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RESEARCH ARTICLE

Seeing and Having Seen: On Suffering and Intersubjectivity

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Abstract
Within bioethics, two issues dominate the discourse on suffering: its nature (who can suffer and how) and whether suffering is ever grounds for providing, withholding, or discontinuing interventions. The discussion has focused on the subjective experience of suffering in acute settings or persistent suffering that is the result of terminal, chronic illness. The bioethics literature on suffering, then, is silent about a crucial piece of the moral picture: agents' intersubjectivity. This paper argues that an account of the intersubjective effects of suffering on caregivers could enrich theories of suffering in two ways: first, by clarifying the scope of suffering *beyond* the individual at the epicenter, i.e., by providing a fuller account of the effects of suffering (good or bad). Second, by drawing attention to how and why, in clinical contexts, the intersubjective dimensions of suffering are sometimes as important, if not more important, than whether an individual is suffering or not.

Keywords: caregivers; ethics; intersubjectivity; moral witness; suffering

Introduction

> There are only two paths open to those who must witness suffering: (1) pretend it is something else —predictable, resectable, eventually curable, spiritually enhancing, the thing that happens to others —or (2) see it fully and endure the sequelae of having seen.[1]

Consider the following scenario: Anne is the primary caregiver for her mother, Maggie. Anne is in her early 50s and Maggie is in her mid-70s. When Anne's father—Maggie's husband—passed away several years ago, Maggie moved in with Anne at her daughter's urging (neither of them wanted to be alone). Since then, Anne has noticed a steady decline in her mother's general interest in doing much of anything, plus her mobility and overall health. Maggie has stopped driving. She used to go for a walk every morning, but a bad knee and chronic lower back pain give her trouble now. Anne and Maggie still have dinner and watch television together most nights. Anne insists they go out for a cappuccino at their favorite café by the waterfront on Sundays. It takes a lot of coaxing to get Maggie out of the house and in the car, but she seems content once they get there. At home, Maggie spends a lot of time laying down or watching her shows. Sometimes, she sits quietly by the window. Maggie's memory is slowly worsening. They have emergency contact numbers, instructions, and reminders written in big letters on sticky notes around the house.

Maggie reluctantly agreed to knee replacement surgery last year. The surgery went fine, but Maggie's recovery was rocky—she acquired Covid during the post-operative period—and rehabilitation (physical and occupational therapy) has been challenging. Maggie sometimes participates in rehabilitation sessions but often states that she is tired and "doesn't feel like it today." Anne continues to take Maggie to all her appointments and work with the therapists to engage her mom, but she can tell Maggie is

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miserable. Anne feels bad that Maggie is on her own all day while she's at work. She sees how her mom struggles with small tasks and how her knee and back continue to pain her. Anne helps Maggie with most daily living activities, including showering. When friends or Maggie's doctors ask if Anne has thought about finding an assisted living facility for Maggie, Anne shakes her head and relays that "Mom told me she never wanted to go to one of those places. I made a promise I would never put her in a home." She worries not just that her mom is unhappy, but that she is suffering through each day.

Reflecting on Anne and Maggie's situations, ethicists might (rightly) ask questions about Maggie's experience, including whether she is, in fact, suffering and, if so, in what ways. They might encourage dialogue between Maggie, Anne, and Maggie's clinical care team, to clarify her values and preferences regarding her care as she gets older. They might invoke concepts like quality of life, caregiver distress, burnout, burden, or compassion fatigue to help explain what is going on. They might propose strategies to try and get both Anne and Maggie some additional support. They might even call attention to society's failures when it comes to supporting our aging population. It may turn out that Anne is mistaken about her mother's suffering; Maggie may be comfortable with this phase of her life and think Anne shouldn't worry so much. But whatever Maggie says, it might be that Anne still thinks her mother is suffering—Anne perceives it to be so, regardless of Maggie's reassurances. This might eat away at Anne. She may feel that, while nothing is likely to change, aside from her mother's needs only increasing with time, she has an obligation to be there for her mother, come hell or high water. That is, Anne may feel that her mother's experience requires both recognition and some kind of response from her, that is, that it entails a call to moral obligation.

