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PRESENCE AND THE PARADOX OF TIME FOR PALLIATIVE CARE CLINICIANS: A PHENOMENOLOGICAL STUDY

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ABSTRACT

Background: A presence of quality is recognized as a central competence for palliative care clinicians in their mission to accompany patients and families in their end-of-life journey. However, PC clinicians' capacity for presence may be affected by the increasing emotional, professional and organizational demands of their working environment. Those demands may, in turn, affect quality of care and clinicians' health. To our knowledge, no previous study has aimed at a better understanding of how PC clinicians view and experience presence in their day-to-day work, although this holds the potential of generating insights to help clinicians develop and cultivate a high-quality presence towards dying patients.

Methods: We conducted in-depth qualitative semi-structured interviews with 10 PC clinicians working on a specialized PC ward, later analyzed using Interpretative Phenomenological Analysis.

Results: Results account for three essential themes describing the experience of presence; connection to the self, to the other and to the meaning of care. Results also suggest that presence was lived and experienced within a very particular relation to time, which appeared to our participants as a significant challenge in achieving high-quality presence.

Conclusion: The stressful working environment in which PC clinicians daily evolve appeared as a threat to presence for our participants. Paradoxically, cultivating presence with mindfulness may be a promising tool to better cope with the competing demands of work and to foster clinicians' resilience to stress.

KEYWORDS: Presence, Palliative care clinicians, Meaning, Mindfulness, Connection, Temporality, Interpretative phenomenological analysis

INTRODUCTION

Palliative care (PC) is defined by its holistic and humanistic approach to end-of-life care. Its mission is to relieve the physical, psychological, social, spiritual and existential suffering of dying patients and their families [1]. As a result, the very nature of PC relies on the quality of presence of those clinicians* who support patients and their families in their journey towards death [2]. For end-of-life patients, a caring presence creates a space of healing and closure [3]. Therefore, it is expected for PC clinicians to offer a good quality of presence to patients and families, while providing physical comfort and psychosocial support. Some writings even suggest that the capacity for presence be a required competence for PC clinicians [4].

However, embodying a presence of quality may be challenging for PC clinicians, especially when considering the different stressors they experience on a daily basis [5-8]. It is a well-known fact that to witness the intense suffering of patients and families, to experience cumulative griefs and to be exposed to death daily is emotionally challenging for PC clinicians [5-7]. Additionally, PC clinicians must deal with professional and organizational stressors such as staff shortages, the increasing technologization of care, ethical dilemmas and interpersonal conflicts [9,10]. The cumulative effects of those stressors may affect clinicians' health and well-being and lead to compassion fatigue [11], or to burnout [9,12-13]. Exhaustion incidentally affects PC clinicians' quality of presence, and even the general quality of care they provide. Over the past decades, many studies have attempted to develop interventions to support PC clinicians' resilience to stress and to help them cultivate a presence of quality to themselves and to patients [6,14-15].

Despite how instrumental presence is to the delivery of adequate PC, and despite the challenges associated with a presence of quality in PC, very few researchers have shown interest to study the ways in

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which PC clinicians understand and experience presence. Moreover, no consensual definition seem to exist for the concept of presence, although it is described as a central competence for PC clinicians [16]. In the general nursing literature, however, a few conceptual analyses of presence may be found [17-19], which have both brought to light certain dimensions of presence, and revealed that the concept is often confused with other phenomena such as empathy, mutuality and reciprocity [17-19].

The lack of a consensus around the concept and understanding of presence in the literature showcases an evident difficulty in translating to words an essentially subjective phenomenon. This may in part explain why the studies exploring the experience of presence from the subjective point of view of the clinicians themselves are so scarce. To our knowledge, only the doctoral research by Hain has approached the practice and development of presence among health care providers, specifically in the context of intensive care [20]. This study carries the merit of having given a voice to nurses regarding their experience of presence, however it is not specific to PC. Furthermore, PC is a field which carries its own issues and challenges, and those may influence the way in which presence is understood and experienced by clinicians.

RATIONALE AND OBJECTIVES

The PC literature links the quality of presence for PC clinicians and quality of care, yet, ironically, working in PC involves specific challenges that may affect the capacity for presence among clinicians. Moreover, no studies have attempted to get an in-depth understanding of the meaning of presence for PC clinicians. Such an understanding may shed new light on the concept of presence and its experience. In this study, we aimed at better understanding the lived experience of presence among PC clinicians, in the hope of generating new insights on ways to support PC clinicians in cultivating a presence of quality.

