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THE HUMAN SIDE OF CARE: COMPASSION AS EXPERIENCED BY PATIENTS

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INTRODUCTION

As healthcare systems increasingly shift toward more humanistic and person-centered models, compassion has emerged as a foundational element of quality care and a defining feature of professional identity among caregivers [1,2]. Conceptualized through varied means, including as a personality trait, ethical stance, and clinical skill, compassion manifests through a range of verbal, non-verbal, and behavioral expressions, shaped by contextual, cultural, and individual factors.

In recent years, empirical research on compassion in healthcare has gained momentum, particularly through qualitative approaches that capture the complexity of how compassion is both conceptualized by professionals and experienced by patients [3]. From the perspective of clinicians, compassion is often framed as a moral obligation and a multidimensional construct encompassing personal attributes (e.g., empathy, sensitivity), relational competencies (e.g., active listening, effective communication) and enabling organizational conditions [4,5]. However, despite its normative and theoretical prominence, compassion remains unevenly integrated into medical and health sciences curricula, clinical practices, professional development programs, and health policy frameworks [6]. Many healthcare professionals report feeling inadequately trained to recognize, cultivate, and apply compassion in their daily practice, which raises concerns about the sustainability and authenticity of compassionate care [7].

From the patient's standpoint, compassion is consistently described as a deeply comforting and healing experience, particularly when conveyed through concrete gestures and the acknowledgment of suffering by healthcare providers [8-10]. Compassion has been empirically linked to improved patient satisfaction, reduced emotional distress, and strengthened therapeutic relationships [11,12]. Conversely, although less frequently documented, the absence of compassion can result in significant emotional harm, including feelings of abandonment, humiliation, anger, and a loss of trust in both caregivers and the healthcare system [13,14]. Despite its recognized value, the expectation for compassionate care remains insufficiently met across many healthcare contexts.

The documented gap between caregivers' conceptualizations of compassion and patients lived experiences in clinical settings reveals a critical epistemological and practical tension. While healthcare professionals often articulate compassion in abstract or normative terms, patients tend to evaluate it through embodied interactions that reflect attentiveness, emotional presence, and recognition of suffering. This divergence underscores the need to study compassion not only as a theoretical construct or professional competency, but also as a relational and experiential phenomenon situated within specific interpersonal and institutional contexts.

Previous research has documented patients' and families' experiences of compassion in ways that remain partial and fragmented. Durkin (2018) synthesized qualitative studies to describe compassion as a professional virtue expressed through behaviors such as presence and individualized care, but this research relied largely on secondary interpretations and lacked direct patient voices [15]. Bramley & Matiti (2014) captured emotional impacts through narratives of nursing care, emphasizing the importance of gestures and other forms of communication, yet framed compassion as an individual attribute [16]. An ethno-specific study explored perceptions among South Asian patients, linking compassion to a culturally adapted behavior and respect for beliefs [17].

Across these studies, compassion was often conceptualized cognitively—as a skill or culturally adapted behavior—while its emotional dimension was underexplored or treated in isolation. Further, the relationship between healthcare professionals' behaviors, perceptions of compassion, and the emotional experiences of patients and their relatives remains underexplored, underscoring the need for studies based on patient and family narratives.

Documenting the lived experiences of patients and their families—both in terms of how compassion is cognitively described in clinical settings and how it is emotionally felt, interpreted, and embodied—is essential for advancing a more comprehensive understanding of relational dynamics in care. Such documentation helps identify conditions that foster or hinder compassionate interactions, while also illuminating areas of rupture, unmet expectations, and opportunities for improvement. Patients and families possess unique experiential knowledge that can enrich clinical practice and pedagogical frameworks by offering insights often overlooked in normative discourses. Their perspectives serve as a critical counterpoint to institutional narratives, anchoring compassion in the realities of care and contributing to the development of more responsive, ethically grounded, and human-centered healthcare systems.