Background

Within bioethics, two issues have dominated the discourse on suffering: the nature of suffering (including who can suffer and in what way) and whether suffering is ever grounds for providing, withholding, or discontinuing certain interventions, e.g., providing aid in dying or discontinuing life-sustaining treatments. The discussion has largely focused on subjective experiences of either acute episodes of suffering in inpatient settings or persistent suffering that is the result of terminal, chronic, or mental illness. While these issues are of philosophical interest and ethical and practical importance, there remains limited discussion within bioethics of the relational, intersubjective dimensions of suffering, including the experiences of caregivers like Anne, who—in Rita Charon's words in the epigraph of this essay—"see" suffering and "endure the sequelae of having seen."

The effects of caregiving are well studied, including its social, psychological, physical, and financial costs on domestic caregivers.[2,3,4] Feminist scholars have written extensively on the largely ignored value of domestic caregiving.[5,6,7] We also know that exposure to suffering can affect someone socially, psychologically, and at a physiological level.[8] However, the intersubjective effects of caring for someone who is suffering have not been incorporated into the bioethical discussion of suffering. The intersubjective effects of suffering can end up mattering a great deal at the bedside; it's not just whether Maggie is suffering, but Anne's *perception* of Maggie's suffering and how it affects their intersubjectivity and decision-making that matters.

Broadly, "intersubjectivity" refers to "the variety of possible relations between people's perspectives," including how we share, understand, and interact with each other's subjective experiences.[9,10] Understandings of intersubjectivity vary, but it is typically understood as the situated, embodied awareness or attribution of intentionality, feelings, and beliefs to others. For the purposes of this paper, it is helpful to distinguish between primary, secondary, and open intersubjectivity. Primary intersubjectivity describes a basic form of mutual recognition—the first emergence of shared attention and emotional connection between subjects. Secondary intersubjectivity describes shared attention toward objects, and the aware, intentional sharing of experiences and perspectives and simple forms of related communication. Open subjectivity describes the more complex, flexible, and reflective engagement with others' perspectives that occurs between subjects, including the ability to reflect on one's own subjective experiences, recognize that others have their own unique perspectives, empathize with, and respond to others.[11,12]

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Maurice Merleau-Ponty describes how open subjectivity involves the continuous construction of meaning through our interactions with others, recognizing the provisional and interpretive nature of our understanding.[13]

The aims of this paper are twofold: first, to critically review philosophical theories of suffering and morally valuable responses to it, with an eye to whether this body of scholarship considers the intersubjectivity of agents in contexts of suffering. Second, this paper aims to advance an argument for an understanding of suffering that is sensitive to intersubjectivity. It argues that—in contexts of illness and medical decision-making—the intersubjective dimensions of suffering end up being as important, if not more important, than whether someone is suffering or not or in what way. This is something that has not been explicitly attended to by bioethicists when they invoke suffering. It explores the intersection of three concepts: bearing witness, attending to, and accompaniment, including how they get us closer to an account of the intersubjectivity of individuals like Maggie and Anne.

Before beginning, a brief note: my goal here is not to defend a particular existing theory of suffering (e.g., objective, sensation-based, or values-based) or distinguish suffering from pain and other related phenomena. I also wish to remain agnostic about the value of suffering for the one who suffers and whether suffering requires awareness or rationality. While I am interested in both paid/professional and unpaid/familial caregivers, I will focus on home-based, unpaid caregivers like Anne.

