

Atlantis

Critical Studies in Gender, Culture & Social Justice
Études critiques sur le genre, la culture, et la justice

Atlantis
Critical Studies in Gender, Culture, and Social Justice

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Sarah Costantini

Volume 47, Number 1, 2026

"Healing is an Act of Communion": Critical Perspectives on Women's Health, Wellness, and Disease

URI: <https://id.erudit.org/iderudit/1125567ar>

DOI: <https://doi.org/10.7202/1125567ar>

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Publisher(s)

Mount Saint Vincent University

ISSN

1715-0698 (digital)

[Explore this journal](#)

Cite this document

Costantini, S. (2026). Healing in Unexpected Spaces: A Reflection of the Care Assemblage of My Master's Thesis. *Atlantis*, 47(1), 25–28.
<https://doi.org/10.7202/1125567ar>

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Healing in Unexpected Spaces: A Reflection of the Care Assemblage of My Master’s Thesis

by Sarah Costantini

Author: Sarah Costantini is a doctoral candidate at the University of Guelph. She holds a Master of Science from the University of Guelph and an Honours Bachelors of Arts from the University of Toronto. Her research focuses on exploring avenues for care justice and challenging normative ways of approaching care and treatment for those living with and/or healing from eating disorders.

Introduction

In a time where limitations abound, standardized bio-psychiatric models dominate, and harm so often occurs in the eating disorder (ED) treatment system (e.g., Holmes, Mason, and Semlyen 2021; Lester 2019), alternative avenues for healing need to be explored. As an ex-patient and now researcher in the ED field, I have found myself reflecting on my healing journey, troubled by how the space conventionally deemed healing (formalized ED hospital programs) caused harm to me that remains viscerally evident today.

In this reflection, I speak back to the (un)care I experienced during an inpatient ED treatment admission in 2021, illustrating how possibilities of care, supportive of my healing, expanded unexpectedly in the subsequent research space of my master’s degree project. I begin by highlighting literature that complicates care in conventional ED treatment and follow with a brief description of care during my thesis. I then bring you to a specific treatment moment to introduce how my master’s research resulted in a radical alteration to the care assemblage surrounding my healing. Thinking through care as an assemblage enables attendance to the human and non-human factors and forces—such as treatment guidelines, clinician actions, emotional responses to distress, and physical spaces—which become implicated in care and also enable recognition that altering these connections changes the whole assemblage (Jackson and Mazzei 2013). Healing is a deeply personal experience. Thus, in reflecting on the altered care assemblage surrounding my healing, I provide only a snapshot of how unexpected spaces can facilitate healing journeys, pulling into view the critical need to re-envision the conceptualization of healing spaces and resist the dominant bio-psychiatric focus in ED treatment, which can be deeply limiting, and, at times, harmful.

Care and Eating Disorders

Care, as a concept and practice, has been taken up in relation to EDs in ways that challenge care as inherently good (LaMarre et al. 2023; Lester 2019; Musolino et al. 2016). For example, Lester (2019) depicts how tensions faced by clinicians due to insurance requirements and treatment mandates result in providers adopting strategies to withhold care while construing this as a therapeutic act. Care, here, becomes restricted to those who comply and “willingly” engage in recovery. Exploring care for individuals with EDs deemed “resistant,”

Musolino et al. (2016) highlight that when practitioners attend to how individuals experience care, they can open possibilities of care, expand relationality, and move beyond bio-psychiatric models.

Despite some acknowledgement of the vast complexity of care in ED treatment (LaMarre and Rice 2021), “good care” in ED treatment remains centred on medical stabilization, nutritional rehabilitation, weight restoration, symptom intervention, and behavioural change (American Psychological Association [APA] 2023). Strategies to achieve these aims typically follow a standardized, problem-focused, time-limited, and adherence-based approach heavily rooted in cognitive-behavioural therapy (CBT), with change measured through biometric data (Geller et al. 2021; Lester 2019). Both service users and clinicians feel the effects. Treatment protocols expect patients to adhere to stringent rules, resulting in a denial or minimization of their specific needs, as their experiences become decontextualized within the treatment space. Clinicians must enforce standardized treatment practices to meet required goals under institutional pressures, regardless of what their training and experience tells them (Costantini 2024). Literature indicates that such institutional pressure drives high rates of clinician turnover and burnout (Accurso et al. 2024).

Exploring the Ruling Relations of Carework

Care took a central role in my thesis. Taking an institutional ethnographic approach, I explored how the carework of clinicians is shaped and coordinated by broader institutional processes of administration, management, professional authority, and cultural discourses—the “ruling relations” (Smith 1987; 2005)—in inpatient, day-patient, and live-in ED treatment programs in Ontario. My work explicates how institutional discourses of care-as-cure and gold standard (evidence-based) treatment come to organize clinicians’ carework in moments of treatment non-adherence—when clients struggle to adhere to ED treatment directives (Costantini 2024). As clinicians elaborated on carework, it became apparent that a misfit exists between their desires for collaborative care and institutional pressures to follow increasingly standardized treatment directives, resulting, at times, in informally coercive practices.