This study aims to deepen the understanding of compassion in healthcare based on narratives from patients and families. More specifically, it seeks to document how the behaviors and attitudes of healthcare professionals either align with or diverge from experiences of compassion, and to identify the emotions experienced in response to these interactions from the patients' perspective.

METHODOLOGY

This study is based on an interpretive descriptive qualitative design, grounded in a constructivist epistemology as proposed by Thorne [18]. This approach allowed the authors to capture the complexity of the phenomenon under study through the subjective narratives of patients, emphasizing the diversity of experiences and meanings attributed to compassion.

Recruitment and Data Collection

A non-probabilistic convenience sampling method was used to form the focus group discussions (FGDs). Recruitment was conducted via an invitation letter detailing the study's objectives and participation modalities. The letters were sent by the Human Simulation and Citizen Participation Program (PSHPC) and the Users' Committee of the Integrated University Health and Social Services Centre of Estrie. Semi-structured interviews were conducted in person and co-facilitated by the principal investigator and a patient partner, who was also designated as a co-researcher in this project. An interview guide was developed following Kallio and collaborators framework, which consisted primarily of open-ended questions with optional probes (see Appendix 1). Through their use of varied communication and facilitation techniques—such as active listening, reformulation, and probing questions—the facilitators not only supported participants in expressing nuanced reflections beyond the original scope of inquiry, but also enabled a deeper exploration of the contextual elements shaping their experiences.

The guide supported consistent yet flexible data collection and facilitated the emergence of rich, experience-based findings. A reflexive journal was also kept by researchers throughout the research process to document analytical insights, decision-making rationales, and reflections as a complementary source of transparency to enhance the study's methodological rigor [19-20].

DATA ANALYSIS

This process was conducted iteratively and concurrently with data collection. Audio recordings were fully transcribed and subjected to a rigorous inductive thematic analysis, combining a vertical approach (in-depth analysis of each FGD transcript) and a horizontal approach (grouping of emerging themes) [21]. This dual reading enabled the identification of manifestations and lived experiences of compassion, both in its presence and absence. *Manifestations* refer to the observable expressions of compassion—or its lack—through, for instance, behaviors, attitudes, or interactions displayed by healthcare providers. In contrast, *lived experiences* encompass participants' subjective and internal responses, including how these manifestations were felt, interpreted, and integrated into their personal care trajectory.

An initial level of co-analysis was carried out by the principal investigator (DG) and the co-researcher (MH-L), resulting in summary syntheses of lived experiences. These were electronically sent to participants for validation and feedback on the collective interpretation. Participants were invited to review a synthesized summary of the analysis and indicate whether it accurately reflected their contributions. They could either confirm the synthesis, propose modifications, or request a follow-up discussion. Overall, participants confirmed that the analysis produced by the research team accurately reflected past discussions. No participant proposed additional changes or deletions, and no substantive modifications were requested. Consequently, their feedback reinforced the study's findings. A thematic analysis, assisted by NVivo software, was subsequently conducted by the research assistant (GL). The active involvement of the patient-partner throughout the study—especially in co-facilitating focus groups and analyzing data—enhanced the credibility of the approach by offering a unique, informed perspective. Participant validation through summary feedback and researcher triangulation, supported by debriefing sessions, enhanced the accuracy of interpretations, reflexivity, and methodological transparency, while contributing to the reduction of bias.

ETHICAL CONSIDERATIONS

The project received ethical approval from the Research Ethics Committee of the CIUSSS de l'Estrie–CHUS. All participants signed informed consent before data collection. To safeguard participants' emotional well-being, measures were put in place, including access to psychological support services. Confidentiality of the data was rigorously maintained through the anonymization of personal information. All documents, transcribed data, and audio recordings were securely stored, with access restricted through dual authentication protocols.

