

Chapter 11

The Concept of Best Interests in Clinical Practice

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11.1 Introduction

The role of staff members in acting in a child's best interest is similar to that of the parents, but the opinions of professionals have greater weight. (Hallström and Elander 2005)

The most frequent theme (in 89.1 % of all interviews) was “doing right by my child,” conveying parents' desire to make decisions in the child's best interest (...) in an unselfish manner. (Hinds et al. 2009)

Estimating an individual's best interests indirectly demands placing a value on that life. It seems that we are prepared to place less moral value on a human life just born than one that has begun to develop attachments. (Armstrong et al. 2011)

The real question is not so much about identifying which medical alternative represents the best interests of the child, but rather about identifying a harm threshold below which parental decisions will not be tolerated. (Diekema 2004)

(...) due to the variability demonstrated above, the BIS is neither internally nor externally consistent. (Salter 2012)

The Best Interests Standard is a difficult and controversial concept, and its implementation in clinical practice faces substantial concerns from conceptual and linguistic points of view.

Within this chapter, I aim to present of how a concept of best interests of the child could be applied in clinical practice in a consistent manner. I do not defend or question the “best”-language itself, which is under critique mainly because of its rhetorical power based on inconsistent or normatively weak arguments (Holm and Edgar 2008; Salter 2012). Nevertheless I would contest a rash discard of the concept of “best interests”. The herein presented approach is essentially shaped by my own

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daily work as a medical doctor in pediatrics and it is informed by excerpts from semi-structured interviews with health care professionals conducted from 2008 to 2012 including a comprehensive review on medical literature regarding the use of best interests (Streuli 2011; Streuli et al. 2014). Although I hope to advance the efforts of promoting the well-being of the child, I'm well aware of the limits of the applied methods, which do neither have the normative strength to confirm nor to discard the best interests standard as a leading concept in pediatrics. But my intention is a different one. Much more I will argue for a less normative but nevertheless comprehensive idea of the concept of best interests. Thereby speaking of "best interests" does not imply a normative principle but rather a motive to sharpen our perspective for a continuing attempt to understand what we use to call "children", what we think is "best" for them and to what "principles" we should adhere to in our efforts to respect the child and its family.

11.2 Premises on What Is in the Best Interests of a Child in Clinical Practice

Recommendations concerning the best interests of the child tend to contain vague and sometimes conflicting interpretations. In clinical practice, however, best interests are applied on a regular basis and normative statements in a particular situation usually are ready-to-hand (Streuli et al. 2011). As indicated by the opening quotes there are some variability in talking about best interests, which sometimes lead to the conclusion that the concept of best interests "is neither internally nor externally consistent" (Salter 2012). To have an idea of differing interpretations, which may lead to inconsistency, I will start with presenting some important underlying assumptions and premises, which I repeatedly found in interviews and daily practice.

11.2.1 The Child as a Subject Subjected to Parental Authority

Parents are widely seen responsible for their minor children, including decision-making concerning their child's development and health. The associated authority is either based on the assumption that parents do qualify best to respect their child's needs or on the overarching value of the family and the underlying assumption of an "intimate relationship" (Downie and Randall 1997). According to the first perspective parental authority is an implication of the best interests of the child, according to the second perspective best interests of the child is an implication of the value of a family. In clinical practice both perspectives are important. Therefore, parents do hold the authority to act in ways that are *not* necessarily for the child's good (e.g. change of residence of a family due to personal but not

financially compelling reasons) but at the same time do have responsibilities concerning the needs of an individual child, independent of efforts to preserve and enhance the family as a whole (e.g. the prohibition of child-labour for increasing the family income). In short, there is much, but not endless room for parental authority.

Of particular interest for pediatric ethics is the notion that parental authority not only includes the power to make decisions on behalf of the minor child but also the decision of how much participation parents like to share with their minor offspring. The question about the point, where a child receives authority in decision-making hence depends on one hand on the child's competence to make a decision but on the other hand largely on the parents' concept of participation, education, and what for them seems best for the child. The increasing awareness of the burdens among children with cancer who are not sufficiently informed might have changed the relationship between medical professionals, parents and the child during the last years. But current literature still gives little guidance about the implication of parental authority in clinical practice. However, from a clinician's point of view the question of parental authority also implies the question of how parents can be supported in applying authority in difficult situations. Using the example of differences (or disorders) of sex development (DSD), also called intersex, we are just starting to learn how important it is to strengthen the parents' competence in talking about difficult issues with their minor children and exert authority in complex clinical situations (Streuli et al. 2013).

