method as effective in enabling patient expression and for facilitating engagement of patients with others. A number of responses from attenders revealed that they had experienced learning about patients’ care experiences after the gallery viewing as well about the importance of the patients’ voice. Some also described learning about patients as persons. The majority of attenders agreed the gallery exhibit had an impact on them and some left with a commitment to or ideas about actioning on their learning through a range of specific or general activities. The most common of these, in descending order, were:

1. Take the time to communicate with patients and hear what they have to say
2. Keep the gallery experience alive and share the learning
3. Don’t take the impact of ‘small things’ for granted
4. Bring hope and optimism

The experience of patient co-researchers

Process themes

The gestalt of the patient co-researcher experience of Photovoice was positive as revealed in a synthesis of data from interviews and field notes. In terms of process, nine themes (in bold) were identified (see Table 2). The individual patient co-researcher experiences (within case) were reflected by between three and eight of the nine themes with no two co-researchers experiencing the same composite of themes.

All eight patient co-researchers demonstrated creative focus, a clear idea of what messages they wanted to convey in their photographs. Not one co-researcher displayed any difficulty translating their message into a photograph of something metaphorically representative of that message. Seven made very specific reference to enjoyment of their Photovoice experiences, even though challenge and fatigue featured for some. Five of the patients were impacted by communication and/or cognitive deficits, revealed by a lack of depth in their narratives or in the discussion they were able to engage in with gallery exhibit attenders. Memory difficulties made it hard for some patient co-researchers to
recall the meaning underlying some of their photos over time, particularly when there was a stretch of time between various phases of the project. In addition, fatigue levels in five of the patient co-researchers made it necessary to monitor and adjust the timing of activities as well as the length of time they were expected to engage in Photovoice activities.

The collaborative and democratic nature of the Photovoice experience was highlighted by five patient co-researchers through the theme of working together. There was a spirit of teamwork and an ease in achieving consensus over issues that arose during the project, including details surrounding the gallery exhibit and selection of the photographs that would be presented to represent community needs. Five patient co-researchers highlighted the process as a way to speak on behalf of others, reflected in the theme advocacy. They spoke of the inability of some patients to express themselves verbally and the consequent need for an alternative means of presenting their views. Photovoice was identified as an effective alternative, described by four patient co-researchers as a unique and effective opportunity for expressing themselves, one that some wished other patients could benefit from.

Hesitancy to engage in Photovoice at the beginning and/or throughout the process was explicitly identified by four of the patient co-researchers, thematically captured as trepidation. While a concern that the process would be time consuming was identified by one, the greatest fear expressed was of how staff might respond to the messages in the photographs. Finally, one patient co-researcher expressed disappointment, speaking about the lack of depth she perceived in her co-researchers’ photographs, as well as in the gallery exhibit discussions she experienced with the advocates. Her expectations of the work were, at times, not met.

### Table 2: The patient co-researcher experience of Photovoice

<table>
<thead>
<tr>
<th>Patient co-researchers</th>
<th>PROCESS THEMES</th>
<th>OUTCOME THEMES</th>
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<tbody>
<tr>
<td></td>
<td>Creative focus</td>
<td>Enjoyment</td>
</tr>
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<td>1</td>
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<tr>
<td>8</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>TOTAL</td>
<td>8</td>
<td>7</td>
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Indicates theme is present in the case

### Outcome themes

From the patient co-researchers’ perspective, there were eight outcomes of the Photovoice project. Table 2 indicates which outcome themes were identified in which cases. None of the outcome themes
was consistent across all patient co-researchers’ experiences. The individual patient co-researcher experiences (within case) were reflected by between one and six of the eight themes, with no two researchers experiencing the same composite of themes.

The feeling of being heard was identified as an outcome of the Photovoice experience by five patient co-researchers. This theme of **empowerment** was aptly captured in one patient’s statement:

> ‘Some people think when they see patients that there is no being in there... we had a chance to show them the being.’

Close to the outcome of empowerment was the perception of three patient co-researchers that Photovoice had been effective in **messaging** - conveying patients’ needs and wants. This outcome was more about the effectiveness of Photovoice for communicating a message and less about the emotive outcome of being empowered and heard. There were five patient co-researchers who displayed **pride** in the Photovoice work through their eagerness to share the work with as many individuals as possible. They enthusiastically suggested ways to disseminate and make permanent the photographs and narratives so the work would not disappear. One expressed his pride through his description of feeling ‘exalted’.

Photovoice led to four patient co-researchers feeling they had a better understanding of their patient peers and what was important to them. This theme of **knowing others** involved learning the universality of patient needs and wants, a surprise to some of the patient co-researchers. Learning about others aside, two simply highlighted **interaction** as a valued outcome of Photovoice, particularly the gallery exhibit component. Increased interaction with others, whether or not those interactions led to any continued relationships, was appreciated. **Personal growth** was also experienced by three patient co-researchers, who clearly expressed change in themselves; they identified some personal strength or ability that developed through their involvement in the project.

