

OPIOID-DEPENDENT MOTHERS IN MEDICAL DECISION MAKING ABOUT THEIR INFANTS' TREATMENT: WHO IS VULNERABLE AND WHY?

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Résumé de l'article

Les nourrissons nés de femmes dépendantes aux opioïdes sont généralement admis dans des unités de soins intensifs néonataux pour la prise en charge du syndrome d'abstinence néonatale (SAN), et leur traitement nécessite une prise de décision médicale. Ce n'est pas seulement la vulnérabilité des nourrissons, en termes d'incompétence et de dépendance médicale, qui est présente dans ces circonstances, mais aussi la vulnérabilité situationnelle des mères, qui découle de la possibilité de leur participation à la prise de décision médicale concernant leurs enfants. La vulnérabilité est un concept qui a souvent, sinon toujours été relié à des individus. Dans cet article, nous suggérons que, dans certains cas, les évaluations et les attributions de vulnérabilité aux individus ou aux populations ne permettent pas de saisir tous les aspects de la vulnérabilité. Nous demandons si cette évaluation individuelle est suffisante pour identifier toutes les vulnérabilités qui apparaissent dans la situation. De plus, nous suggérons que l'« unité » d'attribution de la vulnérabilité, généralement une personne qui est une cible probable de dommages ou de violations morales, ne devrait pas simplement être réduite à l'individu. Au contraire, l'unité devrait dans certains cas être considérée comme une entité de nature interpersonnelle. Le type de vulnérabilité réelle que nous identifions dans cet article est intrinsèquement intégré dans une relation dyadique, et les notions de vulnérabilité qui décomposent les relations sociales en individus risquent de manquer la vulnérabilité en question. Nous développons ce type de vulnérabilité en discutant du rôle des mères dépendantes aux opioïdes dans la prise de décision concernant le traitement de leurs enfants.



OPIOID-DEPENDENT MOTHERS IN MEDICAL DECISION MAKING ABOUT THEIR INFANTS' TREATMENT: WHO IS VULNERABLE AND WHY?

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ABSTRACT:

Infants born to opioid-dependent women are typically admitted to neonatal intensive-care units for management of neonatal abstinence syndrome (NAS), and their treatment requires medical decision making. It is not only the infants' vulnerability, in terms of their incompetence and medical condition, that is present in those circumstances, but also the mothers' situational vulnerability, which arises with the possibility of their engagement in medical decision making regarding their infants. Vulnerability is a concept that has often, if not always, been traced back to individuals. In this paper, we suggest that in some cases evaluations and attributions of vulnerability to either individuals or populations fall short of capturing all aspects of vulnerability. We ask whether this individual-based evaluation is sufficient for identifying all the vulnerabilities arising in the situation. Moreover, we suggest that the "unit" of vulnerability attribution, typically a person who is a likely target of harm and/or moral violations, should not simply be reduced to the individual. Rather, the unit should in some cases be seen as constituted by an entity that is interpersonal in nature. The kind of real vulnerability that we identify in this paper is inherently embedded in a dyadic relationship, and notions of vulnerability that decompose social relations into individuals run the risk of missing the vulnerability in question. We elaborate this kind of vulnerability by discussing the role of opioid-dependent mothers in decision making about their infants' treatment.

RÉSUMÉ :

Les nourrissons nés de femmes dépendantes aux opioïdes sont généralement admis dans des unités de soins intensifs néonataux pour la prise en charge du syndrome d'abstinence néonatale (SAN), et leur traitement nécessite une prise de décision médicale. Ce n'est pas seulement la vulnérabilité des nourrissons, en termes d'incompétence et de dépendance médicale, qui est présente dans ces circonstances, mais aussi la vulnérabilité situationnelle des mères, qui découle de la possibilité de leur participation à la prise de décision médicale concernant leurs enfants. La vulnérabilité est un concept qui a souvent, sinon toujours été relié à des individus. Dans cet article, nous suggérons que, dans certains cas, les évaluations et les attributions de vulnérabilité aux individus ou aux populations ne permettent pas de saisir tous les aspects de la vulnérabilité. Nous demandons si cette évaluation individuelle est suffisante pour identifier toutes les vulnérabilités qui apparaissent dans la situation. De plus, nous suggérons que l'« unité » d'attribution de la vulnérabilité, généralement une personne qui est une cible probable de dommages ou de violations morales, ne devrait pas simplement être réduite à l'individu. Au contraire, l'unité devrait dans certains cas être considérée comme une entité de nature interpersonnelle. Le type de vulnérabilité réelle que nous identifions dans cet article est intrinsèquement intégré dans une relation dyadique, et les notions de vulnérabilité qui décomposent les relations sociales en individus risquent de manquer la vulnérabilité en question. Nous développons ce type de vulnérabilité en discutant du rôle des mères dépendantes aux opioïdes dans la prise de décision concernant le traitement de leurs enfants.

INTRODUCTION

More and more infants are born to drug-dependent mothers in North America and Europe (Parolin & Simonelli, 2016, p. 1). Infants born to opioid-dependent mothers are typically admitted to neonatal intensive-care units for management of neonatal abstinence syndrome (NAS), which causes serious morbidity due to the history of the mothers' actions during pregnancy (McQueen & Murphy-Oikonen, 2016, p. 2470). The infants' treatment requires medical decision making. The infants are vulnerable in several respects. They lack competence and they suffer from a condition that requires medical attention. Their position exposes them to an increased risk of being subjected to harm and moral wrongs (see Hurst, 2008). However, these infants are not the only vulnerable party in the medical decision-making situation regarding their well-being and health.

