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Research article

Understanding of 'person-centred care' in an oncology ICU: Associative group analysis

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ABSTRACT

Purpose: To describe how healthcare professionals, patients, and their significant others understand the concept of 'person-centred care' in an oncology ICU.
Methods: This study followed the associative group analysis (AGA) method, a quali-quantitative research approach.The population included healthcare professionals, their patients, and significant others in a four-bed oncology adult intensive care unit. Whole population sampling (n = 22) allowed all healthcare professionals to participate. Maximum variation purposive sampling was used to identify patients and their significant others (n = 22). Data were collected during either face-to-face or telephonic individual interviews. Free associations were weighted using a validated weighting system. Words with similar meanings were then grouped into themes. The themes were then deductively grouped according to the domains of the Person-centred Practice Framework.
Results: Participants had a limited understanding of person-centred care and could only identify six of the 23 constructs of the Person-centred Practice Framework. Healthcare professionals embraced the idea of person-centred care, but their understanding of the concept remains vague. Person-centred care remains conceptual in this oncology intensive care unit because the interpretation and operationalisation of the concept are misaligned at various health service levels.
Conclusion: Organisations should invest in work-based learning to enable staff to understand the concept of person-centred care. Healthcare workers also need to self-evaluate how they work and be able to adjust their working style to be more person-centred.

1. Introduction

Globally, healthcare professionals embrace person-centred care as a key component of sustainable, affordable, quality care [1–5]. Person-centred care has become a philosophy of healthcare systems where people are placed at the centre of the care process, focussing on the needs of patients, healthcare professionals, and organisations [6]. To promote good care experiences, patients are placed at the centre of their care and healthcare professionals engage authentically with patients and their significant others [7]. A significant other is an individual who is in a meaningful relationship with and offers emotional support to the patient [8].

Person-centredness challenges the biomedical care model, which focuses mainly on disease and its progression [9]. Biomedical care is also associated with a culture of task-oriented practices and dehumanising patients [2]. The biomedical approach encourages

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discipline-focussed care, resulting in a multidisciplinary rather than a collaborative interprofessional person-centred approach [10]. Treatment is often fragmented, uncoordinated, and unsustainable [5] and patients and their significant others are often excluded from decision-making processes [11].

The biomedical model of care is usually followed in highly technical intensive care unit (ICU) environments, including oncology ICUs. In ICUs, healthcare professionals focus on the physiological stability of patients, which may be a barrier to person-centred care [12,13]. Person-centred care is particularly important when treating patients with unique emotional needs. For cancer patients in particular, emotional support can enhance communication outcomes [14]. Healthcare professionals working in oncology ICUs should respect and care for patients and their significant others holistically and compassionately, considering that people have different values, preferences, and needs. Patients and significant others value communicating with healthcare professionals and appreciate being part of the decision-making process [15,16].

Person-centredness was first used in the field of gerontology in the 1980s [17] and has been widely used in healthcare since then [18]. To apply person-centeredness in healthcare, McCormack and McCance [6] developed the Person-centred Practice Framework, now a recognised nursing model (Fig. 1).

Person-centredness is underpinned by principles including treating people as individuals, respecting their rights as a person, building mutual trust and understanding, and developing positive relationships [6]. The Person-centred Practice Framework has five interrelated primary domains: 1) the macro context, which reflects strategic and political factors that influence the development of person-centred cultures; 2) pre-requisites, which focuses on the attributes of professionals; 3) the practice environment or the context in which healthcare is experienced; 4) person-centred processes, which focuses on engaging and creating connections between people and 5) the outcomes of person-centred practices [19].

Many healthcare systems worldwide, including oncology ICUs, have incorporated person-centred care models into their philosophy of care and policies to improve healthcare performance [3]. Implementing person-centred care at the unit level remains problematic [20,21]. In this study, patients in an oncology ICU, and their significant others, voiced concerns about poor communication with healthcare professionals, were excluded from decision-making and healthcare professionals having negative attitudes. These patient experiences do not reflect person-centredness in the oncology ICU.