RESULTS

The findings of this interpretive qualitative study shed light on the multifaceted nature of compassion as experienced within healthcare settings. Through the narratives collected during two focus group discussions, a diversity of profiles and experiences revealed rich relational dynamics—sometimes marked by the transformative presence of compassion, and other times by its painful absence. This section first presents the participants' profiles, then explores the concrete manifestations of compassion in caregiver–patient interactions, and finally examines the emotional and relational impacts of its absence. The narratives highlight profound issues of recognition, dignity, and humanization at the heart of the care relationship.

Participant Profiles

The study was conducted with twelve participants divided into two focus group sessions, lasting 1 hour and 52 minutes and 1 hour and 38 minutes respectively. The composition of the groups reflects a notable diversity in terms of gender, age, educational background, and socio-professional status, allowing for a rich array of perspectives on the experience of compassion in healthcare. Gender distribution was balanced, with six women and six men. Regarding age, most participants (64%) were aged 55 and older, suggesting a broader experience with healthcare, both as patients and caregivers. Age ranges spanned from 25 to over 65 years, ensuring generational diversity in the narratives.

In terms of education, participants had varied levels ranging from high school diplomas to master's degrees, with a predominance of post-secondary education (college and university). This diversity enriched the interpretations and expectations regarding compassionate practices. Participants' main occupations were also heterogeneous: some participants were active in the workforce, others were retired, caregivers, volunteers, students, or on medical leave. Several held multiple roles, such as retired and caregiver or student and worker, reflecting the complexity of life trajectories and contexts in which compassion is experienced.

MANIFESTATIONS AND EXPERIENCES

The findings of this interpretive qualitative study offer a rich and nuanced understanding of compassion in healthcare, as lived and narrated by patients and their caregivers. Through the analysis of lived stories collected during focus group discussions, relational dynamics marked by the presence or absence of compassion emerge, revealing deep and sometimes contrasting emotional effects.

Presence of Compassion: A Transformative Relational Experience

Participants from both focus groups converge on a definition of compassion as an authentic human presence, grounded in listening, recognition, and engagement. Compassion is described as a relational, communicational, and human practice that can profoundly transform the care experience.

Compassion first manifests in the quality of the relationship between caregiver and patient. It is described as emotional and physical proximity, expressed through simple yet meaningful gestures: sitting at the same level as the patient, holding their hand, greeting warmly, taking time to explain, validating understanding, or simply being present. One participant shared, "*The doctor stood up and came to sit next to me. That made all the difference*" (FG#1). This proximity helps break the implicit hierarchy between caregiver and patient, establishing a human-to-human connection. When these behaviors are carried by a respectful and benevolent attitude, they generate feelings of safety, dignity, and trust.

Participants also emphasized that empathetic listening is at the heart of the compassionate experience. It involves paying attention to the person's story, going beyond technical evaluation, and showing genuine interest and presence. As one participant reflected, "*sometimes not speaking at all, just being there*" (FG#2). They stressed the need to be seen and understood in their uniqueness, to move beyond labels and diagnoses and recognize the human being in front of them: "*She didn't see the addict, but the little girl who was suffering*," said one participant. This recognition helps restore dignity and strengthen humanity.

Considering the person's needs, goals, and pace is also perceived as a powerful marker of compassion. This attitude allows the patient to feel welcomed, respected, and valued, as reflected by this study's participants. When caregivers acknowledge the patient's strengths, experiential knowledge, and vulnerability, they help establish a therapeutic relationship based on co-construction and reciprocity: "*He took the time to understand my situation, my abilities, and limitations*" (FG#2). Compassionate communication also involves word choice and tone: "*Even humor, when appropriate, can make a care experience more positive*" (FG#1).