Also, the mothers' layered vulnerability that arises with the possibility of them engaging in medical decision making regarding their infants is present in those circumstances. It has been reported that decision-making practices do not support mothers' participation (Axelin et al., 2018, p. 14). Medical decision making about infants can be very stressful for the parents: not only are they typically ill equipped to handle the terminology and less familiar with the medical facts than are the medical staff, but they also feel stressed due to their children's distress. Furthermore, mothers with a history of drug use seem to have yet another layer of vulnerability. Their drug use is a background condition in the situation and thus very likely to bring about further emotional distress in the medical decision-making process (undermining trust, raising issues of stigma, introducing the question blame for the children's condition, etc.).

However, in our paper we question whether this heavily individual-based way is sufficient for evaluating the situation in terms of vulnerability. Although these individual-based vulnerabilities are important, we suggest that they fall short of capturing an aspect of vulnerability that is in play in the situation. In particular, we argue that the special relationship of the mother and child calls for an additional approach. The approach we are suggesting acknowledges that this relation is essential to the immediate and future well-being of both mother and child, not only separately but together. We suggest that, at least in the case under study here, we need to consider the mother and the child as a dyad, an entity that cannot be reduced to either of them.

THE CONCEPT OF VULNERABILITY AND ITS CURRENT CHALLENGES

Vulnerability is a concept that has raised a lot of discussion in recent decades in the bioethical literature. It is often discussed in health-care ethics as a relational or intrinsic property of the patient or research subject (e.g., Ganguli-Mitra & Biller Adorno, 2011; Bracken-Roche et al., 2017). This kind of starting point may often be useful, but it does not seem to capture all the possible vulnerabilities in the context of health care. For instance, vulnerability that arises from

society's structures may be missed (see, e.g., Anderson, 2017, p. 49-55)—here, namely, the hierarchical health-care system. In turn, attempts to broaden the notion have their own problems. Indeed, there has been discussion about whether the concept of vulnerability is “too broad and poorly defined to be of any practical use” (Mackenzie et al., 2014, p. 6). As it has been acknowledged that all human beings are finite, defined by their limitations and consequently vulnerable, we face the problem of identifying the groups that require attention because they are vulnerable in a way that goes beyond the human condition of being vulnerable (e.g., Dodds, 2013, p. 182; ten Have, 2016).

On the other hand, some have voiced concern that identifying context-specific needs of groups or labelling them may result in discrimination and other undesirable outcomes, particularly for the members of those groups (Luna, 2009). For instance, labelling addicted individuals as vulnerable in research has most likely been done with good intentions—e.g., to protect the individuals from harm and moral wrongs.¹ Yet, when research on heroin-assisted treatment was setting off with its first studies, a bioethical concern was raised as to whether the users were competent enough to consent voluntarily to this kind of research (Charland, 2002) and, later, it was asked whether the psychological and social circumstances coerced the users into participating in the research (Henden, 2013). The label seemed to deem the addicted individuals less able to make decisions that touched upon their drug consumption. Their agency was considered to consist of their inability to control their drug consumption, even when their repeated failures on previous treatment regimes could also be read as the drug users' persistence in seeking help for their situation (see Uusitalo & Broers, 2015; 2016). Drug-use-related vulnerability highlighted the problems related to their agency and thus ran the risk of characterizing them merely as individuals driven and coerced by their drug use. Their motivation to get better was not acknowledged—at least not in the bioethical discussion. All in all, as vulnerability in health care and in society often implies something that calls for more attention and additionally may require special measures, it becomes important to identify different kinds and degrees of vulnerability that are in play in particular cases (see, e.g., Straehle, 2017).

The discussion on vulnerability in health care and in society in general has revolved around two aspects in particular. On the one hand, the vulnerability of the individuals who need care is discussed in terms of duties of care. This idea is based on the point that dependence is a form of vulnerability that requires action from a particular person—i.e., care (Dodds, 2013, p. 182-183). Children are dependent on their caregivers and thus the caregivers have a duty of care towards their dependents. Medical institutions, however, may carry the duty without having specific person-to-person dependence: patients who are dependent on hospital care do not impose the obligation on a specific member of the medical personnel—rather, the duty is grounded in the institution and, insofar as the medical staff belongs to the institution, the staff is obligated to provide care (see, e.g., Swanson, 1991). On the other hand, Robert Goodin (1986), for instance, has argued for a conception of vulnerability that is inherently social in

nature. For instance, the illiterate are not vulnerable by some inherent property, but, as the modern world requires at least a certain degree of literacy from agents, it makes the illiterate vulnerable. Goodin's point about the way vulnerability is typically constructed by the social reality is a valuable point in the sense that vulnerability as a position need not imply that the agent lacks individual physical or psychological abilities to function in the health-care system, or in the world in general. Rather, it may well be that the vulnerable are in a position in which they are likely to experience harms and moral wrongs because they have not had the chance to acquire the required competencies, such as literacy. Questions of justice are critical in protecting the vulnerable.

In this paper, we follow the kind of view on vulnerability that Samia Hurst (2008) has suggested and that others have developed (e.g., Martin et al., 2014)—namely, that “we should define vulnerability in research and healthcare as an identifiably increased likelihood of incurring additional or greater wrong” (Hurst 2008, p. 191). In light of this, we understand vulnerability to be something that places the vulnerable entity in circumstances in which the likelihood of moral wrongs rises and the wrongs are targeted at the entity in question. It should be noted that, when we discuss vulnerability in terms of moral wrongs and harm, we imply that the object of those moral wrongs and harms is something that can actually be can be harmed and wronged.

We think the view that vulnerability has layers is compatible with what Luna suggests (Luna 2009). Luna illustrates her view by discussing how being a woman can be considered as a vulnerability in some cases and not in others. Being an addicted individual may indeed be the same kind of issue. Luna, as well as Hurst and her colleagues, is interested in the cases in which there is already a motivation to take action due to identified vulnerability. Thus, the function of the concept is to pick out the cases in which more attention, if not action, is required.