Background: theories of suffering and morally valuable responses to it

In this section, I canvas the philosophical literature on suffering, with the goal of clarifying whether and to what extent theories of suffering acknowledge the intersubjectivity of agents in contexts of suffering. Broadly, theories of suffering can be broken down into three categories: objective, sensation-based, and values-based theories.[14,15,16,17,18,19] The theoretical literature on suffering establishes a close connection between the questions of "what is suffering?" and "what is it like to suffer?" Phenomenological theories attempt to understand our embodied experience of suffering from the perspective of the subject.[20,21,22,23,24] I will not rehash the details of these theories here. What is important for our purposes here is that theories of suffering focus on understanding suffering from the subjective experience of the one who suffers—on the perspective and experiences of the Maggies of the world; they are largely silent about the intersubjectivity of suffering individuals and those who care for them. Within clinical ethics, there is occasional mention of caregivers' perceptions of patients' pain and suffering and some discussion of the issues that arise when different views of suffering appear at the bedside.[25,26]

While theories of suffering have focused on defining suffering from a subjective perspective, moral philosophers have extended their gaze to those beyond the sufferer. Despite the silence of theories of suffering on its relational dimensions, suffering is typically viewed as warranting some form of moral response from those who witness or are otherwise aware of it. Moral philosophers have advanced normative claims regarding one's obligations to the "suffering other," especially within certain relationships (e.g., those between a patient and caregiver or clinician).[27,28,29,30,31,32] There is general agreement among moral philosophers that—whether it be because it produces harmful effects, undermines our role-based responsibilities (or the categorical imperative), or reveals some flaw in our character—there are certain responses to suffering that are morally problematic. There is also general agreement that certain kinds of responses are morally valuable.[33] Dispositions such as empathy and compassion, shock, horror, and mercy, which are grounded in recognition of the "suffering other" and respect for them as an end in and of themself, have been discussed at length in the philosophical literature. So, too, have their corresponding vices (think of indifference, sadism, delight, cruelty, callousness, blindness, dismissiveness, failure to take someone's suffering seriously, etc.).[34] Accounts of morally valuable responses to suffering are often tied to situational features and one's social or professional roles and relationships. They sometimes describe actions, and at other times describe the role of affect, motives, and attitudes dispositions when it comes to recognizing and responding to the suffering of others.[35,36]

The kinds of moral responses discussed by moral philosophers are *general* in nature. There is typically little context provided regarding *who* is suffering, and the particular moral, social, and political

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relationships or structures *they* exist within. This moral, social, and political context is crucial to thick accounts of suffering, including who is exposed to suffering and tasked with the labor of attending to it.[37] The examples offered in the philosophical literature also largely focus on acute episodes of suffering (e.g., during a hospital admission) from a subjective perspective. Where they do discuss the experiences of others, the focus is typically on the actions that can be taken to alleviate suffering. They say little about situations where someone's suffering cannot necessarily be alleviated or "pretended away," but the "having seen" still occurs, and the relationship between agents persists.

The goal of this section has not been to settle disagreements between proponents of different theories of suffering or to advance any arguments about what kind of responses or virtues are morally valuable. My goal has been to clarify whether theories of suffering engage with the experiences of others beyond the suffering individual, including the intersubjectivity of agents in contexts of suffering. When accounts of suffering do consider the role of those beyond the sufferer, the discussion has focused on their *obligations*—not on caregivers' perspectives or experiences, or the intersubjectivity of people like Anne and Maggie. While some philosophical accounts discuss the role of partiality, proximity, blame, responsibility, and social biases in (1) our obligations to those suffering and (2) regulating our responses to suffering, they are silent about how relationships between agents and their intersubjectivity inform contexts of suffering. In short, the relational dimensions of experiences of suffering are underdeveloped. Some phenomenological accounts of suffering discuss "the philosophical primacy of the ethical acknowledgment of the suffering other" or what Charles Taylor characterizes as a "deep involvement in others' experiences."[38,39,40,41] While most philosophical theories of suffering focus on the subjective perspective (i.e., from the perspective of the one who is suffering), phenomenological accounts of suffering lay a foundation for the intersubjectivity of agents.[42] In the next section, I will explore three concepts—"bearing witness," "attending to," and "accompaniment." I argue that these concepts help build an account of the intersubjectivity of agents like Maggie and Anne in contexts of suffering.