Care was also integral to how I engaged in research and self-reflection, becoming more than strictly an orienting concept for data collection and analysis. Brannelly and Barnes’s (2023) book *Researching with Care* offered a starting point for embedding care in my research. Drawing on the feminist ethic of care, Brannelly and Barnes (2023), attend to the relationality of the research process, illustrating how research goes beyond technicality of methodology, creating and re-creating relationships to participants, to experience, and to literature. In turn, thinking about why I undertook this research, my relationship to the research topic, and how this differs from the clinician participants, became a starting point for me to centre care in the research process (Brannelly and Barnes 2023).

The Care Assemblage

The Memory

On December 2, 2021, I was barely four hours into an inpatient admission for the eating disorder that had come to consume my life. Both relieved and scared to be there, knowing without major intervention my life was in danger, I was also terrified for the changes to come. Deeply distressed, paralyzed by fear and racing thoughts, I struggled with my first meal, shutting down and refusing to engage. Right after this meal, the psychiatrist, the “expert” in treatment, standing outside my room, said, “You can either eat or go home and die.” It slammed into me like a truck, the response visceral, simultaneously increasing my self-hatred, strengthening my desire to give up, and diminishing all hope that I could ever be free of my eating disorder. This moment, when I needed care and kindness, I was starkly dismissed, threatened, hurt, and denied care.

Four years later, this moment remains crystallized in my memory, continuing to evoke a strong reaction. While I recognize how critically I needed treatment to sustain my life at the time, I do not view that time or space as supportive of my healing. As this memory has continued to resurface, it has driven my path into ED scholarship, motivating my desire to explore avenues that complicate the practice, regulation, and experience of care in ED treatment.

What I experienced as deeply uncaring at a time when I was seeking care contrasts sharply to the alternate care relations I experienced throughout my master's degree research. Reflecting throughout, and particularly in the final writing stages, it became increasingly clear how healing the research had been. I could quite distinctly see where drastic strides in my healing took root—from engaging in more food challenges to increased flexibility in eating and life to engaging more socially—as I found a research space to which I felt deeply connected and that provided support along the way.

In one of the final meetings with my advisory committee, I shared how doing this work had driven a level of healing I never thought possible, nurturing my life in entirely unexpected ways. As my advisor shared, a care assemblage had (re)formed, driving a project that held care in all elements—from thinking about the topic to engaging with clinicians (participants) to the analysis and writing to my own personal ED healing. Thinking of my research process and of my healing journey as an assemblage deeply resonated. This allowed me to recognize and engage with how research processes and technicalities, emotions and emotional responses, and relationships with myself and my history, research participants, my committee and others connected, dis-connected, and re-connected in complex and multi-directional ways.

Considering the research space as a care assemblage allowed me to reflect on how the alteration of connections within this assemblage—from my treatment admission to the end of my master's—had shifted and changed the assemblage (Jackson and Mazzei 2013). Specifically, I think of the alteration of my sense of safety in the care assemblage of the research space in comparison to that of treatment. The care assemblage of treatment, formed by stringent rules, confinement to a hospital ward, threats, intense anxiety, and distrust in providers vastly impacted my (un)care experience. There, my struggle to comply with the mandatory rule of meal completion was met with anger, punishment, threats, and loss of the freedom of movement. Where compassion, understanding, and empathy held minimal space, a deep sense of distrust, lack of safety, and sense of unworthiness emerged. When I think of this, and the connections of relationships that formed this, I question how healing could have possible when some of the core components of care—interdependency, compassion, and safety—were so starkly missing. This question goes beyond my experience to that of the larger ED system, which is marked by bio-psychiatry, minimal resources, and long waitlists that likely create pressure for clinicians to engage in such threatening statements to enforce symptom abstinence and move people through treatment quickly such that those waiting for life-saving treatment can gain access.

The care I experienced in the research space greatly differed, as collaboration and connection stood strong in this assemblage. Any struggle I faced was met with understanding and willingness to work collaboratively to find a solution. A deep level of care for the participants, their voices, and their raw honesty came from all who engaged. Finally, my connection to the research topic, honest conversations with participants, and sense of support through each stage from those involved, facilitated a commitment and motivation to my personal healing that I had never experienced, nor thought possible in the past.

My research taught me the depth of the importance of care for healing, as well as how healing involves a complex array of relationships from a multitude of different forces. This reflection is my personal example of finding healing in unexpected spaces. For many, the academic space, too, can be harmful, yet through my master's research, surrounded by a group of critical scholars, a support system, and sense of finding space in research, I found myself healing in ways I once did not see as possible. While this is my personal journey, I believe it can offer a lens for exploring care assemblages and their complex relationships that can both infringe upon and facilitate healing beyond conventional treatment spaces.

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