11.2.2 The Child and Its Family as a Relational Unit

As mentioned above the intimate family can be a justification for parental authority. At the same time the assumption that the parents and the child are a relational unit with significant influences on the development and well-being of children is a cornerstone of the concept of best interests (Coleman 2002). It is a common and central claim that the patient's family and the health care team must work cooperatively with each other and communicate effectively to provide the best patient care (Committee on Bioethics 2007). Based on early research concerning the impact of bonding, pediatricians see the child's outcome regarding physical and emotional health, including cognitive and social functioning, strongly related to the (patch-work) family's functioning as a unit (American Academy of Pediatrics 2003). A significant inability of providing certain conditions for an effective bonding between the parent and the child can lead to protective measures against parental authority. An example could be seen in a single parent with severe depression and repeated hospitalizations, who has not been able to give sufficient love and attendance to the child without support from a foster family. In another example of an unconscious dying child with acute worsening conditions the premise of relational units may be used for balancing the parents' need for having some more time with their dying

child against the inclination not to prolong distress by invasive procedures like intubation for mechanical ventilation.

Moreover, the values within a relational unit also provide guidance in situations, where the harm principle as a base for child protection measures, as proposed by Diekema, might not be sufficient (Diekema 2004). In the example of a depressive single parent, the need of the child for emotional warmth and security may demand certain supportive measures independent of the mere quantification of resulting harm, because harm in this particular situation may be of rather hypothetical consequence. In my experience the act of fostering the relationship to a continuing (professional or personal) person of trust usually cannot be done by a court but needs a long-term relationship to the child and its environment (e.g. school teacher, psychologist, social worker etc.). In the second example of a severely ill and unconscious child the principle of do-no-harm is also of great significance but not the sole argument. Although one could certainly argue that parents *prima facie* do not have the right to demand invasive, potentially harmful and medically not indicated treatments, there are other normative aspects than solely the harm principle. Moreover, the harm principle itself is a multifaceted concept as shown below.

11.2.3 The Child as a Vulnerable Person

It is a frequently heard premise that children are characterized by their exceptional vulnerability. Its source can be grouped into primary and secondary origins. Primary origins of the vulnerability of the child are related to the absolute or relative child-like weakness, frailty, and immaturity, which objectively make the child dependent on others in particular situations. Vulnerability in pediatric hospital settings, however, is not just bound to primary biological and psychological constitutions of the child but also to the imbalance of power between adults' and minors' concepts, spaces, and bodies. Drawing a line between adulthood and childhood involves the danger of a certain "adulthoodism", which is associated with a conscious or unconscious control of children by demanding obedience and conformity, independent of evolving capacities to participate in a process of decision-making (Bricher 2000). This may lead to the denial of rights and, subsequently, to the accentuation of vulnerability.

An extreme form of such secondary origins of vulnerability was proposed in 1964 by Solnit and Green under the name of the "vulnerable child syndrome", observed in families which experience the premature death of a close person, recovery from a nearly missed death in infant- or childhood, or burdening situations during pregnancy. In the absence of a biomedical or psychological disorder in the child, the authors reported overemphasized and secondarily enforced vulnerability associated with pathologic separation problems, overuse of medical care services, and overprotectiveness (Green and Solnit 1964).