**Discussion**

The results of this study suggest that visual methodologies like Photovoice may be useful adjuncts to survey methodology when evaluating the outcome of practice development work towards person-centred practices. Photovoice did indeed facilitate patients’ expression of care experiences, making explicit what matters to them in the context of living in complex continuing care and, by extension, what is likely to lead to their satisfaction with care. The aspects of care that were revealed as important ranged from very precise caregiving activities (for example, the use of a small spoon when assisting with eating) to the general relational competencies of care providers (such as ‘be comforting’). Influential advocates who attended the gallery exhibits attested to the learning they took away, while the hosts of the showings – the patient co-researchers – expressed confidence that their messages had been communicated. What was less evident was the effectiveness of Photovoice in facilitating action for service improvement based on patients’ care experiences.

Photovoice makes up for some of the limitations of survey methodology when evaluating patient satisfaction. Surveys have been criticised for: a lack of specificity or meaning of questions and their relative importance as quality indicators (Wysong and Driver, 2009; Otani et al. 2011); for the questionable representativeness of survey content, most often developed by ‘experts’ alone rather than with patients (Castle et al., 2005); for the lack of timeliness between patient responses to a survey and reporting of results (Quinn, et al., 2004); and for the frequent disconnect between quantitative
data and patient comments (qualitative data) (Santuzzi, et al., 2009). These deficiencies make it difficult to decide how best to structure quality improvement priorities based on survey results. In contrast, the use of Photovoice in this work afforded the opportunity for influential advocates to see (photographs), read (narratives), and ultimately hear (interactions with patients) about very discrete caregiving actions that impact on patient satisfaction in the moment. Patient co-researchers were in charge of deciding what community needs they wanted to message and were available to qualify their messages through discussions at the exhibit, leaving influential advocates enlightened about what matters from the patient perspective. These benefits of Photovoice affirm what others have identified as strengths of the methodology (Hergenrather et al., 2009; Catalini and Minkler, 2010).

Despite enhancing learning about patient satisfaction and the impact of specific indicators, Photovoice did not lead to organisational actioning on that learning during the course of this study. That is, patient co-researchers did not universally identify actual changes in their care experiences as a result of Photovoice. Influential advocates left with ideas about how to enhance patient satisfaction and with the intent to engage differently with patients, but their follow-through was not apparent to all patient co-researchers. Perhaps the study was not long enough to capture any changes that might eventually emerge. Or perhaps the lack of action experienced was more a reflection of the distance we have yet to travel in creating a culture of person-centredness.

Rozenblum and colleagues (2011) studied clinician responsiveness to the needs and expressed preferences of patients and found that even when clinicians think it is important to obtain information about patient expectations and respond adequately, they often fail to follow through on that response. They suggest this is in part due to clinicians’ lack of knowledge about how to cope with and respond to patient expectations. If our clinicians fit this category, it speaks to ongoing gaps in the prerequisites, care environment factors, and care processes required for person-centredness to thrive (McCormack and McCance, 2010). Perhaps our clinicians are as yet lacking in interpersonal skills and clarity of beliefs and values (prerequisites) and perhaps we still struggle with power sharing and with innovation and risk taking (care environment). It may be that even if our staff better understand what matters to patients, they don’t yet know how to work with patient’s beliefs and values and provide holistic care (care processes). Photovoice may have helped us better understand what matters to patients but as an organisation, we are not yet person-centred enough to act on that understanding. The theme of trepidation revealed by four of the patient co-researchers supports this proposition: in an organisation that had mastered the culture shift towards person-centredness, would patients need to worry about staff reactions to their expressions of need and want?

This study supports the propositions of others that survey methodology alone is insufficient to measure the results expected from effective person-centred practices, particularly patient satisfaction (McCormack and McCance, 2010; de Silva, 2014). Photovoice emerged as a more meaningful and effective method for facilitating patients’ expression of care experiences in ways that stirred emotions, and inspired and enlightened others. From Photovoice we received the information needed to gauge our successes and developmental opportunities for enhancing the person-centredness of our practices. While we were not so naïve as to expect that Photovoice would lead to a revolution in our care practices, we hoped that more of our partner patient co-researchers would experience some shifts in the their care experiences as a result of their Photovoice involvement. However, the lack of identifiable action on the learning from the gallery exhibits was nonetheless a useful learning point for the future. We have reason to suggest that while we have created an openness to engaging with patients and hearing their stories, we have perhaps fallen short in supporting staff through the development of their skills and the building of a care environment that helps them act on what they hear. Our practice development work has new paths to follow going forward.

Limitations
The research question regarding Photovoice effectiveness might have been better answered by more robust processes for tracking outcomes over time from multiple perspectives rather than relying solely
on asking patient co-researchers after six months if they had experienced any change. The results of this study represent the experience of Photovoice in one organisation only and may not be transferable to all complex continuing care contexts.

Conclusions
Practice development work at the West Park Healthcare Centre has highlighted the challenge of evaluating patient satisfaction with care experiences in ways that stimulate action for service improvement. Photovoice proved to be effective in revealing what matters to patients with sufficient specificity, depth, and meaning to enlighten and inspire. Its lack of apparent impact on service improvement suggests more work is needed to understand the link between knowing what matters to patients and responding to that knowing through observable practice change. The person-centred nursing framework provides guidance for the prerequisites, care environment and care processes that might clarify that link and close the gap between caregiver intent and action.

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

References

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