We used a refined version of the Person-centred Practice Framework [6] to describe healthcare professionals', patients' and their significant other's understanding of person-centred care in an oncology ICU.

2. Methods

2.1. Setting

The study was conducted in a four-bed oncology adult ICU in a private hospital in Gauteng province, South Africa. Specialised care is provided to people 18 years and older who have been diagnosed with haematological cancer and are critically ill. Each patient, most of whom are immunocompromised, is cared for by one nurse in an isolation room to prevent hospital-acquired infections. Patients are cared for by a multidisciplinary team comprising permanently employed registered nurses (9), an oncologist (1), haematologists (4), nephrologist (1), an infectious disease physician (1), medical officers (3), physiotherapists (2), dieticians (3), an occupational therapist (1), a pharmacist (1), an infection-prevention registered nurse (1) and a full-time social worker ((1). Whole population sampling

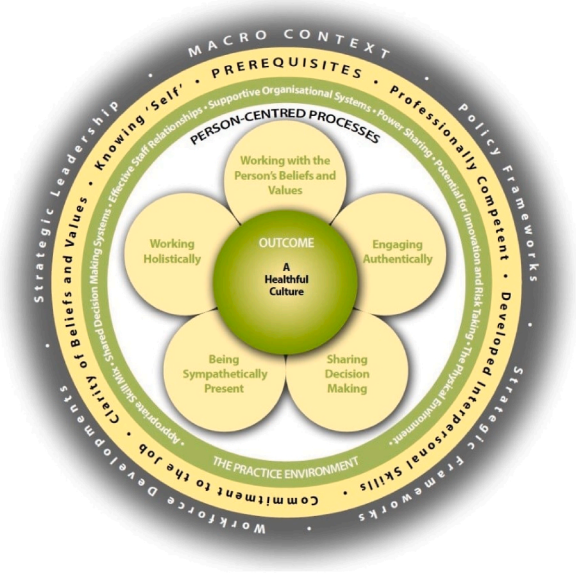

Fig. 1. Person-centred Practice Framework *(with permission from McCormack & McCance, 2016).*

allowed all healthcare professionals to participate.

3. Methodology

This study followed the associative group analysis (AGA) method, a quali-quantitative research approach. In AGA, respondents provide free association to a stimulus word, in this case, person-centred care, representing qualitative data. The responses are weighted and tallied, hence the quantitative component. Theoretically, the subjective free associations collected in AGA reflect the core beliefs and possible behaviour of participants In AGA, first responses are given larger scores as it is assumed that the earlier the response, the closer the relationship is to the meaning of the stimulus [22,23,25].

Researchers can establish subjective understandings of a group while accounting for cultural and religious similarities and differences [22,24].

Ethics approval was granted by the Health Sciences Research Ethics Committee of the associated university (UFS-HSD 2018/0436/1906) and the hospital group. Participants gave written informed consent and agreed that the data may be published. Confidentiality of participants was maintained through collecting depersonalised data which were stored on a personal computer within a secured file and will be kept for five years.

All 27 healthcare professionals working in the oncology ICU were invited to participate in the study by the second author, also a staff member at the hospital. Whole population sampling allowed all healthcare professionals to participate. The purpose of the research was discussed at a monthly meeting, where she distributed information leaflets, consent letters, and ethics approval letters. Twenty-two healthcare professionals consented to participate.

The patient and significant other population included people who were admitted to the oncology ICU over 18 months before the study started. Heterogeneity regarding race and gender guided quota sampling. English literacy was a requirement. We excluded people who were 18 years and younger, hospitalised at the time of data collection and received high doses of analgesics, narcotics, and sedatives that could impair their cognitive function. Table 1 shows the sampling grid and the final sample size of the patient and the 'significant other' population. The sample size was affected by time and financial restrictions.

We phoned patients to explain the research process and the value thereof and then asked if they wished to participate. One person declined due to a traumatic admission, and another one could not remember his/her ICU admission. Willing participants received the information leaflet and had time to consider voluntary participation. Potential participants were contacted at a mutually agreed upon time to obtain informed consent and provide an opportunity for questions.