Nevertheless, vulnerability has often, if not always, traced back to individuals or populations that are constituted out of individuals, like children. We question this individualistic approach when it becomes the only way of analyzing and evaluating vulnerability. In this paper, we argue that, in some cases, evaluations of vulnerability and attributions of it to either individuals or populations simply fall short of capturing the potential harms imposed on the stakeholders.

Instead, in this paper, we suggest that the “unit” of vulnerability, the likely target of harm and/or moral violations, should not be reduced to individuals exclusively.² The vulnerable need not be an individual—rather, it can be a dyad (or something else). It should be seen as a unit that is somehow inherently interpersonal. The vulnerability we discuss concerns the well-being related to important relationships, and breaking down social groups into individuals does not do justice to real-life situations, such as the case under study. In what follows, we elaborate this view by discussing of the role of opioid-dependent mothers in the decision-making process about their infants' treatment. We start by pointing out

that parents should be engaged in medical decision making that concerns their infants' treatment. Second, we argue that, instead of only weighing the pros and cons of the situation for the infant, for the mother (and for the nurses, for the paediatrician, and so on), we also need to be able to look beyond the individual and professional interests and recognize that the issue involves other units that should be taken into consideration. What is noteworthy is that the vulnerability of these units cannot merely be traced to individuals. Without recognizing that the mother and the child are a unit, a dyad, we may, in our evaluation, end up bringing about further harm and inflicting moral wrongs on them as a dyad.

It is typically agreed that vulnerability is a relational concept. The source of vulnerability may differ and consequently also the nature of potential harm. In what follows, we consider whether the source of vulnerability in the case of opioid-dependent mothers' medical decision making about their infants' treatment derives from imperceptibility of the unit that requires special attention. As vulnerability should always be evaluated and analyzed in a context, we begin by paying a closer look at the setting of our case.

MOTHER-STAFF MEDICAL DECISION MAKING IN A CLINICAL SETTING

Infants born to opioid-dependent women are typically admitted to neonatal intensive-care units (NICU) for management of neonatal abstinence syndrome (NAS), which can cause serious morbidity, and even mortality (McQueen & Murphy-Oikonen, 2013, p. 2470). If infants' withdrawal symptoms are not treated, these cause dehydration and convulsions, which in turn have a negative effect on infants' growth and can result in brain damage and even in death. Infants are also under severe stress due to irritability, sleep disturbance, and excessive crying (Kocherlakota, 2014, p. e550).

In medical decision making about infants' treatment, it is obvious that the patients themselves are not capable of making decisions about the medical treatment. Furthermore, in these kinds of circumstances, the surrogate decision maker cannot employ strategies such as advanced will, or otherwise infer the counterfactual interests of the patient, as the patient has not (yet) been in a state in which it could have been able to inform the surrogate of its interests.³ It is then quite common to consider the decisions in a way that would benefit the patient the most. The best-interests standard in bioethics states that the surrogate decision maker should "determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks and costs" (Beauchamp & Childress, 2001, p. 102).⁴ The medical professionals arguably have superior knowledge of medicine in this kind of decision making. However, we maintain that the decisions cannot be made solely by the health-care personnel, as medical care should be adapted to aspects other than mere medical issues of the infant's current condition. Thus, the decision making should also involve the parents.⁵

In fact, there are many reasons why parents do seem to be suited for this kind of decision making.⁶ First, it has been argued that the parents care deeply about the welfare of their child, because their concerns are seen to be motivated by the best interests of the children, and the parents also know the child's needs better than anyone else. It has even been argued that parents have a unique understanding about their infant's needs. Second, they are also the ones who endure the consequences of the treatment, for better or for worse (Focquaert, 2013, p. 449). Furthermore, it has been shown that when the medical staff and the mother try to collaboratively make the treatment decisions, it also increases the adherence to care (Entwistle & Watt, 2006, p. 273). Third, it is the parents' right to raise their children according to their own values and standards, as each family's life is based on their preferences, and, fourth, parents as surrogate decision makers are seen to promote family intimacy (Focquaert, 2013, p. 449).

The American Academy of Pediatrics (AAP), for instance, advises paediatricians to respect parents' first-hand understanding of the behaviour and needs of their child. In fact, not only should the paediatricians respect the parents' understanding, but they should also actively ask about parents' observations and integrate the parents' preferences into the care plan (AAP, 2003, p. 693). They should involve parents to the decision-making process by utilizing patient-centred communication skills, as shared decision making is regarded as a prerequisite for evidence-based medicine. This means that, in order to optimize care, both the doctor's medical information and the preferences of the infant and of its family as expressed by the parents are required (Entwistle & Watt, 2006, p. 269; Hoffmann et al., 2014, p. 1296).

The most common challenge in shared decision making in this context is that doctors fail to fully appreciate the value of parents' contribution in medical decision making about the infant's treatment in a clinical setting (Greisen et al., 2009, p. 1748). Furthermore, health-care professionals also worry that parental presence may somehow curtail their own clinical discussion, pose limits to resident teaching, unnecessarily lengthen medical rounds, and compromise patient confidentiality (Cameron et al., 2009, p. 525; Abdel-Latif et al., 2015, p. F206). In the case under study, the express distrust of the parents that health-care professionals may have is comprehensible in light of the professionals' distress in and frustration at not being able to comfort or console the infants through the withdrawal process, which would not exist were it not the case that the mother had consumed opiates during pregnancy. In these circumstances, the professionals may also experience abusive, aggressive behaviour from parents if the parents feel that they are being blamed, for instance (Maquire et al., 2012, p. 283). It is also recognized that doctors' negative presumptions about parents may result in them excluding the parents from medical decision making (Axelin et al., 2018, p. 15).