11.2.4 The Child as a Participating Person with Evolving Capacities

As children develop and acquire enhanced competencies, there is a continuously reduced need for direction, and consecutively a greater capacity to take responsibility for decisions affecting their lives. Speaking of best interests, there is always a need to balance the understanding of children as active agents in their own lives, with their own understanding of value and happiness, entitled to be listened to, respected, and granted increasing autonomy in the exercise of rights, while they are also entitled to protection in accordance with their relative immaturity and youth. The concept of evolving capacities, introduced in Article 5 of the Convention on the Rights of the Child, provides the basis for an appropriate respect for children's agency, without exposing them prematurely to the full responsibilities normally associated with adulthood (Committee on the Rights of Children 1989; Lansdown 2005). There is little literature about the relation between the best interests of the child and autonomy, but they are sometimes believed to be oppositional, as the risks resulting from autonomous choice could be contrary to the child's best interests (Buchanan and Brock 1989; Partridge 2010). Other authors do not share these concerns and draw a strong link between the ability to understand, communicate, and value certain choices and the ability to cope with the burdens of illness and its treatments (Alderson 1992). Both perspectives, however, do have in common that they perceive the acknowledgment and support of evolving capacities as a delicate and important issue, while an all-or-nothing discussion between the autonomous versus the vulnerable child would hardly reflect reality. For example, in clinical practice there is a widespread awareness of the importance of play and toys in a child-friendly clinical environment, acknowledging the value of childhood itself. At the same time plays and toys, including children's book are frequently used to explain concepts and obtain opinions of topics such as chemotherapy, side effects, suffering or death – topics, which often are reserved for the adult world. However, we always must be aware that autonomy and evolving capacities are concepts coined by an adult understanding of competence and decision-making. Nevertheless there are a myriad of specific competences of a child to discover, to respect and to build on. On one hand this draws a connecting line to a particular form of vulnerability and the problem of “adultism” mentioned above, on the other hand it leads us to the last premise of the child and the prospect of its future state.

11.2.5 The Child and the Prospective Future Person

Normative statements based on adult concepts may conflict with a value system of a child. While children in some aspects do have the capacity and the right for having their very own value system, the common adult perspective (above introduced as “adultism”) typically argues that children only have an incomplete value systems

closely related to still evolving capacities and limited life experiences. A value system, according to this perspective, is perceived as mature as soon it coincides with a value system and the underlying capacities of a “fully developed” adult. As so often, when two extremes are opposed, both do have at least some weight: While professionals try to respect the child’s own perspective and values, it is also necessary to consider in some regards the future person with different phases of life. This happens by caring for the child’s health and education based on principles such as protection and provision (Streuli et al. 2011). While the children’s rights approach combines the principles of protection and provision with the demand for participation, thereby including the respect of evolving capacities, Feinberg’s well-known account of the child’s right to an open future focuses almost exclusively on the preservation of prospective opportunities in later life, with the aim of “[sending the child] out into the adult world with as many open opportunities as possible, thus maximizing his chances for self-fulfillment” (Feinberg 1980; Salter 2012). While Feinberg’s perspective certainly is compatible with the respect of evolving capacities, as far as open opportunities also depend on capacities learned earlier in childhood, the open future account is still highly prescriptive, fully dominating opportunities in childhood by future opportunities in a hypothetical state of adulthood.¹ There is, however, another aspect of the child and its prospective phases of life, which is less intrusive but equally powerful for clinical practice: the perspective of evidence-based medicine, which urges professionals to collect and implement data and insights from mid- and long-term results. A particularly difficult example can be found again in the treatment of children with disorders of differences of sex development, where recent studies shed a critical light on the outcome of surgical sex assignment and the absence of follow-up data for many years (Köhler et al. 2012). Therefore, returning to interpretations of best interests, I would argue, that the collection and consideration of data regarding long-term outcome after childhood is an essential part of the best interests of a child.

11.3 The Triad of Best Interests in Clinical Practice

The short and probably incomplete summary of five premises suggests that inconsistencies are not primarily part of an inconsistent concept but the (inevitable) consequence of tensions between different values and perspectives in clinical practice. Medical indication is bound to a medical professional’s opinion. However, daily care and choice reach far beyond medically indicated therapy or support. Professionalism in clinical practice embraces innovative approaches of planning, delivery and the evaluation of health care grounded in a mutually beneficial

¹Feinberg’s approach fails to show why the open future argument is applicable on children (e.g. desires and wishes in childhood should be sacrificed for the opportunities of an adult person in her 30s) but not on adults (e.g. desires and wishes of a person in her 20s should be sacrificed for the opportunities of an adult person in her 60s).

partnership among patients, families, and providers that recognize the child's needs, the child's evolving capacities, and the importance of the family in the child's life (Committee on Hospital Care and Institute for Patient- and Family-Centered Care 2012; Lansdown 2005). In a nutshell, this is what the best interests of the child in clinical practice are aiming for: a well-considered implementation of multifaceted needs, aims and conditions.