Data collection occurred either face-to-face or telephonically and was one-to-one. We followed a standard data collection process irrespective of the mode of delivery. Demographic data were collected and recorded on the top left-hand corner of the data collection sheet. The date and participant codes were recorded in the top right-hand corner. Subsequently, the participants were asked to *'write down the words that immediately come to mind when you think about person-centred care'*. Participants were requested to write down words or short phrases within 1 min. During telephonic interviews, the researcher wrote the words verbatim and repeated them to the participant at the end of the interview.

3.1. Data analysis

Firstly, free associations were weighted using a validated weighting system where the first word was allocated 6, and the following words 5, 4, 3, 3, 3, 3, 2, 2, and 1 for the remaining words or phrases [22]. This method assumes that the first response was the most meaningful and was then scored accordingly. The weighting system was developed based on the coefficient of stability in comparative studies [25]. The three authors independently scored the responses to promote reliability. We then grouped words with similar meanings into themes. Differences were discussed until we agreed on the grouping and meaning. The elements per theme were tallied where a high score indicate priority themes.The three authors independently labelled the responses as positive, negative or neutral and reached consensus through discussion [22,25]. Lastly, the themes were deductively grouped according to the domains of the Person-centred Practice Framework [6].

4. Results

Mostly female healthcare professionals, who were nurses participated in the study (Table 2).

Most of the patients who participated in this study were male Caucasian patients (Table 3).

Table 4 provides the weighted score, the average of the weighted score, and the number of responses.

Participants only identified six of the 23 constructs of the Person-centred Practice Framework. Direct quotations support the research findings and healthcare professionals are indicated as HCP, and patients and significant others as PS.

Table 1
Target population and samples of patients and significant others over the 18 months before data were collected.

Target population (N = 72)	Total Count (%)	Sample (n = 22)
African	19 (26.3)	6 (27.3)
Caucasian	50 (69.4)	15 (68.2)
Other	3 (4.3)	1 (4.5)

Table 2
Demographic data of healthcare professionals working in an oncology ICU, who shared their understanding of person-centred care.

Profession	Gender		Race		Total
	Male	Female	African	Caucasian	
Doctors	4	2	0	6	6
Nurses	2	10	10	2	12
Physiotherapist	0	1	0	1	1
Dietician	0	1	0	1	1
Pharmacist	0	1	0	1	1
Social worker	0	1	0	1	1
Total	6	16	10	12	22

Table 3
Demographic data of patients and significant others (SO) who shared their understanding of person-centred care in an oncology ICU.

Race	Male		Female		Total
	Patient	SO	Patient	SO	
African	2	1	2	1	6
Caucasian	5	3	4	3	15
Other+	1	0	0	0	1
Total	8	4	6	4	22

Table 4
Results of the associative group analysis for each domain of the Person-centred Practice Framework.

Domain	Themes	Weighted Response Total (average), sample size	
		Healthcare professionals	Patients and significant others
Prerequisites	Attitude	57 (3.6)n = 16	60 (2.6)n = 22
	Knowledge	11(5.5) n = 2	11 (2.8)n = 4
	Skills	3 (3)n = 1	–
	Values	22 (3.67)n = 6	6 (6)n = 1
Practice environment	Organisational culture	−1 (−0.1)n = 9	12 (2)n = 6
	Illness severity	9 (1.8)n = 5	11 (1.8)n = 6
	Interprofessional team	51 (4.6)n = 11	–
	Unit atmosphere	–	−1 (−0.5)n = 2
Person-centred care process	Engagement	58 (3.6)n = 16	18 (1.5)n = 12
	Decision-making	9 (4.5)n = 2	–
	Sedation	3 (3)n = 1	14 (4.7)n = 3
Outcome	Positive care experience	17 (4.3)n = 4	47 (+3.6)n = 13
	Mental health	26 (2.6)n = 10	−31 (−2.6)n = 12

