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‘Doctor Knows Best’: Reconsidering Paternalism in the NICU

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Abstract : Paternalism, in its traditional form, seems largely incompatible with Western medicine. In contrast, Family-Centred Care, a partial response to historically authoritative paternalism, carries its own challenges, particularly when operationalized as family-directed care. Specifically, in neonatology, decision-making is left entirely to Substitute Decision Makers (most commonly parents). Most models of shared decision-making employ both the parents’ and medical team’s perspectives but do not recognize the inherent asymmetry of information and experience – asking parents to act like physicians to evaluate technical data and encourage physicians to refrain from strong medical opinions and proposals. They also do not fully appreciate the difficulties in adjudicating which perspective to prioritize and, moreover, how to mitigate disagreement. Introducing a mild form of paternalism can harness the unique skillset both parents and clinicians bring to shared decision-making and ultimately work towards decision-making in the best interest of the child. The notion expressed here is that within the model of shared decision-making, mild paternalism is prioritized inasmuch as optimal care is prioritized. This mild form of paternalism is known as Beneficent Paternalism and justifies our encouragement for physicians to root down in their own medical expertise to propose treatment plans informed by medical expertise, standards of care, and the parents’ values. This does not mean that we forget that paternalism was historically justified on ‘beneficent’ grounds; however, our recommendation is that a re-integration of mild paternalism is appropriate within our current Western healthcare climate. Through illustrative examples from the NICU, this paper explores the appropriateness and merits of Beneficent Paternalism and ultimately its use in promoting family-centered care, patient’s best interests and reducing moral distress. A distinctive feature of the NICU is the fact that communication regarding a patient’s treatment is exclusively done with substitute decision-makers and not the patient, i.e., the neonate themselves. This leaves the burden of responsibility entirely on substitute decision-makers and the clinical team; the patient in the NICU does not have any prior wishes, values, or beliefs that can guide decision-making on their behalf. Therefore, the wishes, values, and beliefs of the parent become the map upon which clinical proposals are made, giving extra weight to the family’s decision-making responsibility. This leads to why Family Directed Care is common in the NICU, where shared decision-making is mandatory. However, the zone of parental discretion is not as all-encompassing as it is currently considered; there are appropriate times when the clinical team should strongly root down in medical expertise and perhaps take the lead in guiding family decision-making: this is just what it means to adopt Beneficent Paternalism.

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