The parents, in turn, may experience different kinds of challenges in the shared decision making: participating in the decision making may further increase their anxiety and confuse them (Cameron et al., 2009, p. 524). In fact, some parents state their preference to withdraw from medical decision making, as they feel

they lack the required competence (Sawyer et al., 2015, p. 5). Not being fully familiar with the terminology and the processes can, furthermore, be difficult for parents: they may have trouble following the medical decision making or participating in discussions in a reciprocal manner, even when they are invited to take part. Therefore, the health-care professionals should recognize and take into account the situational vulnerability of the parents and provide them with emotional support and accessible information (Subramony et al., 2014, p. 202).

In light of this discussion, it seems clear that not only are the infants vulnerable, but in this kind of decision making, the parents can also be vulnerable.⁷ The vulnerabilities of these two positions, however, depend on different factors: The infant is incompetent to the fullest degree in almost all the relevant aspects regarding decision making, not being able to consent itself (as well as struggling with health). The parents have to make decisions in a context in which they not only may feel they have an insufficient amount of knowledge and understanding of the medical information (and in which, due to this expressed or perceived ignorance, they are susceptible to discrimination and prejudice by the medical staff), but also may endure strong emotional pressure. However, we suggest that there is a yet another layer of vulnerability that does not fall on either of these positions or individuals in those positions alone. We argue that it is not enough to consider the possible harms and benefits merely in terms of the individual stakeholders. What we suggest is that the analysis of vulnerability should also take into account the unit of the mother and child. We argue that it adds an important dimension to the discussion of vulnerability. Let us return to the case to illustrate this.

MEDICAL DECISION MAKING AND SHORTCOMINGS IN THE INDIVIDUALISTIC APPROACH

Consider again the infants born to opioid-dependent women. Like other parents, these mothers should be included in medical decision making.⁸ For clarity's sake, it should be noted that these women may or may not be addicted.⁹ First, like other mothers, their decision making in this context is most likely motivated by the best interests of the child. It is true that continuous opioid use may well numb the user's affections and consequently affect the motivation to care for the infant and its best interests (Parolin & Simonelli 2016, p. 2). In addiction literature, it is often claimed that the drug user's brain has been "hijacked" by the drug (e.g., Hyman, 2007).¹⁰ A telling quote from a recovering heroin-addicted individual exemplifies the common view of addicted individuals on this matter: "I didn't give a fuck about anyone or anything apart from just getting my next fix" (Neale et al., 2012, p. 86). This could be seen to undermine the claim that parents "care deeply about the welfare of their children"—at least in relation to these mothers (Focquaert, 2013, p. 449). However, we suggest that this is a hasty conclusion. Drug use may dictate addicted individuals' lives, but it is not an all-or-nothing issue. Even if drug use may motivate the majority of the mothers' actions, it does not necessarily rule out that they have other motivations, too.¹¹ The medical decision making takes place in the hospital, and by taking the time

and showing up, the mothers already give indication of a motivation other than drug use. In fact, having a child may well be a very strong motive to become abstinent and remain abstinent from drug use (Ashley et al. 2003, p. 37).

Moreover, it was suggested that the parents typically know the child's needs better than anyone else. Maybe a little counterintuitively, this is probably even more the case when it comes to infants suffering from withdrawal. In medical care, NAS scoring is used to attend to this challenge for the infants. It is a decision-making tool for setting the pace of weaning the baby from opioids. The scoring measures the signs and symptoms indicating central nervous system hyperirritability (e.g., high-pitch cry, fragmented sleep) and dysfunction of the autonomic nervous system (e.g., sweating) and gastrointestinal tract (e.g., loose stools) resulting from prenatal exposure to opioids. Infants are assessed in four-hour intervals between feedings, but in two-hour intervals if the scores are above eight¹² (Finnegan et al., 1975; Kocherlakota, 2014, p. e556). The mothers are likely to hold a different kind of expertise of the drug and of its withdrawal symptoms that could be utilized in the care.¹³ Their unique understanding is partly derived from an origin held in disrepute—the mothers' history of drug use—but at the same time it should be regarded as an asset for providing information for the optimal care of infants affected by neonatal abstinence syndrome.

Furthermore, we maintain that in order to reach effective treatment outcomes, the mothers should be not only informants but also active participants in the decision-making process, as long as they are competent to do so. This latter point is not self-evident, however. As mentioned, addicted individuals' competence to make decisions has been questioned in different settings, and there have been ongoing debates about their ability to consent to different kinds of research and treatment voluntarily (see Charland, 2002; Foddy & Savulescu, 2006; Levy, 2006; Walker, 2008; Henden, 2013; 2016; Uusitalo & Broers, 2015; 2016). Firstly, if the mothers have mental-health issues and trauma in their background, their competence to handle stressful situations and make decisions in them may consequently be compromised. Many opioid-dependent individuals do seem to have comorbidities (e.g., Green et al., 2009; Heffner et al., 2011) and this should naturally be taken into account. However, it is safe to conclude, other things being equal, that (previous or current) opioid use per se does not impair their rational abilities to understand the relevant information needed for making a decision (e.g., Morán-Sánchez et al., 2016; WHO, 2010) or for actually consenting to research or treatment. If they are competent in this sense at making informed decisions regarding their own involvement in treatment and research, why would they fall short in making similar kinds of decisions for their infants?