4.1. Pre-requisites

The pre-requisites for person-centred practice include professional competence and characteristics such as attitude, knowledge, and skills [19]. Participants had a good understanding of these pre-requisites. Healthcare professionals responded with phrases such as '*must be sensitive about what people can hear*' (HCP 10); '*caring and compassionate*' (HCP 15); '*to think about our critical patient*' (HCP 11); '*supportive*' (HCP 11); and '*helpful*' (HCP 20). Patients and significant others also identified the following values in their understanding of person-centred care '*nurses forget about themselves*' (PS 11); '(*nurses] … are kind towards the patient and understanding*' (PS 16); and '(*nurses] … are compassionate and really make time for you as the bystander*' (PS 18). Healthcare professionals mentioned '*accuracy in diagnosis*' (HCP 15 & HCP 17) alluding to the knowledge component of competency. Patients and significant others mentioned that '*healthcare professionals were well trained*' (PS 22), and that nurses working in the oncology ICU are '*much better trained than those nurses working in the wards*' (PS 03). Values were represented by seven responses, of which six were made by healthcare professionals. Healthcare professionals mentioned the following values, '*dignity*' (HCP 19), '*respect*' (HCP 11), and '*first do no harm*' (HCP 18). Patients and significant others mentioned the value of '*equal treatment*' (PS 01).

4.2. The practice environment

There were 15 responses related to organisational culture, nine from healthcare professionals and six from patients and significant

others. Healthcare professionals responded that: '(*they) … struggle to implement person-centred care in practice*'(HCP 17); '(*person-centred care] … takes too much time to implement*' (HCP 20); and they mentioned that there is '*no organisational* support *in the form of debriefing, counselling or training …* (*for person-centred care implementation]*' (HCP 21).

In the illness severity theme, there were 11 responses, five from healthcare professionals and six from patients and significant others. Healthcare professionals responded with terms including: ' … *these are patients who need help always*' (HCP 12) and '(*patients in the oncology ICU] … having a poor prognosis*' (HCP 18). Patients and significant others responded to terms including: '*you realise the condition is critical*' (PS 09) and '(*in the oncology ICU] there are specific nursing care more than in a ward*' (PS 03).

Healthcare professionals (n = 11) viewed the interprofessional team as ' … *patients, doctors, registered nurses, social worker, physiotherapist and dietician* (HCP 08), …*teamwork* … (HCP 06), and … *family, patients, nurses, doctors, multi-disciplinary team* [HCP 22) Patients did not mention the interprofessional team as a component of person-centred care. Patients and significant others described that their experiences in the oncology ICU provoked negative emotions such as feelings of 'extreme *isolation and abandonment'* (PS 14). Healthcare professionals did not comment on the unit atmosphere.

4.3. Person-centred processes

Person-centred processes include the themes engagement, decision making, and sedation. Engagement was represented in 28 responses, 16 from healthcare professionals and 12 from patients and significant others. Healthcare professionals included engagement by responding to terms such as: "*healthcare professionals must explain to the family regarding the ICU environment*" (HCP 10); "*Participation with the patient and involvement of the patient and family*" (HCP 03); "*Information sharing*" (HCP 05), "*Provide feedback …*" (HCP 17); and "*Explain every procedure*" (HCP 13).

Patients and significant others supported engagement through the following responses: "*Explained and provided feedback and kept us up to date*" (PS 14); "*Always available when he* (*the patient] needed something and never left him* (*patient] alone*" (PS 05); and "*Took care of my family when I was not there, informed them*" (PS 22). Two healthcare professionals (HCP 01 and HCP 05) wrote '*decision-making*', but they did not mention the shared aspect of decision making. No patients or significant others mentioned shared decision-making. However, both groups of respondents mentioned sedation, which may potentially hinder engagement and shared decision-making.

5. Outcomes

The domain of outcomes is represented by the themes, positive care experiences and mental health. All participants mentioned feelings related to positive care experiences such as '[Feeling] … *happy and fulfilled*' (HCP 01) and '(Feeling] … *satisfied'* (HCP 16), '*Good care, no problem. Nothing went wrong*' (PS 07), '*Looked after me very well*' (PS 22), and '*I complained and it was corrected*' (PS 12).