METHODOLOGY

To develop a deeper comprehension of the lived experience of presence for PC clinicians, we conducted an in-depth qualitative and phenomenological inquiry embedded in a constructivist paradigm [21]. We followed the approach, process and guidelines of Interpretative Phenomenological Analysis (IPA) [22].

Participants

The study received the approval of the ethics committee of the health institution where it took place. Participants were all members of the same specialized PC team. We recruited 10 participants (8 nurses and two PC professionals) for in-depth semi-structured interviews. The final sample size is in accordance with Smith and Osborn's [22] recommendation for IPA studies. The sociodemographic characteristics of the participants are presented in Table 1.

	Mean (ET)	Range
Age	43.5 (14.25)	21- 56
Years of experience in PC	9.43 (8.07)	5 months – 25 years
Means hours/week spent with patients	6.78 (4.22)	18 h – 45 h
Gender	Number of participants	
Women	<i>n</i> = 9	
Men	<i>n</i> = 1	

Table 1 Participants' characteristics

Data collection

Each participant was interviewed for about an hour in a private space of their workplace, chosen to protect confidentiality. The interviews took place during or after their shift, according to participants' preference and with the approval of the PC unit's managers. Interviews were conducted by a trained PhD candidate in clinical psychology. In order to preserve important aspects of the participants' discourse and with their approval, each interview was audio recorded. Participants were invited to express the meaning of presence as a PC clinician to them. We also inquired about their understanding and experience of presence by using prompts and asking for specific examples of times they felt present or didn't. After the interview, reflexive notes were taken by the interviewer on the contextual characteristics of the interview, as well as insights and intuitions on possible emerging themes and/or theme organization. Interviews and reflexive notes were then discussed with the main researcher.

Data analysis and rigor

Keeping with our goal of an in-depth analysis, the interviews were entirely transcribed. To facilitate the analysis process, we used both paper transcription and the N'vivo software. Our process was based on Smith and Osborn's interpretative phenomenological analysis (IPA) and our analyses followed the process suggested by the authors [22]. The steps involved 1) annotating significant excerpts in the margin regarding the experience of presence, 2) noting potential emerging themes and describing participants with keywords, 3) listing the emerging themes and 4) linking different themes and organizing them according to their similarities. At this point, themes were systematically documented with participants' quotes, using the N'vivo software. The final steps involved a reduction of the number of themes by uniting them under more general concepts that relayed the essence and meaning of the experience of presence. Themes that did not have quotes supporting them were either eliminated or reorganized under more general themes, and priority was

given to themes that appeared to be supported by many participants. All transcriptions and personal notes were then reexamined to ensure that the final organization represented each participants' experience, and that it was coherent with the reflexive notes taken after the interviews. Furthermore, all decisions made during the analysis process were documented in a reflexive journal and most were also discussed with the research team to ensure rigor [23].

RESULTS

The final analysis allowed for a description of the experience of presence including three essential themes. Our understanding suggests that PC clinicians experience presence as a process of connecting 1) with the self, 2) with the other and 3) with the meaning of care. Such connections occur in a particular temporality that appeared to affect the experience of presence for PC clinicians. Each of the three themes, as well as the temporality in which presence is experienced, will be further analyzed in the following section, supported by participants' narratives.

Presence: Connecting with the self

A few participants described their experience of presence as an internal and personal process of being connected with themselves. According to them, presence must first include the ability to free oneself from any thought or preoccupation, in order for the whole person to be present.

I don't know how to describe it, but we're all there. [...] To be fully present, it's not just being there like, it's more than that. [...] And, it's as if all your senses are there, it feels like your spirit is even there. Y'know, it's beyond being just mentally present.

Presence would also allow awareness of oneself, of one's emotions and physical sensations, in order to better connect with the self.

It's like knowing myself. Knowing what I want, what my values are. And listening to myself, like what my emotions are telling me, what I feel physically.

Being present is also being present to what's happening to you at this moment. (...)

Uhm, so, I feel present, I feel awake. I feel like I'm listening to myself and what I see and how I'll react.

Being present to oneself was also described and experienced as an authentic connection with the self, leading to a sense of well-being and peace.

It's what I feel on the inside, in my head and also to express (...) Because if you're honest about that, I mean, if you're connected and you express your true feelings, so I guess on the

inside you really feel more at peace. (...) Yes, to be real and connected to what you feel and what you think, that's being present for me.

I think that when we're totally present with ourselves we're... I think you feel good, and it's a satisfaction.