When a caregiver acknowledges their limits, even as a specialist, they do not relinquish competence but humanize the relationship. This transparency creates a space of trust where the patient feels respected, heard, and considered a partner in the care process. Patients' stories reveal that this posture of humility breaks the implicit hierarchy; "*Admitting you don't know, and saying it*" (FG#2), opens the way for a relationship where medical and experiential knowledge coexist and complement each other. Admitting limits, uncertainties, or even emotions—"*She temporarily stepped out of her medical role and entered the human realm; she even cried with us*" (FG#1)—strengthens the caregiver's credibility and validates the patient's experience, demonstrating that "*beyond medical science, there is humanity*" (FG#1). This posture also reduces pressure on the patient, who no longer has to conform to an idealized image of the omniscient caregiver. It allows the healthcare professional to shed the burden of infallibility and open a more sincere, respectful, and human dialogue.

Participants also highlighted the importance of support throughout their experience; "*I'm with you on this journey*," said a doctor to a cancer patient to illustrate support. Being guided, assisted with procedures, or simply being visited after an intervention are gestures that reflect care for the illness without infantilizing the person. This distinction between managing the medical condition and respecting the patient's autonomy is central to a form of compassion that fosters empowerment.

Absence of Compassion: An Experience of Rupture and Suffering

Participants' narratives reveal that the absence of compassion leads to care experiences marked by loneliness, anger, and a sense of abandonment. Behaviors perceived as cold, distant, or mechanical are experienced as forms of dehumanization. Deliberate disregard for the patient's words, refusal to consult or acknowledge their expertise, and stigmatizing attitudes contribute to a one-sided view of the situation that denies the person's wholeness. Compassion is not limited to the caregiver–patient relationship; it also includes relatives, whose roles are often ignored or minimized. "*I was informed of my husband's transfer by voicemail* […] *they didn't speak to me, didn't consult me*" (FG#1), said one participant, feeling excluded from administrative decisions with major consequences for the family.

Participants also described situations where judgment based on age, disability, or mental health diagnosis led to decisions made without their consent, and even to humiliating remarks: "*As soon as he heard 'addiction,' the judgment came… and then you lost all your rights*" (FG#2). Comments like "*Aren't you tired of being in the hospital?*", often delivered in a harsh or condescending tone, are perceived as a negation of the person and experienced as verbal violence, often generating humiliation and anger. According to participants, non-verbal cues can also be hurtful: "*She threw the CD on her desk*," (FG#1), conveying contempt or indifference. These experiences were described as traumatic, undermining trust in caregivers and the healthcare system.

All participants agreed that in a care context, the caregiver's words hold strong symbolic power. When used to belittle, infantilize, or demoralize, they can deeply affect the patient: "*The lack of compassion… it can really degrade you*" (FG#1). Testimonies from the focus groups show that such discourse is experienced as a form of violence that weakens the therapeutic relationship and compromises trust: "*It's like I didn't exist*" (FG#1). This type of communication harms the patient's self-esteem and may discourage them from expressing their needs or concerns. The impact is even greater when such remarks are made during vulnerable moments, such as a difficult diagnosis, loss of autonomy, or prolonged hospitalization. The patient may feel devalued, isolated, even abandoned by those meant to support them: "*I couldn't see the light at the end of the tunnel*," "*I felt degraded, subhuman*." The absence of compassion thus has profound emotional and psychological repercussions that can even compromise treatment adherence.

Several participants recognized that systemic barriers—such as workload, time constraints, and administrative pressures—can hinder the expression of compassion without necessarily implying malicious intent. As one participant noted, *"We have to put ourselves in the caregivers' shoes too."* While they expressed empathy toward the realities faced by caregivers, they also stressed that the absence of ill intent should not minimize the significance or impact of these experiences.

One participant remarked, *"The patient has a job to do. It must tap into my motivation and engagement"* (FG#2), offering a perspective that positions the patient as an active and empowered contributor to the care relationship. This view contrasts with traditional representations of the patient as a passive recipient of compassion. Instead, it affirms the patient's role in fostering a relational dynamic grounded in mutual engagement, motivation, and collaboration. As another participant shared, *"We talk differently when we feel we're with someone equal on a human level"* (FG#2).