Healthcare professionals (n = 10) acknowledged the importance of mental health, for example 'Support – *emotional, spiritual, and physical*' (HCP 22); '*Emotional status of patients and family … (must be considered) … they are at risk for anxiety and depression*' (HCP 13); and '*Must not only think about physical in ICU, emotions get ignored … (must consider) … the spirit or psyche of the patient*' (HCP 10). Patients and significant others wrote '*my wife spent a year in a psychiatric hospital due to the hospitalisation*' (PS 03), '*a lot of memory loss*' (PS 02, PS 06).

6. Discussion

In our study participants only identified six of the 23 theoretical constructs included in the Person-centred Practice Framework [19]. It is likely that the policies in this healthcare institution focus on person-centred care but do not pay attention to person-centred culture [6,21,26]. The participants in our study reported that they are not supported by the organisation to implement person-centred care and there is evidence that the macro context is an influential core factor for developing person-centred cultures [27,28]. Several actions at the team and organisational level are required to support person-centred care, for example setting team goals, team responsibilities, person-centred routines, person-centred workloads and person-centred staff roles [29].

6.1. Pre-requisites

In our study competence, which refers to attitude, knowledge, and skills as well as values were highlighted. Competent healthcare professionals are associated with improved patient outcomes [30,31] and the ideal competencies will depend on the context or situation [32]. In oncology ICUs, healthcare professionals require specialised competencies to manage critically ill patients [31,33] and are often cross-trained in oncology, bone marrow transplant, and end-of-life support. Rendering person-centred care requires additional competencies, such as understanding the philosophy of implementing people-centred care [2], knowing yourself, and being person-centred [6]. Person-centred practice also depends on the core value of respect [6]. Values and beliefs influence everything we say and do, including how we perceive the world and how we respond to the people around us. Values are also important when practising person-centred care in the critical care nursing context [33,34].

6.2. Practice environment

The practice environment focuses on the context in which care is delivered, including organisational culture [3,5,35]. Organisational culture refers to a group's values, beliefs, and characteristics, which lead to a common identity and set a standard of acceptable

behaviour [36]. Ideally, organisational culture should include the core characteristics of person-centred care. The themes highlighted by the participants included organisational culture, illness severity, interprofessional team and unit atmosphere. Healthcare professionals in acute care settings, such as oncology ICUs, often experience barriers to delivering person-centred care, such as severe illness and delivering care in a highly technical environment [37]. Nurses in acute care settings have reported that they base their care on the biomedical model, which may prevent them from practising person-centred care [20]. Person-centred care is less likely to be implemented in high-quality healthcare settings such as ICUs and patriarchal hierarchical systems such as in South Africa [20] and Mediterranean countries [38]. In this study, healthcare professionals, patients, and significant others mainly responded positively to organisational culture.

In oncology ICUs, delivering patient-centred care depends on healthcare professionals recognising and understanding that patients are presenting with serious chronic and life-limiting disease [39]. In our study, healthcare professionals acknowledged that patients were severely ill and required specialised care. Nurses working in this environment play a pivotal role in caring for critically ill patients and therefore require cross-training in aspects of oncology as well as critical care nursing. Due to the disease's nature and technology, many critically ill patients are unconscious or intubated, unable to communicate their thoughts and experiences [40,41], which is another barrier to implementing person-centred care. Caring for critically ill and terminal patients in oncology ICUs may also exacerbate compassion fatigue and burnout of healthcare professionals [41].

In our study, patients and their significant others also experienced negative emotions related to the unit atmosphere. Patients in an ICU in the Netherlands also reported feeling isolated and abandoned [40]. Critically ill patients often face imminent death, which is associated with feelings of extreme isolation, loneliness, and abandonment. The cascade of negative feelings sets the tone for people's memories and experiences regarding their critical illness [42]. If an experience can indicate the tone or atmosphere in the ICU, improving patient and family experiences may improve the atmosphere of the ICU [43].

