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COMMENTARY 3 OPEN ACCESS



The Empirical and the Philosophical in Empirical Bioethics: Time for a Conceptual Turn

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Some bioethicists engage with empirical work on stakeholders' values, attitudes, and experiences as a basis for theorizing ethics in the context of healthcare. Related to this empirical turn, a debate is being conducted about how to combine empirical research with normative analysis. In this commentary, we are concerned with the more rarely discussed question of how to integrate philosophical, conceptual work into empirical bioethics (hereafter referred to as EB). We suggest that EB should make one more turn after the empirical one: a conceptual turn.

The commentary offers a three-dimensional approach to doing philosophical empirical bioethics. Specifically, it proposes an integration of hermeneutphenomenology into empirical bioethics. Phenomenological philosophy endeavor, concerned with subjectivity and lived experiences. Central to the phenomenological inquiry that we see as valuable for bioethics is an understanding of subjectivity as embodied and situated in relations with others and the world (Merleau-Ponty 2006). This phenomenological inquiry seeks to unveil and scrutinize the taken-for-granted beliefs, assumptions, and norms that we live by, which are strengthened through repeated expression or action, and only sometimes challenged or questioned (cf. Zeiler and Käll 2014). Furthermore, hermeneutical phenomenology underlines the aspect of interpretation. Human beings are understood as meaning-making creatures that interpret themselves, their bodies, and the world within and through their situated experiences. This interpretation arises through a circular relationship between the subjects and their contexts: the subjects' understandings and expressions of themselves, which are shaped by their lived contexts, also shape these

contexts (Ricoeur 1991). Hermeneutical phenomenology acknowledges that subjective meaning-making and the study thereof arise from this interpretative process. Below, we describe three dimensions of what we call a hermeneutical phenomenology approach to empirical bioethics.

Dimension 1: A hermeneutical phenomenology analysis of lived experiences

A hermeneutical phenomenology analysis of lived experiences of embodiment, illness, suffering, and healthcare treatment, as narrated by patients, their friends and family, and healthcare professionals, contribute to the understanding of the meanings of these phenomena. It acknowledges the situatedness of subjects as helping to shape their perception and self-understanding including possible understanding of their bodies, illness, and medical treatment, *and* that such understanding helps to shape their situatedness. Such an analysis also acknowledges the situatedness of researchers, and that our constitutive contexts can help inform our understanding of empirical accounts.

To give an example, we turn to a hermeneutical phenomenology study of partners' experiences of breast cancer (de Boer, Zeiler, and Slatman 2018). Within this study, a couple named Wesley and Kim talked about how they managed as a family with young children when Kim had breast cancer. In the interview, Wesley said that he felt he couldn't help out sufficiently as he could not give his children "that special something that mothers have." Kim agreed with him, and said that she felt "guilty" for not "being there enough." We see this example as illustrating how narrated experiences are shaped within larger,

normative structures, and how they can help shape these structures. Wesley's narrated experience seems to hinge on his idea(l) of parental support and his understanding of what motherhood entails, and his formulation of this idea is constitutive for the guilt Kim expresses. Phenomenologically, this exemplifies how couples co-shape their affective bodily existence, by defining not only what separates but also what connects them. Furthermore, Wesley's and Kim's narratives are informed by the researcher's way of asking questions and interpreting the answers, such as when they and the researcher took part in silences that allowed the interviewees to formulate descriptions of their experiences. As some other examples, phenomenological analyses of teenage girls' lived experiences of becoming aware that they have no or a small vagina (Zeiler and Guntram 2016) and of parents' experience when their child is born with a disorder/ difference of sex development (Zeiler and Wickstrom 2009) centered on how norms about sexed bodies were expressed, transformed, and questioned, and what such norms meant for subjectivity and agency.

Hermeneutical phenomenology analyses of lived experiences such as the above also contribute to bioethics. To engage critically with norms about bodies or understand what "do no harm" means in a specific case, bioethics has much to gain from an analysis of lived experiences of embodiment. To understand what it means to respect someone's autonomous choice as regards a certain medical treatment, it is likewise central to understand the conditions for such choice for those assumed to make it (cf. Svenaeus 2017; Zeiler 2018).

Dimension 2: Developing concepts

The second dimension of the approach we outline here contributes to and sharpens discussions about the conceptualization of significant phenomena, such as embodiment and illness, identified in the first dimension. This dimension involves the dialectical work of describing and deciphering concepts as they are used by the subjects and the researcher(s) in the empirical material, and conceptualizing phenomena informed by the analysis of lived experiences (Dimension 1). It involves coining new concepts or modifying old ones in order to shed light on phenomena that are central in the analyses above, but that remain underdeveloped in philosophical and/or bioethical research. Such a conceptual development can several philosophical frameworks. with However, phenomenology offers a rich framework for the analysis of topics relevant to bioethics, such as the role of embodiment and illness for subjectivity, perception, choice, and action.

