The ethics of bordering healthcare: A study on healthcare access of undocumented migrants in Brussels (Belgium)

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Background & objectives: This doctoral thesis set its scope as an exploration of the ethical issues that arise due to limitations in the access to healthcare for undocumented migrants. Many governments in countries with public healthcare services have adopted policies differentiating access according to migration status, restricting access to healthcare for undocumented migrants. Alongside the public healthcare services, a parallel network of humanitarian care-spaces has emerged. Humanitarian care practices and restricted public healthcare access of undocumented migrants have been the focus of study in a variety of academic disciplines. In this complex and heterogenous field of literature we identified three gaps, which this doctoral thesis wants to address: First, so far there is limited knowledge on the association between undocumented status and health outcomes. Secondly, the interactions between care practices in humanitarian and public institutions are poorly understood. Thirdly, only limited research has been performed on how health professionals and undocumented migrants in practice deal with dilemmas due to restrictions in access to healthcare services. This study aims to integrate empirical research findings with ethical analysis. It relies on the use of empirical data to inform a moral evaluation of the autonomous health decision making of undocumented migrants, and the ethical responsibility of individual healthcare workers, in a context of restricted healthcare access.

Methods: The empirical research was conducted in Belgium. Belgium has a federal legal framework covering who should account for the provision of medical services to undocumented migrants. The empirical research draws on both quantitative and qualitative data, with the focus on the latter. The qualitative leg of the study integrated multi-site, focused ethnographic observations and in-depth interviews. The relation between the qualitative empirical data and the normative/ethical theorizing is informed by Molewijk's *integrated empirical ethics (IEE)* - approach.

Findings: First, our quantitative study showed important differences in underlying causes of death and mean age at death, between male undocumented migrants and residents in Belgium. Secondly, our ethnographic data show that the provision of healthcare in the framework of the law Urgent Medical Aid in Belgium is characterized by increasing practices of rationing, resulting in contention. Humanitarian care practices and public provision of healthcare to undocumented migrants are deeply interrelated and intertwined. We describe two sub-state level, spatial configurations in Brussels where disputes about who will take responsibility for the healthcare of undocumented migrants lead to politicization and political activism. Thirdly, our data point to the importance of care relations and social networks of undocumented migrants when negotiating barriers in access to healthcare. They actively transform their own actions, feelings and behaviour in the relation with healthcare workers, based on perceptions of what healthcare workers expect and believe on crucial aspects of a care relationship. Their health trajectories depend on the possibility to establish a responsible care relationship, as well as the professional network of the healthcare worker. Fourthly, our findings show that health professional's practices to challenge restrictive government policies are limited and concealed, and are considered as an exceptional, charitable act, both in public and humanitarian settings. Instead, healthcare professionals develop techniques to monitor themselves. They develop

practices to control their own affective reactions. They transform their own clinical practice towards undocumented migrants and perform practical mental exercises to remind themselves of their role in the wider healthcare system.

Discussion & Conclusion: The state-imposed barriers to healthcare access, and the ways they are dealt with, put healthcare workers in a very ambiguous position. The institutional restrictions clearly undermine their professional autonomy. Simultaneously, the informal care practices that emerge in response to these restrictions, open up a space that is less susceptible to influence from external parties, thus increasing the power of the healthcare worker in the therapeutic relation. In this context, healthcare workers and undocumented migrants are forced in a permanent exercise to negotiate and reconsider their position. Many individual healthcare workers and undocumented migrants try to transform the way they act or react, in order to form themselves as ethical subjects in a therapeutic relationship, amidst a reality of multiple, competing accountabilities. These practices rely on an aesthetic understanding of ethical practice and an individualist model of personal responsibility. We argue that the importance that is attributed to personal responsibility risks to obscure how problems in healthcare access are related to structural health inequalities and unjust migrant health policies. Theoretically, this dissertation provides with the impetus to reconceptualize healthcare ethics as a practice of the self, an ethics that is somewhat independent of the traditional professional ethics. Furthermore, it points to the importance of a relational model of autonomy to understand medical decision-making of undocumented migrants.