Second, for the infant's treatment and care, the parents are seen to be able to provide valuable information not only by providing observations, but also by informing the medical staff of their circumstances at home (AAP, 2003, p. 693). The mother with a history of drug use is probably the best person to provide information about her resources in the hospital as well as at home. Nevertheless, whether mothers with a history of drug use actually provide the informa-

tion is another thing: it has been reported that health-care professionals have negative attitude towards mothers who have a history of drug use (Cleveland & Bonugli, 2014, p. 324). The negative attitude may well hinder the mothers' willingness to provide information about circumstances that may be suboptimal for the infant's well-being and they may distrust the processes because of the negativity. The mothers' motivation may further be hindered by their own fears of reporting any kind of disordered circumstances that might undermine their right to raise their child.¹⁴ Furthermore, the mother's motivation to commit to the care plan may also be affected by the way in which she has been taken into (or left out of) the planning and by the manner in which she has been treated by the health-care professionals (Cleveland & Gill, 2013, p. 203). This is an important point and supports our suggestion that the mother and the infant should be considered as a dyad.

The third reason for involving the parents in decision making is their right to raise their children as they choose (Focquaert, 2013, p. 449).¹⁵ It could be argued that mothers with a history of drug use may have lost that right: they have already inflicted harm on their infants during pregnancy by continuing their drug use. This kind of evident cause-effect relation seems quite rare in health care: typically there are risk factors, probabilities, and correlations, but in the case of NAS the infant would not be suffering from opioid withdrawal upon birth had the mother not used opioids during pregnancy.¹⁶ So it is true that neonatal abstinence syndrome is undoubtedly due to the mother's substance use during pregnancy.¹⁷ With this kind of background, it is not a surprise that nurses have expressed strong affection for the infants (Maguire et al., 2012, p. 283). This may stem from worries about the children's long-term mental and physical issues, as well as about the types of environments into which they would be discharged (Maguire et al., 2012, p. 284).¹⁸ Women who use illicit substances are often viewed more harshly by society than men who do are, since women are the bearers and caregivers of young children (Wiechelt, 2008).¹⁹ When this is put in the context of infants requiring medical help due to the mothers' previous drug use, it is easy to understand that prejudice and blame may occur—even when this may hinder and obscure the ultimate goal of reaching the best solution for the infant. In the extreme, these kinds of negative attitudes toward the mothers may result in the undesired consequence of the mothers isolating themselves from their offspring because they feel unwelcome. This, of course, not only further complicates the kind of reciprocal communication required in shared decision making (Cleveland & Gill, 2013, p. 203; Kelly et al., 2013, p. 1-3), but also is likely to have suboptimal consequences for the infant.²⁰ For instance, the disadvantage of the decision to admit infants born to opioid-dependent women to intensive-care units for management of NAS and prevention of mortality is that the symptoms of NAS may be experienced more severely. The infants may exhibit a greater need for pharmacotherapy because of the interference in mother-infant relationship. For these reasons, research on rooming-in supports the close uninterrupted contact between opioid-dependent women and their infants in order to decrease the severity of NAS scores, lessen the need for pharmacotherapy, and shorten hospital stays (Wachman et al. 2018, p. 1368).²¹

In Cleveland and her colleagues' studies (2013; 2014), all mothers described feeling judged by the NICU staff because of their history of drug use. They felt that the staff was unable to move beyond their drug use to recognize some of their positive qualities.²² If the mother is perceived as a one-dimensional drug user, not only does she undergo unnecessary mistreatment as a parent, but this simplification also leaves out important aspects of the mother-child relationship and thus has implications for the infant's well-being as well. If, however, the mother and the child are considered as a dyad, these kinds of threats are pre-empted (Parolin & Simonelli, 2016).

In fact, what we want to question is whether it is sufficient to observe the issue merely from the child's and the mother's perspectives individually. Does this miss something elementary? And also, does it reinforce some vulnerabilities in both by treating their unique relationship as a source of either benefit or harm to each individual? We think it does both and, consequently, suggest that we should also focus on the special relationship that the mother and child have. The relationship is valuable as such and does not reduce to either the individuals' benefits (or harms). On the contrary, the relationship that indeed is in danger of being violated in this context makes the mother and the child vulnerable in a way that cannot be described in individualistic terms. If the dyad is subjected to harm and moral wrongs, it is not only that the mother and the child will suffer, but also that their relationship suffers, and their relation cannot be understood simply by discussing the individuals' losses.

WHAT IS THE DYAD MADE OF?

In order to appreciate our suggestion, a better understanding of the dyad is called for. We argue that the special relationship between the mother and the child adds another layer of vulnerability (that is not a mere aggregate of other layers of the individuals' vulnerabilities). However, as the relationship is a profound feature of both the individuals in that it is not reducible to its effects on the individuals, we suggest another way of seeing the subject of vulnerability here. This idea resonates with the notions of relational autonomy developed by feminist philosophers (see Mackenzie & Stoljar 2000).²³ Our idea, however, differs a little as we see the unique relationship constituting something inherently reciprocal and emergent, thus not entirely reducible to the individuals. This may, however, be only a matter of focus rather than a view radically distinct from the notions of relational autonomy (cf. Mackenzie & Stoljar 2000, p. 22). So how to understand this dyad we are discussing?

One way of characterizing the interpersonal relationship between mother and infant is by utilizing Bowlby's theory of attachment (Bowlby, 1982). We draw on the idea of attachment in our discussion of the case. Attachment is a biological and behavioural-based system aiming to secure contact within the mother-infant dyad which in its turn establishes the infant's cognitive and emotional development through maternal care. The attachment process already starts during pregnancy when the foetus learns the mother's voice and odour and the mother

starts to recognize the foetus's behaviour. After birth, touch plays a crucial role in the further development of the attachment relationship. Communication through physical closeness helps the infant to adapt to extra-uterine life and enables continuous learning between the mother and the infant. This reciprocal process, we argue, can be seen as an emergent aspect of the individuals' unique relationship. The infant's attachment behaviour such as crying signals the need for increased proximity to the mother during distress. The attachment relationship serves as a buffer against distress such as withdrawal symptoms. The establishment of a secure attachment relationship requires regular, sensitive, reciprocal, and consistent interaction between the mother and the infant to guide optimal maternal caregiving (Sullivan et al., 2011, p. 643-647; Parolin & Simonelli, 2016, p. 1-2).