Though some described their experience of presence in relation to themselves, a vast majority of narratives were about presence as an experience in relation to others, especially patients.

Presence: connecting with the other

Most participants described presence as an experience of connecting with patients and family members. Many participants said that signs of distress among patients or their relatives triggered within them a spontaneous will and energy to be fully present, which sometimes could outshine all other demands. Faced with a critical situation, they would not hesitate to stop all other activities in order to accompany a person suffering or dying, as this testimony shows:

There's one [situation] that I remember where I accompanied someone who was dying suddenly. The person was in respiratory distress and there were many people around them who were actively trying to do whatever had to be done, either placing the oxygen or trying to figure out what they had or positioning them or... and then at that point I felt their distress and I said "ouf!" I have to go next to them, I have to go sit down and just be there.

In addition to making clinicians more rallied, sensitive and attentive, presence was described as a movement towards the other, which could be participants' way of telling patients and their families that they are with them, present, connected and available. A look, a touch or attentive listening were reported as different ways to experience and express presence to the other.

I think that, for whatever reason, we had a very strong "connection" and she looked like she trusted me and valued my presence. I don't know what there was in there, what I did to create this connection. But I like to think that when I sat with her, I was very present. I was profoundly aware of her suffering.

I knew I couldn't do much. She didn't really ask me to do much more, you know? She just needed to talk. So I think my role in this was just to be there, present, you know, and just show presence, empathy and support.

Presence: connecting with the meaning of care

Our analyses also brought to light the fact that the experience of presence allowed participants to better connect with and appreciate the privilege of accompanying patients and their relatives. In a state of

presence, participants were better able to grasp the meaning of their work and the importance of their role. As such, a few participants reported that they better appreciated the preciousness of the connection with their patients, as if maybe presence was a window to the beauty of human contact:

(...) because you're touching the frailty of life, the ephemerality of life, the beauty of life, the preciousness of life, everything untouchable, everything that isn't palpable, but that's so important. So I think it contributes to the fact that you want to be even more in the present, you want to be even more aware of the present moment, and to live it as best as you can.

In that sense, the experience of presence seems to allow participants to give meaning to their work with patients in end-of-life care and their families. Many actually noticed that an experience of presence left them with the feeling that their role in certain situations had been important and that they had done what was needed:

I felt that, I felt useful in... because I felt useful to her and I felt, I felt a bit of a sensation of growing because it was something new to me too, just sitting with a person and being there.

Time for presence

Finally, our analyses revealed participants' constant preoccupations with the temporal dimension of presence. Indeed, it appeared that clinicians felt the need to master time in order to successfully be present. Participants found it difficult to offer full presence to another, much less to themselves, through ringing bells, medications to be administered, administrative forms to be completed, interdisciplinary meetings, etc. Most of them reported suffering from a frantic rhythm of work, where there was so much to accomplish in so little time. It seemed difficult for them to be present, with the double burden of being constantly preoccupied by the next thing to do, and of time being fragile and fleeting:

Before we more like, we had more time to be with the patient and the family. But now, it's like such a rush, the day passes so quickly, you do technical things and then it happens. I'm not saying it doesn't happen [...] But I see that it happens less and less because when you have a workload, when you're working, you have to help others and if you have like an assistant, you're going to supervise her too. You get to three o'clock and it's like you didn't, you're thinking, you don't have like today, did I have time to speak to my patients?

Faced with a terrible lack of time in their current professional context, certain participants have only found one solution in order to be present, and that is to make up time... by forgetting themselves. Presence seems to only be possible at the expense of a forgotten coffee break, a missed meal, or getting home late:

Last supper, I had ten minutes. Because mealtime, supper is always very busy. We were two nurses. Sometimes, we're only one nurse, one assistant-nurse on the floor. They all [patients]

call at the time of supper to get help to go to the bathroom and all that. So, you can't leave a patient like that. So, I took ten minutes. I couldn't have supper.

For other participants, the experience of presence seems to require better management of competing demands, at the price of a mental effort. Their presence hence seems to be the result of a conscious choice to slow down and take their time when the situation calls for it, to temporarily ignore the list of tasks to be done, and even to let other patients and their families wait longer:

It's saying no, listen, focus on what we're telling you and that's what, I think, being really present is. Everything you need to do after or what you did before doesn't fit into your capacity for listening or your attitude [...]