To continue with the examples given above: we interpreted Kim's and Wesley's experiences of being sick with breast cancer on the basis of Nancy's (2000) concept of sharing (partage), in order to gain a better understanding of what the relationality of the couple entailed. Through this theoretically informed interpretation of Wesley and Kim's account of relationality, we returned to our theoretical framework, in order to assess how our interpretation shed a different light on Nancy's idea of sharing. Furthermore, the other above mentioned study of norms about sexed bodies exemplifies how this second dimension contributes with conceptual work - in this case on how culturally shared and corporeally enacted norms about sexed embodiment can form embodied agency. The neologism of "excorporation" (as an antonym of "incorporation") has been developed as a tool to help examine and conceptualize painful experiences of how one's lived body breaks in the encounter with others, in ways that engage with analyses of lived experiences (Malmqvist and Zeiler 2010; Zeiler and Guntram 2016).

Dimension 3: Assessing and contributing to socioethical processes

The third dimension of this approach starts from an acknowledgement of the significance of socioethical situatedness. The analyzed lived experiences (Dimension 1) and the conceptual work (Dimension 2) are in a basic sense informed by, and can inform, larger socioethical processes. This third dimension strives not only to identify phenomena that are taken-for-granted in the lived experiences of the kind described above, but also to pinpoint and question taken-for-granted questions or conceptualizations in bioethics as a situated practice. It asks how certain ethical questions and concepts come to be identified and constructed as important within specific social settings and bioethical debates. This implies a departure from classical phenomenology as it does not take subjective situated experiences as primary, but rather emphasizes the constitutive significance of the socioethical world. Paradoxically, however, this move away from phenomenology contributes to the exercise of hermeneutical phenomenology that considers what is taken-for-granted, and to the situatedness of subjects (including bioethicists), in order to explore situated meanings.

If we consider Wesley's and Kim's accounts again, we see how their experiences of relationality shape and are shaped by a socioethical reality. Wesley's perception and experience of what mothers and fathers can and cannot do may be understood in the light of culturally shared normative ideas about the distinct roles of the father and the mother. Such narrated experiences of normatively inscribed capability or incapability may, in turn, intensify and shape ethical questioning about the (distinct) roles of mother and father. Moreover, the questions and approaches we take up as researchers are also socioethically shaped and shaping. For example, our critical focus on relationality and intersubjectivity in the breast cancer study is in part shaped by something that we describe as a discrepancy between lived intersubjective illness experiences and a socioethical reality in which care is becoming increasingly individualized.

The work within this third dimension is similar to work that offers tools for analyses of how something comes to be identified, framed, and emphasized as an ethical problem or solution. Here, we explicitly invite a self-critical bioethical scrutiny, and ask how sociopolitical processes and presuppositions shape the ethical questions and concepts that are perceived as important in bioethics, whether and why these questions and concepts should or should not be seen as ethically important. We ask what the taken-for-granted questions, concepts, or dimensions of bioethical work are, and whether and how some of these need to be revised. This dimension turns a critical and constructive eye on bioethics itself. It examines the ethical implications of specific conceptualizations in bioethics, including the conceptual work in Dimension 2. In the breast cancer study, this examination could lead to a critical constructive stance of bioethical discussions of care, and a normative discussion of which conceptualizations and ethical issues should be deemed to be important, and why.

Conclusion

With this approach, we want to engage with empirical research philosophically, and with philosophical questions empirically. We seek to integrate the empirical and the philosophical in the bioethical, and to ensure that empirical bioethics engages with conceptual work. Bioethics has gained much from the empirical turn. It is equally crucial that bioethics spells out and deals with interrelated conceptual challenges in narrated lived

experiences, theoretical philosophical frameworks, and socioethical realities. It is time for a conceptual turn.

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References

de Boer, M., K. Zeiler, and J. Slatman. 2018. Sharing lives, sharing bodies: Partners negotiating breast cancer experiences. Medicine, Health Care and Philosophy 22 (2):253-65.

Malmqvist, E., and K. Zeiler. 2010. Cultural norms, the phenomenology of incorporation, and the experience of having a child born with ambiguous sex. Social Theory and Practice 36 (1):133-56.

Merleau-Ponty, M. 2006. Phenomenology of perception. London: Routledge.

Nancy, J.-L. 2000. Singular plural. Stanford, CA: Stanford University Press.

Ricoeur, P. 1991. From text to action: Essays in hermeneutics II. Trans. K. Blamey and J. B. Thomson. London: Athlone Press.

Svenaeus, F. 2017. Phenomenological bioethics. London: Routledge.

Zeiler, K. 2018. On the autós of autonomous decision making: Intercorporeality, temporality, and enacted normativities in transplantation medicine. In Existential medicine, ed. K. Aho, 81-100. London: Rowman and Littlefield Int.

Zeiler, K., and L. Guntram. 2016. Sexed embodiment in atypical pubertal development: Intersubjectivity, excorporation, and the importance of making space for difference. In Feminist phenomenology and medicine, eds K. Zeiler and L. F. Käll, 141-60. New York: SUNY Press.

Zeiler, K., and L. F. Käll (eds.). 2014. Feminist phenomenology and medicine. New York: SUNY Press.

Zeiler, K., and A. Wickstrom. 2009. Why do 'we' perform surgery on newborn intersexed children? The phenomenology of the parental experience of having a child with intersex anatomies. Feminist Theory 10 (3):359-77.