Treating the mother and the child as separate individuals increases the risks of violating the important relationship between them. The splitting of the mother-infant dyad has deleterious effects on the infant's emotional and cognitive development and maternal mental health (Flacking et al., 2012, p. 1033). By increasing maternal stress, separation or the fear of separation also increases the vulnerability to drug use. The childhood attachment relationship forms a prototype for later close relationships (Parolin & Simonelli, 2016, p. 152), highlighting the long-term consequences of ignoring the formation of a secure mother-infant dyadic relationship. Pregnancy and the idea of parenthood may provide a strong motivation for the drug-dependent woman to become abstinent. However, the disruption of the dyadic relationship also lowers the mother's motivation to become and remain abstinent (Ashley et al., 2003, p. 37).

Currently, there is a shift from an individual-based care approach to a dyad-based care approach toward NAS, since the care targeted at mother-infant dyads has been found to improve maternal self-esteem, mental health, abstinence, and mother-infant interaction, which all have led to improved child behavioural and emotional development (Parolin & Simonelli, 2016, p. 5). Based on this evidence, it is justified to consider the needs of both in equal measure during care. The infant has a role in facilitating the mother's care, not only indirectly benefiting from the mother's treatment. It could be argued that parenting itself is a treatment for the mother (Parolin & Simonelli, 2016, p. 5).

Furthermore, opioid-dependent mothers often have insecure attachment relationships in their own past. Without additional support, this pattern is easily passed on to the next generations. Dyad-based care provides a secure opportunity for the mother to explore traumatic past experiences and recover from those. This is important in that it can be a means to becoming more virtuous and thus contributing to well-being not only on the individual level but also on the level of the population. Without a chance to intervene in the passing on of the insecure attachment style and in light of the increasing number of NAS infants being born in North America and Europe, the sheer number of the stakeholders facing these challenges is bound to increase.

While attachment theory discusses the mother and the child individually in some sense, we advance that, due to the inherently reciprocal and emergent nature of the relationship, agency builds upon attachment and is thus something more than a mere aggregate of the individual agencies combined.

WHAT DOES VULNERABILITY AMOUNT TO WITH REGARD TO DYADS IN THE CASE OF MEDICAL DECISION MAKING?

Vulnerability in health-care ethics should be a concept that picks out the subjects and situations requiring further attention and possibly further action in terms of prevention and protection. Problems arise because, among other things, the circumstances in health care can be complex and intertwined. As discussed above, medical decision making typically involves certain kinds of vulnerability: the patient is dependent on others due to that person's condition and medical care ultimately consists in the involvement of health-care professionals with respect to the patient's interests and health. Most of the time, though, it does not mean that the patient or the patient's advocate has no say about the treatment. We have already brought up factors in the previous chapters that speak in favour of having the parent involved in medical decision making concerning an infant's treatment. In addition to being reasons for including the parent in decision making, these factors can also make the parents vulnerable under the circumstances.

Traditionally, parents have been allowed to participate in the health care of their offspring by providing "natural functions" such as caregiving and feeding. Medical decision making is the most challenging role in health care and it has been seen as a hierarchical and medical-staff-based process. The practice of shared decision making in medicine has been introduced, even though the parents who actually succeed in participating are typically academics who have adopted medical terms and explain their views by making reference to cause and effect (Axelin et al., 2018). This kind of medical decision making is characterized by "the best interests of the child" and, even if the parent is participating in the decision making, his or her well-being is left aside. By treating the mother and the child as a dyad, we shift the focus from the child to the well-being of the unit—in some sense, this a relational well-being that realizes itself in both stakeholders.

Often, being designated as vulnerable in health care raises the requirements not to inflict harm on the vulnerable and also protect the vulnerable from harm, but the picture makes the shared decision making a little challenging, as the parties exhibit different degrees and kinds of vulnerability. What makes issues even more complex is that there may well be conflicts of interest among the health-care professionals, the mothers, and the infants. Even when the parties seemingly share a common goal—i.e., the optimal care for the child—there may be disagreement on what the optimal treatment is. It may be worthwhile to scrutinize the premises of the goal of the baby's optimal health. For instance, the view that intensive care is the best kind of treatment for the infant suffering from NAS

may turn out to be something less than optimal, depending on the measured standards. Instead of polarizing the mothers and their infants over their interests, these interests could be seen as relational to the point that we could view mother and infant as a dyad. The mother and the child are a unit of agency. Their relation shapes their agency in this context.

We assume that the challenges the dyad encounters are somewhat similar to those of parents, as the mother is still confronting the medical staff and the challenges that come out of the context. Yet there is a difference, and we claim that it may well be to the benefit for both individuals in the dyad to be participants in medical decision-making in this way, as the child is ensured “a more able agency” when the mother is invested in the decision making on a new level. Also, the dyad enables the mother to participate in decision making on better justified grounds, as she is part of the target of intervention. By treating the mother and the child as a dyad in the decision making would probably decrease the layers of individual vulnerabilities, as depolarization of the mother and child is likely to reduce individual stress deriving from the threat of disruption in the attachment relationship.

POSSIBLE OBJECTIONS

There are some obvious objections to our suggestion. The most evident objection, in our eyes, is to point out that there are cases in which the mother is not concerned about the infant’s well-being and continues harming and wronging the child. There is a wealth of research supporting this kind of view (Parolin & Simonelli, 2016, p. 2). Our intention is not to claim that the evidence does not hold. We are not defending mothers who intentionally harm and wrong their offspring. What we are questioning is the assumption that the mother is not concerned about the well-being of her infant just because she did not abstain from using the substance during pregnancy. Using psychoactive substances during pregnancy simply does not suffice as evidence for intentional harm or even liable neglect.