SUMMARY OF KEY FINDINGS

Table 1 presents a comparative overview of the manifestations and emotional impacts of compassion in healthcare, as experienced by patients and caregivers. The table highlights key dimensions such as relational gestures, communication style, emotional engagement, and systemic awareness, offering a clear contrast between compassionate and non-compassionate care.

Table 1. Summary of Key Findings

Dimension	Presence of Compassion	Absence of Compassion
Relational Gestures	Sitting at eye level, holding hands, warm greetings, being physically present	Cold, distant, mechanical behaviors; lack of eye contact; absence of physical proximity
Communication Style	Respectful tone, empathetic listening, validating understanding, appropriate humor	Harsh or condescending remarks, verbal violence, infantilizing or moralizing language
Recognition of the Person	Seeing the patient beyond diagnosis (e.g., recognizing suffering, uniqueness)	Stigmatizing attitudes, judgment based on age, disability, or mental health; ignoring patient's voice
Emotional Engagement	Caregivers showing vulnerability, admitting limits, expressing emotions (e.g., crying with patients)	Emotional detachment; refusal to acknowledge psychological suffering or emotional needs

Support and Accompaniment	Statements of solidarity (“I’m with you on this journey”), follow-up visits, assistance with procedures	Lack of follow-up, exclusion from decisions (e.g., family not consulted), feelings of abandonment
Therapeutic Relationship	Co-construction of care, mutual respect, shared decision-making	One-sided decisions, lack of collaboration, undermining patient autonomy
Impact on Patient	Feelings of safety, dignity, trust, empowerment, motivation	Feelings of humiliation, anger, loneliness, degradation, loss of trust, emotional trauma
Systemic Awareness	Recognition of caregiver constraints; patients expressing empathy toward caregivers	Systemic barriers (e.g., time pressure, workload) leading to professional burnout or neglect
Symbolic Power of Words	Words used to comfort, validate, and humanize	Words used to belittle, exclude, or dehumanize; experienced as symbolic violence

DISCUSSION

The results of this qualitative study illustrate that compassion, when present, transforms care into a human encounter. It is grounded in concrete behaviors, sincere recognition, and respectful communication. Its absence, on the other hand, can intensify suffering and undermine the therapeutic relationship. These narratives call for a transformation of practices based on listening, education, and the valorization of patient knowledge. Participants’ statements echo the work of Baguley et al. (2022) and Barker et al. (2023) [10-12], which shows that patients associate compassion with simple yet meaningful gestures: a look, a smile, a gentle voice, an open posture. These elements are also present in the findings, where patients emphasize the importance of eye contact, warm tone, and physical and relational proximity. Conversely, harsh or demeaning remarks cause deep wounds. These experiences confirm that compassion is not limited to intention; it is expressed through language, non-verbal cues, and attentiveness to the other [3, 13].

Recognizing the expertise of patients and caregivers, along with the co-construction of care, aligns with the patient partnership movement [22, 23]. Participants appreciated professionals who considered their goals, experiential knowledge, and lived experiences—an approach consistent with the principles of the Montreal Model and its call for ethical transformation in practice [24]. The patient-partner’s active involvement throughout the study positively shaped the co-facilitation dynamic, fostering trust and openness among participants. The well-documented benefits of compassion—such as increased trust, engagement, and patient empowerment—further support this approach [9, 10, 25, 26].

Despite these convergences, some results highlight concerning gaps between caregivers' practices and patients' perceptions. Several participants reported experiences lacking compassion, marked by cold attitudes, stigmatizing remarks, or exclusionary behaviors. These experiences align with Eriksen et al, who analyzed formal patient complaints and identified dehumanizing dynamics in care settings [8]. A significant tension lies in the non-recognition of psychological suffering and emotional vulnerability. While literature emphasizes the importance of considering the person holistically [5, 25], some stories reveal an exclusive focus on physical symptoms at the expense of listening to subjective experience.