Bearing witness, attending to, and accompaniment

In simple terms, bearing witness involves taking the time to stop and listen, not look away, engage in ongoing cycles of action, reflection, and remembrance, and create and tell stories or speak up about what is seen, especially where there would otherwise be silence.[43,44,45,46,47] In Quaker theology, "testimony" refers to words or actions that bear witness to the work of God and God's truth. The Quaker tradition calls on individuals to, "Bear witness to the humanity of all people, including those who break society's conventions or its laws… Seek to understand the causes…"[48] From early in Quaker history, "testimony" has referred to the ways in which the Quakers testified to the untruthfulness of certain claims, practices, or ways of life. However, "bearing witness" and "testimony" are terms that have come to be used much more broadly, and now have secular, legal, and postmodern implications in addition to religious implications. In *Witness to War: An American Doctor in El Salvador*, Charles Clements—himself a Quaker—writes of what he felt was the duty to bear witness, "to measure events with your own eyes and to attend to what you've seen."[49] Some might think that this is precisely the kind of work being undertaken by caregivers like Anne.

In *The Ethics of Memory*, Avishai Margalit suggests that to become a moral witness, "one has to witness the combination of evil and the suffering it produces: witnessing only evil or only suffering is not enough."[50] The moral witness has what Margalit calls "knowledge-by-acquaintance." Margalit stresses that "the paradigmatic case of a moral witness is one who *experiences* the suffering—one who is not just an observer but also a sufferer."[51] The defining characteristics of moral witness include: courage in the decision to bear witness, moral complicity in the events that constitute the testimony, certain risks to the witness, and something whose testimonial mission has a "moral purpose."[52,53] Bearing witness is more than just simple observation; it is a moral response that involves recognizing one's responsibility.[54] Dawn Hood-Patterson and Brian Carter characterize bearing witness as an action of passivity—a "deep attunement to the circumstance, to the nature of things." They write:

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> The principle of non-action is essential when understanding bearing witness because it forces us to: (1) recognize that the circumstances and contexts of illness are often beyond our control and (2) we are asked to stay, abide, remain with the person who is ill. Non-action is not inaction or the absence of action, rather the 'action' is an abiding awareness of the other person, recognizing the potential that they might experience physical or existential suffering, with a steadfast commitment to 'therapeutic presence' and non-abandonment.[55]

While often invoked in the same breath as bearing witness, "attending to" and "accompaniment" are characterized slightly differently in the literature. In *Attending Children: A Doctor's Education*, Margaret E. Mohrmann explores the variations of meanings of "attending to" that shape her practice as a pediatrician.[56] Mohrmann describes a particular kind of close observation and attunement or responsiveness to someone else's needs. The cases she draws on to explore the theme of "attending to" involve situations where there is no "fix" or "cure" to be found, but the caring relationship consists of attention to small, human details, more immediate needs, and a kind of watching or "waiting on." Other accounts describe the deep sense of responsibility for/to the other and vulnerability that characterizes relationships of "attending to."[57] Alongside forms of attending to that center on listening and waiting, Mohrmann discusses "accompaniment"—the watching over or application of oneself to the care or service of another.[58] Hood Patterson and Carter characterize accompaniment as co-action—they describe a kind of "moving through the experience together" that accompaniment entails.[59] There are elements of Anne and Maggie's shared experience that are captured by accounts of bearing witness, attending to, and accompaniment. Together, these concepts draw attention to the intersubjectivity of agents in contexts of suffering.