There may be other explanations for drug use during pregnancy. Active use of opioids may for some reason or another affect women’s regular monthly cycles and thus it may well be that the woman is simply unaware of her pregnancy until the very last months (Neale et al., 2012, p. 113). It is also plausible that the opioid-dependent women do not know the negative consequences of their opioid use for their foetuses and infants. Furthermore, it should be noted that mother-infant separation is the cause of some of the negative aspects of the infant’s condition and, yet further, that even drug addiction does not always compromise parenting (Parolin & Simonelli, 2016, p. 3). There is evidence that the effects of caregiving skills outweigh the effects of intrauterine exposure to drugs (Parolin & Simonelli, 2016, p. 4). Another viable explanation is that the reasons for opioid use are beyond the woman’s control and that there is no feasible option other than continuing to use opioids, even if the woman knows that this is most likely to have harmful consequences for her offspring.

A follow-up objection would be to argue that it is better for the child to be placed in an environment with stable care and to point to the facts that opioid-dependent women are likely to have depression and to be in economically and socially disadvantaged, as well as being dependent on opioids (Powis et al., 2000; Pajulo et al., 2001, p. 147-148). This may well be so, but it does not automatically mean that the mother is less motivated and able to provide care for the infant. As we have argued above, it may well be that the dyadic relationship may well be a safeguard against the external challenges in the suboptimal environment. Treating the mother and the infant as a dyad is likely to reduce the mother's stress and fear of being separated from her infant, thus leaving her with more resources to tackle other challenges— whether they are drug related, such as issues around stigma, or have to do with something else, such as lack of education. Also, acknowledging the dyad's vulnerability in this context calls for measures in the health-care and social services that are targeted toward enabling the dyad's well-being.

Thirdly, our view can also be challenged with the argument that we have naturalized the mother-infant dyad to such an extent that it becomes an exemplar of essentialism. Here we bite the bullet in the sense that, in this case, attachment also relies on biological factors. However, our view is far from essentialist. In cases where the mother and child are not biologically related, the rules of attachment apply. Consider the case of adoptive mothers. They have a strong motivation to be caring toward the children, similar to that of biological mothers, and have described strong ownership of the babies. They have reported feelings of joy and happiness of having a child (Koepke et al., 1991). As the adoptive mother lacks the shared experience of pregnancy and birth with the infant, it is essential for mother-infant attachment that the mother and the child have the possibility for physical closeness and get to know each other as soon as possible (Smit et al., 2000). Even in the case in which the treatment decision is not optimal for attachment, it could be argued that once it is made in collaboration with the mother and the medical professionals, it increases the mother's commitment and trust in the care plan and in this way also benefits the infant. This suggests that becoming a dyad does not require a biological history of pregnancy together.

This list of objections is not meant to be exhaustive, but rather illustrates how our view can be defended against some typical arguments that are presented in the discussions of drug-using mothers and their children.

CONCLUDING REMARKS

In some sense, the point is simple—the mother and the child are a unit, a dyad, in this context. However, this point is important. The way in which we discuss issues shapes the way in which we address them. This kind of “looping effect” motivates our discussion (see Hacking, 2012).

Vulnerability should be considered in context according to its kind and degree: there are different layers of vulnerability, the most general of which all

humankind shares. We hope to have shown that the use of the concept of vulnerability should not be limited to individuals and their interests. Rather, in some cases vulnerability lies inherently in the relation of individuals and cannot be reduced to those individuals without losing some of the value of the unit—here, the mother-child dyad. With the acknowledgement of this ethical content in the case of medical decision making regarding the infants of opioid-dependent women, the stakeholders' well-being is likely to improve, as it is understood in a more thorough way.

In fact, it should be noted that the vulnerability of opioid-dependent mothers in medical decision making for the optimal care for the infants is an issue that seems to be present, but which has not been addressed properly in health care (cf. Benoit et al., 2015). In general, the complete separation and polarization of the interests of the mother and the infant may be counterproductive in the decisions that have long-term implications for the well-being of both parties and of their relationship.

Moreover, this kind of idea of vulnerability does not have to be limited to mother-child dyads, but it is easy to see that couples who have literally spent their whole lives together cannot be evaluated and treated merely as individuals when, for instance, decisions are made for their care. The Western health-care system is dominantly individualistic in the sense that individuals are treated as separate entities. Couples may be separated due to the structure of geriatric care. It is not only health care that is structured in this way; there have been reports from homeless drug users that they would rather sleep outside than go into shelters, as they want to be with their partners. These kinds of cases suggest that we need to reconsider the ways in which we structure the society in order to allow room for dyads and other entities to flourish as well.