The here presented concept has strong similarities with the theoretical concept of Loretta Kopelman (Kopelman 1997). Kopelman defines the Best Interests Standard as an umbrella term, by identifying its employment, first, as a threshold for intervention and judgment (as in child abuse and neglect rulings), second, as an ideal to establish policies or prima facie duties, and, third, as a standard of reasonableness. In my opinion Kopelman's concept of a triad is capturing the needs and requirements regarding interactions with children and their families best. In practice, the best interests of the child are not limited to a punctual approach of solving conflicts and averting harm, but deeply related with a comprehensive understanding of the child's need to develop within a functional system of caregivers and heteronomous as well autonomous capacities. In the following three paragraphs I will show a way, which captures the best interests of the child best, from an empirical and philosophical perspective. The here presented triad slightly differs from what Kopelman earlier proposed. The following approach embraces and modifies also the classic definition of Brock and Buchanan, which conceives the best interests standard literally as a maximal best solution, as well as a proposal by Diekema, who argues for interventions against parental authority exclusively based on the harm standard (Buchanan and Brock 1989; Diekema 2011; Salter 2012). After presenting central premises, on which discussions regarding the best interests of the child are based, I will next present three different but complementary discourses from which statements regarding the best interests and based on the proposed premises arise.

11.3.1 The Optimum

The main discourse from a clinical point of view could also be called a standard of optimum care and choice. Finding an optimum is a process, which takes place within a continuously changing field of multiple choices and different forms of care. The discourse about the optimum is characterized by changing perspectives, needs, and capacities of a child and its environment, including its family and a particular health care system. The idea of an optimum is based on the observation that decisions in clinical practice often refer to a level of effort that strives to maximize the benefit for a particular child over a long time period without significantly decreasing the ability of the family or its environment to support the continuation of a certain level of care and choice. Although a particular patient might be the center of considerations, the optimum care and choice is based on the premise of the family as a unit and therefore takes all family members into account. The optimum typically

corresponds to an effort level somewhere between the maximally best solution mentioned by Brock and Buchanan and the “good-enough parenting” mentioned by Winnicott (Buchanan and Brock 1989; Winnicott 1965). Most health care professionals I interviewed were in accordance that “just” good-enough or suboptimal care or choices would not be in the best interests of the child and should be encountered by prevention or additional support. Nevertheless, the standard of optimum care and choice reigns on the important role of parents in deciding on behalf of a child, which is not yet or no longer capable of deciding for itself. Whether a certain care or choice is rather “good-enough” or “maximally the best” therefore depends on the mutually beneficial partnership among patients, families, and providers formed by a dynamic process within the triangle of the patient, the parents, and the responsible professionals.

11.3.2 The Threshold Value

Statements considering a threshold value refer to situations where a certain stakeholder loses its significance in favor of interdisciplinary, democratically legitimated expert groups (e.g. child protections services, ethics committees and/or courts). Threshold values of best interests are primarily based on the principle of non-maleficence and distinguish acceptable from unacceptable courses of action or consequences. While the best interests as an ideal or an optimum are represented by a multitude of differing principles, the threshold value is primarily guided by a negative definition of best interests focusing on the prevention and/or protection from harm. As a consequence, the effect of threshold values is limited to situations where significant and obvious harm occurs or very likely will occur. Therefore every optimum is surrounded by certain borders, which demarcate an area, where parents, in relation with the minor patient and the supporting professionals do have a certain freedom to act in regard of their child’s need and capacities.

Health care professionals typically are well aware of the difficulty of defining such threshold values and the nuances involved. Whether the harm principle should be the leading argument or just one argument *inter alia*, will not be discussed here. However, contrary to individual and close partnerships within the area of optimum care and choice, the threshold values should be based on well-considered resolutions by transdisciplinary working groups, ethic committees, courts, and other democratically enacted authorities. Although the threshold value as a part of the best interests of the child governs the limits of parental consent, parents have an important role in determining what a threshold value is. As a consequence, a threshold value is closely associated with the assisted search for an optimum. By defining threshold values based on children’s rights and modern child protection services, it became clear that harm to a child can not simply be seen as a sum of threshold crossings but also as a problem requiring knowledge about coping strategies and the

resilience of a child's environment to identify the underlying causes of harmful behaviors or conditions. For example, the best interests of a child living within a family of Jehovah's Witness would be insufficiently covered by only discussing the limits of parents' authority in deciding about life-saving transfusion in an emergency situation (threshold discourse). By making a substantiated decision against the parents' and/or the child's will, the best interests of the child are not yet fully considered. Dependent on particular situations professionals should strive for an optimum in how parents and the child can be prepared, informed and supported in advance and after a potential transfusion. This brings me to a third discourse on which the best interests of the child rely.