Why intersubjectivity matters

An account of suffering that only attends to the experiences and subjectivity of the suffering individual is silent about an important relational dimension of suffering: the intersubjectivity of suffering individuals and those who care for them. An account of intersubjectivity, including the intersubjective effects of suffering on those who are tasked with attending to it, could enrich theories of suffering in at least two ways: First, by drawing attention to how intersubjectivity in contexts of suffering can be a source of knowledge. A closer look at intersubjectivity helps to clarify the transformative effects of suffering *beyond* the individual at the epicenter, i.e., provides a fuller account of the effects of "seeing" and "enduring the sequelae of having seen," in Charon's words. This could have important implications for formal and informal caregivers. Second, by drawing attention to how and why, in clinical contexts, the intersubjective dimensions of suffering sometimes end up being as important, if not more important, than whether someone is suffering or not and in what way.

Reflecting on the themes of bearing witness, attending to, and accompaniment in Anne and Maggie's situation, these concepts draw our attention to how intersubjectivity in contexts of suffering can be a source of knowledge. Through "knowing through acquaintance," i.e., Anne's moral proximity to her mother, she "sees" Maggie's suffering and develops a sense of the truth of both her mother's circumstances and *their* circumstances, including the realities of aging in our society. Intersubjective experiences of suffering can shape not only the self but understandings of the self in relation to others. While Anne may never provide testimony in the way some accounts of bearing witness describe, we can certainly imagine her doing so—whether to friends and family, in the doctor's office, or at her mother's hospital bedside. Maggie herself withstanding, no one else can or will become acquainted with Maggie's journey, her suffering, in the same way. This knowing through acquaintance or "seeing" can be normatively significant—a source of moral understanding or knowledge.[60]

These themes also draw our attention to how suffering can have transformative, intersubjective effects. Anne may find tremendous value in caring for her mother (think of the love and devotion that characterizes many such relationships). She may come to understand herself and her relationship with her mother better. She may experience "growth" or development as a result of engaging with Maggie's experience. Their interests and experiences may become entangled.

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While Anne is not necessarily herself suffering, we can certainly imagine her coming to suffer as a result of attending to Maggie's suffering. In her role are caregiver and caretaker for her mother, and through her choice to bear witness to Maggie's experience, attend to it, and accompany Maggie, Anne may take on certain tasks, risks, and burdens that have not been accounted for by theories of suffering, which focus almost exclusively on the experiences of the suffering individual. Findings suggest that cognition (cognitive activation, information processing, and evaluation), understanding (our affective sharing/emotional resonance), motivation, and reward processing are all implicated when we are exposed to the suffering of others.[61] The temporal dynamics of perception of pain in others appear to consist of two responses: (1) an early emotional sharing component and (2) a late cognitive evaluation.[62,63] It is difficult to say how generalizable findings are, but affective sharing (also known as emotional resonance)—the unconscious sharing of the affective state of another and the first element of empathy to appear during ontogeny—has been shown to be a consistent neurological response to suffering stimuli.[64,65] For some participants, this translates into empathic understanding, the conscious awareness of the emotional state of another person, and empathic concern, the motivation to care for someone in need.[66] But affective sharing can also occur independent of conscious perspective-taking and higher levels of cognitive understanding. Essentially, even when we are unaware that we are doing so, we can share in the pain and suffering of those around us.

Reflecting on the intersubjectivity of agents in contexts of suffering brings into sharper focus the kind of moral labor undertaken by caregivers like Anne. Without Anne and others' willingness to continue to bear witness, attend to, and accompany someone they care for and about, Maggie's experience could become invisible or only attended to by relative strangers. Certain morally and socially valuable qualities within relationships, such as sensitivity to one another's vulnerabilities, patience, the preservation of dignity, and sacrifice, may be less likely to develop. Anne's role is marked by a curious duality of action and passivity; she is engaged in the everyday "doing" of caregiving, but there is no intervention to be had with respect to what Anne sees as her mother's suffering—no "resectability," no cure, in Rita Charon's words—aside from the daily acts that constitute their routine. Anne may experience distress or feel complicit in her mother's suffering, but it is not the kind of moral distress described in the clinical ethics literature, e.g., in the case of the bedside nurse who feels complicit in wrongdoing. Anne's experience is marked by acceptance or their shared experience. She is both a watcher and a keeper. Importantly, her experience may itself be largely unseen and unattended to.