NOTES

- ¹ Of course there is always a danger that labelling groups as vulnerable ill serves for the group, as it may hinder and even prevent research, thus making treatment of the vulnerable less evidence based (see, for instance, Ross et al., 2004; Farsides, 2017).
- ² It is challenging to find the correct terms to suggest this, as it seems that we can talk only about individuals or groups of individuals, without seeing that they can be constitutive of something that is not simply reducible to the individual. We are suggesting that the entity constituted by the individuals has some emergent property that prevents the analysis from breaking the entity down to the individual level.
- ³ Of course it should be noted that the infant is able to communicate to a certain extent: it can and should be observed whether the infant shows signs of stress or comfort, and these observations should be included in decision making. Nevertheless, the infant is not in a position to express which option it considers the best of the available ones, for instance.
- ⁴ We will discuss the challenges that this kind of view generates more in what follows.
- ⁵ By “parents” we refer to the primary caregiver(s) of the infant (who are typically also the guardians).
- ⁶ There are actually ongoing attempts to improve the current policies on involving parents in the decision making about their offspring’s treatment (see, for instance, O’Brian, 2013; Axelin et al., 2014).
- ⁷ And, of course, members of the staff may also be vulnerable in certain respects, depending on the case.
- ⁸ This is assuming that they are competent decision makers—i.e., they are adults and do not suffer from impairments in their cognitive abilities that would prevent or hinder understanding and the carrying out of the decision making. This point will be discussed in more detail in what follows.
- ⁹ By “addiction,” we mean problems in controlling use. Mere use or dependence is not sufficient for addiction. Furthermore, opioid dependence may be maintained by different kinds of treatment programmes or prescriptions for other purposes. It does not automatically mean problems in control. In what follows, we will occasionally discuss addicted mothers, specifically, as they serve as a kind of extreme example of severe opioid dependence and it could be argued that, once it is established that the addicted mothers qualify for making the decisions, the other opioid-dependent mothers should qualify too, other things being equal.
- ¹⁰ Severe heroin users have been suspected to have defective value system and problems in motivation due to heroin use (e.g., Charland, 2002).
- ¹¹ See, for instance, a survey on the variety of motivations that heroin users have for participating in research on HIV (Fry & Dwyer, 2001).
- ¹² There is a score range of 0–46: A score of eight or lower allows for appropriate drug weaning and eventually a discharge. A score higher than eight requires medication for the treatment of withdrawal symptoms. The scoring is typically conducted solely by the health-care professional and the mother is left out of this aspect of treatment (Finnegan et al., 1975). In fact, the mothers expressed resentment and frustration when the nurses seemed to take over the infants’ care or correct the manner in which the mothers were providing care for their infants (Cleveland & Gill, 2012, p. 203). It could be argued that this practice of scoring leaves out the possibility of utilizing valuable practical knowledge of the withdrawal symptoms. The mother is probably more aware of the subtleties of withdrawal—at least from the phenomenal point of view—although she may lack the scientific knowledge. The disadvantages of this approach include infants experiencing more severe NAS and exhibiting a greater need for pharmacotherapy owing to the interference with mother-infant bonding (Finnegan et al., 1975).
- ¹³ In some sense this is analogous to utilizing the knowledge of heroin-addicted individuals in heroin-assisted treatment: in the beginning of the treatment programmes, the health care professionals determined the dose of heroin required to keep the withdrawal at bay for each individual in the treatment programme, as it was feared that the heroin-addicted individuals

would exploit the system and use more heroin than needed even if they had expressed motivation to enter the programme in order to recover. This led to an unnecessary period of adjusting (typically, first increasing) the dose in the treatment before finding the optimal dose and balancing the symptoms (Perneger et al., 2000).

- ¹⁴ These negative attitudes may arise simply from ignorance. Marcellus et al. (2015, p. 340) reported that the nurses lacked necessary education about substance addiction and that this affected their ability to provide care for the mothers and their infants. This, however, is a problem that has been reported even among the health-care professionals who work with problematic substance users (Pennonen & Koski-Jännes, 2010).
- ¹⁵ This claim does not suppose that parents can ultimately do as they wish, but it is acknowledged that there are provisions that may concern, for instance, the child's right not to be harmed.
- ¹⁶ Compare this to a case of smoking and lung cancer: although it is scientifically established that there is a connection between smoking and lung cancer, there are still several other aspects that can affect each case.
- ¹⁷ However, the fact that the mother has used opioids during pregnancy does not tell anything about whether or not she should be blamed or held accountable for the drug use. In other words, it does not tell us about the circumstances—e.g., the reasons for use—of the mother during the time of pregnancy.
- ¹⁸ In fact, the mothers expressed resentment and frustration when the nurses seemed to take over the infants' care—for instance, the NAS scoring is typically conducted solely by the health-care professional and the mother is left out of this aspect of treatment. The nurses also seemed to correct the manner in which the mothers were providing care for the infant (Marcellus et al., 2015).
- ¹⁹ Of course, not all opioid-dependent women have or are using illicit drugs.
- ²⁰ In general, it seems that scientific evidence is low in the WHO recommendations for the treatment of NAS (WHO, 2014). This kind of lack of information also seems to generate vulnerability as such.
- ²¹ Opioid-dependent pregnant women were assessed antenatally by a multidisciplinary team and provided with education and support. Psychosocial issues were addressed in collaboration with a community programme developed to support addicted mothers. The mother-infant dyad was admitted postpartum to a private room and attended by nurses trained in Finnegan scoring. Infants remained with their mothers unless persistently elevated scores made transfer to neonatal intensive-care units necessary for initiation of pharmacotherapy. With the rooming-in programme, the proportion of infants requiring pharmacotherapy decreased from 83.3 percent to 14.3 percent ($P < .001$) and the average length of stay decreased from twenty-five days to eight days ($P < .001$). The rooming-in experience was rated favourably by participating mothers (Newman et al., 2015).
- ²² The mothers in Marcellus et al. (2015) also reported self-blame. Because of their drug use, several mothers stated that they expected to be judged and felt they deserved it (Marcellus et al., 2015). It is not a surprise, then, that, for instance, in the study by Cleveland & Bonugli (2014), the mothers reported feeling guilt, shame, and helplessness.
- ²³ Feminist philosophers have criticized standard views on autonomy due to the unrealistic idea that autonomy is atomistic independence from others. This highly individualistic view seems implausible when we look at individuals in the context of their lives. Individuals are embedded in the society, and their agency is relational in the sense that it enables the individuals with all kinds of possibilities (Mackenzie & Stoljar, 2000, p. 21-26).

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