

## Editorial:

# Watching My Mother Die – Subjectivity and the Other Side of Dementia

Nancy J Moules & Andrew Estefan

### Preamble: On Subjectivity

Within research traditions, the construct of “subjectivity” is limited and contentious. Subjectivity is often associated with the “personal” in ways that enable it to be diminished or reduced. A reductive perspective of subjectivity means that it is commonly understood as the realm of “personal opinions, assumptions, interpretations, and beliefs” as opposed to the more “objective” and, arguably lauded “observation of measurable facts” ([https://www.diffen.com/difference/Objective\\_vs\\_Subjective](https://www.diffen.com/difference/Objective_vs_Subjective)).

There is an inherent assumption embedded in critiques of subjectivity: if something is measured, it is fact; if something is felt, believed, or interpreted, it is not. Qualitative research has been criticized for being too personal, too subjective (Greenhalgh et al., 2016). Research that focuses on experiences engages interpretation to make meaning of those experiences. Quantitative research engages measurement to make meaning of phenomena. Whereas the tools of the quantitative researcher are seen as a more reliable basis for articulation of “facts,” the interpretations of the hermeneutic researcher cannot (and should not) be measured in the same way. “The theory that *everything* is a matter of interpretation is called hermeneutics...there are no uninterpreted facts of the matter. Every matter of fact is a matter of the interpretation that picks out the facts” (Caputo, 2018, pp. 3-4). Where this becomes problematic is that the worth placed on the different tools and practices of researchers means they are valued differently. Hermeneutic research is easily reduced and dismissed as subjective accounts, and therefore not trustworthy or dependable.

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**Corresponding Author:**  
Nancy J Moules, RN, PhD  
Email: njmoules@ucalgary.ca

Addressing this issue seems to be an ongoing challenge that warrants attention (Moules, Venturato, Laing, & Field, 2017).

Subjectivity is a complex phenomenon and a misused term. The philosophical nuances of subjectivity are overlooked and ignored when it is reduced to simply mean “opinion,” or “experience.” Although subjectivity incorporates both opinion and experience, it is also neither of these things. Some philosophical ideas, such as personalism (for e.g.) reveal or suggest that subjectivity is, indeed, intersubjectivity because of the relational nature of humans. Subjectivity must, then, have an external referent. Can subjectivity qua subjectivity, therefore, ever be known? Personalism also further troubles the idea of subjectivity because, to other “people” we are also objects. What, then, is the nature and experience of the object-subject? Although we are not seeking to answer that question in this paper, we recognize that asking it is a challenge to common assumptions about subjective experience. “Hermeneutics is the theory that the distinction between facts and interpretation bears closer scrutiny...no matter how loudly you proclaim you are just sticking to the facts, you are only raising the volume of your own interpretations” (Caputo, 2018, p. 4). Caputo’s words, here, remind us that subjectivity—the experience of self—is nested within and among our action in the world. Human subjectivity informs our simple choice of what to eat for breakfast; it also informs the uptake of objectivist and constructionist thought.

Subjectivity is contentious because, in neoliberal, instrumentalist contexts (such as the professions), singular, subjective experience is perceived as lacking validity as a source of truth. Subjectivity is, though, a form of becoming. For some theorists, like Marcuse, subjectivity is the cultivation of radical, resistive subjectivities. In this way, subjective is not just “is,” but is shifting, and always forthcoming: a rich site for inquiry.

Take, also, ideas like *bildung* – the education within and through culture. *Bildung* makes subjectivity more than simple opinion or the way the “other” sees it. Subjectivity can be owned and named, we can articulate a self that engages with, and appraises, a world, just as others are at liberty and able to critique the existence of that self. The transaction here implies something beyond subjective opinion, but rather a negotiation of self, knowledge, and understanding between self and world. These conversations are not expressions of a solely subjective state, but an applied debate in which ontological and epistemological tensions are played out in both generative and constraining ways.