Several strategies have been proposed to address negative feelings in ICUs, including improved family involvement and having open or flexible visiting times [42,44]. Families have reported that their experiences of the critical care environment can be improved by genuine, supportive communication in the form of accessible information regarding the condition of their loved one [45], the opportunity to share their experiences with receptive healthcare professionals [46] and cultural sensitivity [45]. Families continuously ask for friendlier hospital environments in the form of dedicated resting and waiting areas [42], refreshment facilities, and health information that addresses their specific needs [44]. Healthcare facilities should also pay attention to patient and family complaints [47]. Although complaints may not necessarily reflect experiences directly, complaints may provide insight into non-person-centred care [47]. Non-person-centred care may lead to emotional, physical, and financial harm, resulting in negative patient and family experiences [47,48]. Patients and families value apology and corrective action from healthcare professionals [49]. Addressing patient and family complaints may improve the overall experience of healthcare users.

6.3. Person-centred processes

In ICUs, most patients struggle to communicate due to being sedated and being confused, which limits the formation of therapeutic relationships [41]. Strategies to improve engagement are similar to strategies for addressing negative feelings. Families could participate in interprofessional rounds, have flexible visiting hours, and healthcare professionals could use structured communication techniques or provide brochures with basic information [44]. Patients and their families should also participate in shared decision-making, where healthcare professionals and patients or families interact and have open discussions to share information and support negotiations [50]. However, communication barriers continue to exist at professional, patient and significant other level [51].

Our study supports the findings by Sevransky, Nicholl, and Buchman [52] that sedation complicates the implementation of person-centred care in ICU as it exacerbates and prolongs the inability of patients to communicate. Patients reported that they had little or no recall of their critical care stay [53], similar to our findings of one patient who declined participation.

7. Outcomes

In our study, participants associated positive patient outcomes with person-centred care. Implementing person-centred care also benefits healthcare professionals, teams, and organisations [28]. Patient-reported care experiences correlate with the quality of care delivered, including patient safety and clinical outcomes [54–56].

Despite the positive associations expressed by patients and significant others, these stakeholders expressed concerns relating to the mental distress experienced by their loved ones following their stay in the oncology ICU. In accordance with Kang et al. [57], Lee et al. [58], and Parker et al. [59], healthcare professionals in our study acknowledged that person-centred care may alleviate mental distress and promote mental well-being.

7.1. Limitations

Our study was limited to one oncology ICU in a private hospital, and our findings should not be generalised to other settings. The sample size of 44 participants may also be regarded as a limitation. Patients could have struggled to recover free associations due to constraints on their working memory following their stay in the oncology ICU. The study did not explore the needs, expectations, obstacles and levers to person-centred care.

8. Conclusion

Although the organisation in our study supports person-centeredness, participants in this study reported on the influence of the macro context on the implementation of person-centred care and identified six of the 23 constructs included in the Person-centred Practice Framework. The benefits of implementing person-centred care were focused on patient outcomes rather than on health-care professionals, teams, and organisations. Healthcare professionals need to be made aware of the benefits of person-centred care for themselves, patients, and their significant others. Organisations should invest in work-based learning to enable staff to understand the concept of person-centred care and to continually self-evaluate how they work and how to adapt to create person-centred cultures.

The findings of this study showed that the practice environment is not conducive to implementing person-centred care. Therefore, leaders in organisations should be authentic and work in person-centred ways to create trusting relationships that strengthen healthcare professionals' commitment to their jobs. Healthcare professionals should feel safe to reflect critically on existing practices and plan innovative strategies to improve person-centred care throughout organisations, including oncology ICUs.

Future research could investigate the views of patients and significant others as two groups. The results of this study could be verified by other methods for example conducting interviews with healthcare professionals, patients and significant others to open up for action.

Declaration

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Data availability statement

Data are unavailable as authors do not have permission to share data.

CRediT authorship contribution statement

Yvonne Botma: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis, Conceptualization. **Hannelie Herselman:** Writing – review & editing, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Tanya Heyns:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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