Moreover, this study makes an original contribution to the literature on compassion in healthcare by revealing a rarely explored dynamic: patients' recognition of caregivers' suffering. This reflective capacity of patients deserves greater recognition in professional training, healthcare policies, and organizational models. Recognizing systemic constraints, such as workload and organizational priorities focused on performance rather than relationships [28], can lead to a form of professional dissonance where caregivers, despite being driven by humanistic values, struggle to embody compassion in their daily work. These findings also invite us to recognize compassion as a shared responsibility, involving an active posture from the patient and an openness from the caregiver to co-construction. This perspective aligns with the work of Naik and Cheu et al., [30,31].

By giving voice to those directly affected, this research sheds light on the clinical environments and the levers for transforming practices toward a form of compassion that is embodied, contextualized, and shared. These findings call for a revaluation of relational competencies in the training and assessment of healthcare professionals. They confirm the importance of integrating patients' experiential knowledge into both clinical and educational practices [27] and of promoting an organizational culture grounded in humanism [28].

This study presents notable methodological strengths, including the use of focus groups to generate rich, contextualized narratives and the integration of a patient-partner, which enhances the validity of the findings and supports a co-constructed understanding of relational and communicational dynamics in care. However, certain limitations must be acknowledged. The convenience sampling—composed of participants already sensitized to compassion and partnership—may introduce bias, while the small, region-specific sample (n = 12) limits transferability to other contexts. The analysis, grounded in subjective perceptions, offers valuable insight into lived experiences but cannot establish causal links with clinical outcomes. Finally, the absence of healthcare professionals' perspectives restrains triangulation and may introduce interpretive bias.

CONCLUSION

This qualitative study sheds light on the complexity and depth of compassion as experienced by patients in healthcare settings. Far from being merely a professional attribute or technical skill, compassion emerges as an authentic human encounter rooted in listening, recognition, and reciprocity. The collected narratives show that compassion transforms care into a relationship, while its absence leads to emotional and relational ruptures with potentially lasting consequences. By revealing the impact of simple gestures, kind words, and respectful attitudes, this research confirms the importance of revaluing relational competencies in clinical practice and health education. It also offers a conceptual advancement by highlighting the active role of the patient in co-constructing compassion and recognizing their ability to perceive and respond to the caregiver's vulnerability.

These findings call for an ethical and organizational transformation of healthcare environments, where compassion is no longer an abstract ideal, but a shared, embodied practice supported by a humanistic institutional culture. By integrating patients' experiential knowledge into care models and training programs, we can build a more just, sensitive, and truly person-centered healthcare system. ■

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APPENDIX 1: INTERVIEW GUIDE

Narratives of experiences in the presence of compassion

Cognitive dimension: You are invited to recall a situation in a care context during which a caregiver demonstrated compassion toward you or toward one of your loved ones. Take a few minutes to remember this person and this situation.

> ➤ *“Who was this person, and what was his / her role in your care or in the care of your loved one? What sets this individual apart? In concrete terms, how did they express compassion? In what care context did this occur? Were there any contextual factors—such as concerns, values, or cultural aspects—that influenced your experience of compassion?”*

Affective dimension: You are now invited to describe your lived experience and your feelings during this compassionate encounter with this person.

> ➤ *How did you experience this compassionate interaction? What emotions did you feel? What impact did this experience have on you? In what ways did this compassionate encounter influence your care?*

Narratives of compassion-deficient care experiences

Cognitive dimension: You are invited to recall a situation in which you feel that a caregiver lacked compassion toward you or toward one of your loved ones. Take a few minutes to remember this situation and this person.

> ➤ *Who was this person, and what was his / her role in your care or in the care of your loved one? Which attitudes or behaviors, from your perspective, indicated a lack of compassion? What contextual factors might have influenced this person’s attitude?*

Affective dimension: You are now invited to describe your lived experience and your feelings during this encounter with this person.

> ➤ *How did you experience this lack of compassion? What emotions did you feel? What impact did this experience have on you? In what ways did this lack of compassion influence your care episode?*