When considering how it is, as people in the world, that we know, even apparently “subjective” judgments are problematic. Taste, for example, is an aesthetic consideration. Taste is the subjective experience of pleasure or displeasure; a person either likes something or they do not. People are, however, also conditioned to find some things pleasurable (a nice latte for example), and other things displeasing (like the smell of durian). The actual physical or physiological response of the body to certain stimuli is precisely that, a biological response that might contribute to a sense of subjectivity, but biology is not subjectivity in and of itself. The fact that around 10% of the population possess a gene that makes cilantro taste like soap is not a singular truth grounded in either objectivity (10% have the gene) or subjectivity (the experience and appraisal of cilantro is a negative one). Therefore, an exploration of the nature and conditions of pleasure is needed in order to explore human experience. The exploration and the finding transcend the limits of

subjectivity as it is commonly understood. One might argue that the limits of science are similarly transcended in such a venture.

The arguments that things (like findings in qualitative research) are “subjective” are based on superficial engagement with what subjectivity means. Even if a singular person can be known as a subject with subjective experiences, it cannot by extension just be assumed that what a person says or otherwise expresses, or how they act, is subjective. For some theorists (consider psychoanalytic feminism, for example), subjectivity is always constituted. That is to say, it is *of something* and that something cannot be ignored, reducing subjectivity to a matter of taste, preference, or disconnected independence of mind over context.

Finally, the boundaries of subjectivity are cultural: the degree to which we experience ourselves as subjective entities is not stable across culture or context. As a result, the reducing of complex expressions of being or presence in the world, as well the meaning-making practices in which people engage, to opinion or anecdote is both naïve and a loss of potential to enrich how connections are made between people in their respective worlds.

This editorial is about personal accounts of interwoven universal human experiences of loss, mortality, and grief. Though one writes within the “limit situation” (George, 2017), the writing can be interpretively linked to the world – a world which is not purely “my own” but intersects others’ experiences so that it becomes recognizable and, in that sense, communal. This is at the heart of hermeneutics: a sense of recognizability and kinship. George’s (2017) beautiful article was in response to Beamer’s (2017) and Moules (2017) reflections of grief and loss but it was also about *his* experience of the loss of his father. This editorial is continuing the conversation. In hermeneutics, one’s experience is often a point of departure either as something to interpret or something that changes our interpretation of things (K. Sweet, personal communication, July 25, 2018).

In continuing this conversation of loss, mortality, and grief, Moules takes on the experience of dementia and the limit situation of memory in the context of dementia. In watching someone experience dementia, there are moments of connection, lucidity, and recall, watching as things become altered (at best), attacked, and finally lost. As Moules’ mother succumbs to the dementia that has claimed and robbed her, we are clearly aware that dementia is not suffered in the singular. Moules, too, is suffering its claim and its theft of her mother and this experience is much more than “just subjective.” “If we truly understand what an interpretation is – which is what we do in hermeneutics – we would never say ‘*just* a matter of interpretation’” (Caputo, 2018, p. 14).

### **The Other Side of Dementia**

I (Moules) am watching my mother die. This is hard but not as hard as it is to watch her suffering in her dying – a suffering that dementia has imposed. I lose her over and over again every day. Rarely now are there glimpses of my mom. I look deep into her eyes and cannot find her and she cannot find me either - - a deeper sorrow and suffering for her - a deeper loss.

Dying is not such a bad thing. Suffering is.

George (2017) reminded us of the limit situation of memory in grieving and I watch the betrayal of memory as dementia, against our will, robs her of her fight to hold on to what and who she knows, just as she knows she is losing all of it.

There is a past that is being lost here, not just her past but my own as well, a past connected to others in our lives. I wrote the following in 2009 for my mother and her two sisters, as well as for my cousins. I read it at the funeral of my mom's eldest sister in 2010.