What does this mean for Anne and Maggie? Work in neuroscience and behavioral science suggests that it's "natural" (i.e., reflexive and ingrained) for us to respond to the pain and suffering of others (affectively, cognitively, and motivationally), especially the unconscious response of affective sharing—something that is integral to intersubjectivity. This means that if Anne—regardless of Maggie's reassurances—perceives her mother to be suffering, she is likely to share in that suffering at an affective level (she will feel that suffering) and spend cognitive energy (processing, reflecting, deliberating) on it. Active (conscious) regulation of negative emotions has physiological and socio-psychological costs; research has shown that it can disrupt communication, reduce rapport, and increase blood pressure.[67] Studies have also shown that exposure to suffering has lasting effects on our neurological patterns and development.[68,69] Anne's experience caring for her mother, and exposure to what she perceives as Maggie's suffering, is likely to change Anne, including her cognitive and affective responses.

In clinical contexts, the intersubjective dimensions of suffering, then, sometimes end up being as important, if not more important, than whether someone is suffering or not and in what way. Decision-making at the bedside is rarely just about the patient. Considering the intersubjective effects of agents in contexts of suffering allows us to broaden our gaze beyond Maggie, to consider how the experiences of others are influencing the situation. Anne and Maggie's intersubjectivity may shape interactions at the bedside and impact medical decision-making in several important ways. It may mean that Anne has insight into Maggie's experience that the clinical team does not, and cannot, have. That insight may inform Anne's assessment of the situation, including what she views as "the facts," whether and how Maggie is suffering, and how they both weigh or balance various considerations. It may also inform Anne's understanding of her moral obligations with respect to her mother. Anne's identity may be tied to her role as a daughter and caregiver in ways that inform which options she can entertain and which

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decisions she views as permissible. It is important to consider that Anne's reactions and decisions—especially if the clinical team is looking to Anne as a care partner and potential surrogate decision-maker for Maggie—may be the result of reflexive cognitive and affective responses or careful, deep engagement with Maggie's experience. Anne's bearing witness, attending to, and accompanying of is something that could be simultaneously meaningful and come at a significant cost to Anne. Anne and Maggie's intersubjectivity, along with Anne, Maggie and the clinical team's intersubjectivity, may end up being central to the dynamics in the room and process of arriving at a shared decision about Maggie's care.

Conclusion

Despite bioethicists' interest in suffering, there remains limited exploration within bioethics of the intersubjectivity of agents in contexts of suffering. Theories of suffering center on subjective experiences of suffering, that is, on the individual, what it is like for them to suffer, and whether suffering is ever grounds for providing, withholding, or discontinuing certain interventions. Despite the silence of theories of suffering on its relational dimensions, suffering is typically viewed as warranting some form of moral response, e.g., by those who witness or are exposed to it. Certain kinds of responses to suffering are viewed as morally valuable and certain "relationships of suffering" (e.g., those of caregivers or clinicians) are thought to entail some moral obligations. In this paper, I have argued that intersubjectivity has not been sufficiently attended to by bioethicists when they invoke suffering. Exposure to suffering can change caregivers not only morally or socially, but also on a physical, embodied level, in ways that intersect with our social and moral roles. Intersubjectivity in contexts of suffering can be a source of moral knowledge and transformation. Attending to intersubjectivity in contexts of suffering can help us to broaden our gaze beyond the suffering individual and consider the effects of "seeing" and "enduring the sequelae of having seen" suffering, in Charon's words. I explored the intersubjectivity of agents in contexts of suffering through three concepts: bearing witness, attending to, and accompaniment. I argued that these concepts provide helpful insight into the intersubjectivity of individuals like Anne and Maggie—something that should be attended to by bioethicists when they invoke suffering.

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