11.3.3 The Discourse of Ideology

Ideology is the most private and individual but also most controversial aspect of the best interests of a child. Ideology is based on particular ideas of what makes life and decisions good and right, independent of democratically legitimated, well-argued, or evidence-based resolutions within the discourse of thresholds. Similar to its origin in the platonic idea, the ideologies exist as archetypes of which only shadows or certain excerpts become visible for the observer. Considering the best interests of a child implies a process of perception, comprehension and translation, and of underlying ideologies in families; but also in health care. Medical professionals should always bear in mind that definitions of what is health and healthy are nevertheless bound to particular perspectives and ideologies. There is however no reason to end up in multicultural relativism. Other than the critically reflected optimum and threshold discourses the discourse of ideology is not necessarily subject of normative statements and judgment. To implement personal and sometimes controversial ideologies is mainly a way to show respect for someone. Moreover it facilitates planning and delivering optimal care and a choice. Therefore, the best interests of the child demand a consideration of the families' ideologies as a starting point for further reflection on the optimum and certain threshold values. This statement is sufficiently vague so that its value mainly can be seen in reducing child/parent/professional conflict.

11.4 Implications

If there is a simple message about best interests in clinical practice, then certainly that best interests are not simple. They are multifaceted, dynamic and sophisticated. However, in contrast to a widely held belief the concept of best interests does not itself balance principles, rights and needs of children and parents but describe and integrate them on several levels or discourses (Ainsworth and Hansen 2011).

Basically it ensures a well-considered implementation of the multifaceted needs, aims and conditions. Table 11.1 offers a matrix, which has to be filled with relevant data, necessary to incorporate these needs, aims and conditions. The concept of best interests thereby does neither represent a particular argument, principle or philosophy nor does it come to use only for situations where the child has no competence at all. For using “best interests” as a meaningful concept it is necessary to differentiate between the discourses of ideology, optimum and threshold based on different perspectives resulting from premises such as parental authority and the evolving capacities of the child. In practical terms this means that a decision on a threshold value made by a child protection service, for instance against the preference of religious parents who reject blood transfusions, cannot be claimed as being in the best interests of the child without aiming at the same time to install a relationship between the child, the parents, and the professionals. Then, and maybe only then, it is possible to learn about the underlying ideology and to offer at least the possibility of sincere reflection on the optimum based on different options (such as overriding parental authority, mechanical blood cell-saver with support by a religious advisor or a step-wise transition to a less fundamental interpretation of religious commands). Under true time pressure, a treatment can be rightly enforced based on a (provisional) juridical decree but the claim of the concept of best interests doesn’t end there. The child has a right to be the subject of a comprehensive assessment, which requires considerations not only of a single time point of a particular intervention or a single principle, but also of subsequent questions and problems regarding the consequences of a certain decision.

As a consequence, there should be no use of the term before trying, firstly, to understand underlying ideologies, secondly, to delineate a particular area of optimum care and choice, and, thirdly, to learn about established or needed thresholds. If only one of these three considerations is missing we should either conceive the concept of “best interests” as a mandate to complete these considerations or refrain from using it.

Table 11.1 A matrix of “best interests”

	Ideology	Optimum	Threshold
Experts	(...) ^a	(...) ^{b,c}	(...) ^d
Parents	(...) ^a	(...) ^{b,c}	(...) ^d
Children	(...) ^a	(...) ^{b,c}	(...) ^d
Future person	(...) ^a	(...) ^{b,c}	(...) ^d

^aAssess, communicate and respect individual values and opinions

^bConsider content, such as development, feeling of security, quality of life, bodily integrity

^cDiscuss inter- and transdisciplinary

^dElaborate thresholds with transparent and democratically legitimated working groups, commissions, and courts

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