In some cases, presence seems to only be made possible by a complete stop, as if not doing anything else could provide this sought-after space for refocusing; as if stopping could void time of everything that usually fills it:

When you're in a situation of stress and then you're telling yourself well I'm a little scattered all over the place, and now you want to be present again, you have to make a downtime. Sometimes, I do it where I stop to realize OK now I'm going to breathe. And then, that, it'll help me to be aware that things are fast-paced and that I need to be regrounded in the end you know.

Yes, that's it, sometimes there are too many things that go too fast. You have a lot of, you changed this one, you have a lot of patients, you have another one calling you, ringing, and you're with this patient, uhm, or like you're telling yourself, I'm not uhm, well, so those are things that I think prevent me, could prevent me maybe from being completely present or fatigue.

In short, the particular temporality of medical settings was revealed to be an inevitable dimension of the experience of presence for the participants of our study. There seems to be so much to do, that the lack of time alone could become an obstacle to quality presence. In this perspective and in the current context of PC, presence would be perceived as a luxury for the nurses, as it requires time, or calls for a different relationship to time. However, although time is fleeting to them, many participants quickly and willingly set aside their own needs and make a strong effort to slow down the pace, in order to get more time with patients and their relatives. Sometimes, they must even halt time to better seize it, as, in their daily whirlwind, presence is automatically secondary.

DISCUSSION

Considering the importance of clinician's presence in PC, as well as the lack of a definition for presence in the literature, this study aimed at better understanding the subjective experience of presence among PC clinicians. Our phenomenological and interpretative analysis allowed for a description of the experience of presence in terms of a connection to the self, to the other and to the meaning of care. This experience is deployed in a very particular context in which the participants perceived the lack of time as a significant challenge in achieving presence.

Though some clinicians did describe their experience of presence in relation to themselves, most of them spontaneously referred to presence as act of caring, something they offered patients and their relatives. This observation coincides with the professional identity of healers, which emanates from a concern for the other often inherent to their calling [24]. However, presence to the self may be an important component of clinicians' experience: as many studies suggest, presence and awareness to the self may be associated with resilience and well-being in health care professionals [25-27]. Moreover, studies suggest that mindfulness, defined as "the awareness that emerges through paying attention, on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment" (p. 145) can promote self-care and well-being for clinicians [28-29]. As the rhythm of working in PC continues to accelerate, self-presence, that can namely be cultivated through mindfulness training, may be a promising avenue to foster self-care and resilience in PC clinicians.

Our results also suggest that the experience of presence may be associated with a connection to the meaning of care. In a state of presence, some reported touching upon the beauty of the caring act [30]. Awareness of meaning and of the impact of care has also been strongly associated with clinicians' resilience to stress in PC settings [31,32]. We suggest that cultivating presence may facilitate meaning-making and resilience to stress. In short, presence, in terms of connection to the self, the other and meaning, appears to be a positive experience for PC clinicians that may, in turn, feed well-being and resilience.

Our results also show that the experience of presence is threatened by the frenetic rhythm of work, namely by the escalating demands and the increasing professional, emotional and organizational stressors that PC clinician face daily. In our sample, participants seemed to understand presence as incompatible with their working environment, as it requires a state of mind that is not oriented towards "doing", but towards "being". To them, a surcharge of work seems to encourage the adoption of an automatic mode [33], characterized by mechanical thoughts and gestures, to maintain efficacy and productivity [34]. Paradoxically, the cultivation of full presence or mindfulness could constitute valuable personal tools to face the challenges of work, with the additional advantage of requiring no extra time. However, to develop and cultivate of presence within such a stressful and demanding environment may require many personal, professional and

organizational efforts and resources. Training and support for PC clinicians to cultivate presence to the self, the other and to meaning seems to be a promising avenue to foster their resilience to stress and prevent burnout.

To our knowledge, this is the first study to explore and understand presence in PC clinicians. Though the contribution of this study is significant, it must be nuanced by the limits of our research. Indeed, in attempting to better grasp a complex and particularly abstract experience, we have chosen the phenomenological approach, part of a constructivist-interpretative paradigm. Without constituting a limit in itself, this subjective process limits the generalization of the results. However, our definition of presence may be transferable to research and PC clinical settings.

CONCLUSION

This study aimed at better understanding the experience of presence for PC clinicians. Our qualitative, interpretative and phenomenological analysis allowed for the description of presence in terms of connection to the self, to the other and to the meaning of care. The stressful working environment in which PC clinicians daily evolve appear as a threat to presence for our participants. Paradoxically, cultivating presence may be a promising tool to better cope with the competing demands of work and to foster clinicians' resilience to stress. ■

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