### *Our Mothers' Kitchen Tables*

*We grew up lingering around the tables in our mothers' kitchens.*

*In our times together as families, our mothers, three sisters, cooked for us all, and then gathered together in the kitchen to do the dishes; Simply a disguise to mark the work that had to be done... But really claiming the place where they could connect alone.*

*I remember us as kids, hanging around, not really helping, but mostly wanting to catch a scent of something secret.*

*In these curiously sacred, yet mundane times, we learned from our mothers how to move seamlessly from laughter to tears, teasing to supporting, listening to telling. We learned what it is to be connected, to be loyal to family.*

*We learned how to love.*

*We hung around hoping to catch a tidbit of gossip, a nuance of sex, a glimpse at the laughter that transformed their lives from minutia to perfection.*

*But mostly we stayed to see who we would become, what we had waiting for us. We stayed to see the almost inexplicable moments when they were just themselves in a way with each other that no one else knew. In these moments, they were not mothers or wives.*

*They were sisters.*

*We grew up lingering around our mothers in the moments when they moved from being mothers to girls; to women who, over years of experiences and love and loss, still found something to laugh about.*

*We grew up with the hope that we too would find tables that were strong enough to hold up such rich history and grounding trust that laughter would always be found, that teasing meant love, and that family is heart.*

*We were well-fed at our mothers' kitchen tables.*

My mom was able to attend that funeral and then she had the 5th of surgeries for her pituitary tumour – a craniotomy this time. I started to lose her then. Dementia is a master thief; it is

stealthy at times, bold at others. It slips in quietly and proclaims itself loudly. This kind of insidious loss does not happen cleanly, and the tables begin to turn at some point.

*Resetting the Kitchen Table*

*The table has changed - -*

*She can't see it.*

*He can't hear it.*

*She is no longer the person*

*she thought she was*

*and then she believes she has lost me as well as herself.*

*I have to dig deep to find her.*

*But there are moments when she shows...*

*I make a random joke and she gets it.*

*He doesn't.*

*The food gets worse; the meal is harder; there is less laughter.*

*And I leave to come back to my own home realizing I miss her.*

*And once again, see nuances and foreshadowing of what I am to become*

*- - the set table that awaits me.*

My father died last year (Moules, 2017), and my mother did well enough on her own until January 2018. Then quickly it was Long Term Care and a very rapid decline deep into dementia, such that she can no longer talk and she is receiving total nursing care. She knows who I am, but it is a limit situation of memory that has betrayed her and left me bereft before she has died. She is dying and I try to grasp George's (2017) limit situation that Gadamer invokes - it give me comfort in his words of memories that are "inexhaustible in their significance" (p. 3), and how I am charged to carry the memory on my own: "The world is gone; I must carry you" (Derrida, 2005, p. 141, citing Paul Celan).

I think too of my friend, Heather, who lost her daughter, Danielle, last year on September 26, and my other friend, Janice, who lost her son, Jordan, last year on December 1, and the memories they carry of worlds gone. "The infinite task posed by the dead" (George, 2017, p. 1) is as limitless as are our efforts to understand (Gadamer, 1960/2003).

Grief, like life, involves a radical and resistive subjectivity (Sebba, 2012). Grief is not just sadness, but sometimes it is relief; there is freedom with loss; there is laughter with tears, or as Crist suggested "As soon as a newborn child feels the first touch of air it falls to crying. The sun must shine upon it for well nigh forty days before it starts to laugh. Oh in this world, tears predominate over laughter" (Crist, 2018, pp. 7-8, citing Gadamer, 1996, p. 153, citing the poetry of Friedrich von Logau). During her life, my mother resisted being "the good minister's wife." She was, at times subversive and, for a woman of her time she may have been thought of as radical, albeit quietly and with careful purpose. Recently, I have come to understand that even had she not resisted being the good minister's wife, she could not have laid claim to such an

experience; some of the women of my father's church can still not let go of their story of her as an unfitting minister's wife. As her memories fail, my mother occupies a different resistive and *radical* subjectivity: she is the "I" without an "I." This is not a simple subjectivity; it is being, becoming, resisting, and, ultimately, succumbing.

We can set the loveliest of tables and we can invite the most loved of guests, but we cannot predict how well the meal will go - we can only do the best setting we can as we carve out the futures for which we can only hope.

### Postscript

Thelma Irene Moules died at 1215 a.m., September 1, 2018. We miss her.



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