

KARINA KUBICIUS*, MONIKA MICHAŁOWSKA**

SHAPING THE BODY OF A CHILD.
INVASIVE MEDICAL PROCEDURES ON INCOMPETENT
PATIENTS – SOME ETHICAL AND MEDICAL REMARKS
ON ASHLEY’S CASE¹

Keywords: static encephalopathy, Ashley treatment, invasive medical procedures, incompetent patients, the right to an open future, best interest

* Karina Kubicius – Student at Faculty of Medicine at the Medical University of Łódź. Her research clusters around paediatrics, gynaecology, oncology and ethical problems they generate.

Address for correspondence: Medical University of Łódź, Department of Bioethics, Lindleya 6, 90-130 Łódź, Poland. E-mail: karina.kubicius@stud.umed.lodz.pl.

** Monika Michałowska – Doctor Habilitated, Adjunct Professor in Department of Bioethics, Medical University of Łódź, Poland. Her research focuses on bioethical aspects of reproductive medicine, feminist approaches to issues such as preimplantation genetic diagnosis, embryo, gamete and mitochondrial donation, human enhancement and cross disciplinary perspective (bioethics/film studies/cultural studies/body, bio and cyborg art) on dying, ageing and embodiment.

Address for correspondence: Medical University of Łódź, Department of Bioethics, Lindleya 6, 90-130 Łódź, Poland. E-mail: monika.michalowska@umed.lodz.pl.

Karina Kubicius and Monika Michałowska have contributed equally to this paper.

¹ Research on this paper was supported by the Ministry of Science and Higher Education, Republic of Poland, under the National Programme for the Development of the Humanities 2016–2019 (Ministerstwo Nauki i Szkolnictwa Wyższego „Narodowy Program Rozwoju Humanistyki 2016–2019”), project number: 0073/NPRH4/H2b/83/2016.

Invasive medical procedures performed on children for non-life-saving reasons, and generally for non-therapeutic reasons, have recently become the subject of intense debate. Various kinds of aesthetic medicine procedures, such as liposuction in the case of an obese twelve-year-old girl, the eyelid surgery performed on an Asian girl adopted by an American surgeon, the application of growth hormone therapy for non-therapeutic reasons (Gilbert, 2009, pp. 14–15; Ouellette, 2010, pp. 959–966) or early “normalizing” treatment in intersex children (Spriggs, Savulescu, 2006, pp. 79–96; Gilham, Hewitt, Warne, 2010, pp. 412–418) can serve as examples. All of these are often considered to violate the right to self-determination, the right to inviolability and the child’s right to an open future.

The case of Ashley X and “Ashley treatment”, the term coined in the subject literature regarding the procedures she underwent, have been sometimes regarded to bear a resemblance to the above-mentioned interventions (Ouellette, 2010, pp. 964–966). As convenient as such a claim may be to categorize Ashley’s case and her treatment as belonging to that cluster, there are significant differences between this procedure and the ones delineated above regarding the patient, the process of medical decision-making and the purpose of the medical interventions themselves.

Ashley’s case and treatment

Ashley was born in 1997. The pregnancy was uneventful and the on-time birth proceeded without complications. At the age of one month, she began to display symptoms of hypotonia (decreased muscle tone) leading to difficulty in feeding, and of choreoathetosis (involuntary twisting and writhing body movements caused by irregular, wandering muscle contractions). An overall developmental delay was also noted. The diagnosis of “static encephalopathy with marked global deficits” was made after a long and extended diagnostic process (Gunther, Diekema, 2006, p. 1014). Since her condition and the treatment are crucial for our analyses and argument, we shall describe them in detail.

Static encephalopathy

Static encephalopathy is a form of irreversible brain damage. The term comprises a wide range of dysfunctions that can be caused by the same central nervous system abnormality. Static encephalopathy may manifest itself as cerebral palsy, mental retardation, blindness or deafness. The location of the damage in the brain and its severity determines the extensity and type of developmental impairment (Golden, 1987, p. 71). Ashley's development did not improve, although she managed to externalize her emotions through mimicry and producing sounds. At the age of six, she maintained the ability to breathe on her own, however, she was unable to speak, eat or move and remained completely reliant on her caregivers. In 2018, after a Whole Exome Analysis, it turned out that GRIN1 gene mutation was responsible for Ashley's condition. GRIN1 is a gene that encodes subunits of N-methyl-D-aspartate receptors (NMDARs) which are crucial in normal brain development and neurotransmission (Chen et al., 2017, p. 2). Its *de novo* mutation presented itself in three-month-old Ashley as hypotonia, abnormal movements and behavior, and disabled her development to progress.

Precocious puberty

Precocious puberty is diagnosed when the first signs of puberty onset reveal themselves before the age of eight in girls, and the age of nine in boys (Siddiqi, Van Dyke, Donohoue, McBrien, 1999, p. 392). There are two main types of precocious puberty, both differing in their origin. Peripheral precocious puberty is a result of the premature secretion of sex steroids in gonads, adrenal glands or ectopic sources, without activation of the hypothalamic-pituitary axis. Central precocious puberty is a consequence of premature activation of the hypothalamic-pituitary axis, premature gonadal maturation and gonadal sex steroids release (Partsch, Sippell, 2001, pp. 293–298; Siddiqi et al., 1999, pp. 392–393). In a population of children with neurodevelopmental disabilities the incidence of precocious puberty is much higher (Partsch, Sippell, 2001, p. 293). Ashley's parents consulted with a pediatric endocrinologist when the girl was six years and seven months old reporting on her precocious puberty. It has been assumed that Ashley suffered from central precocious puberty. According to the endocrine evaluation, she had started to develop pubic hair and breast buds consecutively one year and three

months earlier. Furthermore, during the previous six months her growth had accelerated rapidly, which is called a pubertal growth spurt. When it comes to percentiles for height, she advanced from 50th to 75th within six months (Gunther, Diekema, 2006, pp. 1014–1015). Her speeded-up body growth and premature puberty raised her parents' concerns about the future care they would have to provide, which might be difficult, if not impossible, to handle (Ashley's Parents, 2007, p. 8). They were concerned as to whether they would be able to carry her around and provide daily-care once she had increased in height and weight.

Estrogen therapy

Pubertal growth and epiphyseal fusion are both regulated by a complicated network of nutritional, cellular, paracrine and endocrine factors (Shim, 2015, pp. 8–12). One of them is estrogen that is the sex steroid hormone responsible mainly for the reproductive function in females and for the development of secondary sexual characteristic (Singh, Sanyal, Chattopadhyay, 2010, p. 3). Its effect on growth seems to be biphasic. During the period of puberty, the physiologic level of estrogen promotes growth by stimulating the growth hormone (GH) and the insulin-like growth factor-I (IGF-I) axis (Shim, 2015, pp. 10–11), while the suprphysiologic doses suppress the insulin-like growth factor-I causing growth suppression by accelerated epiphyseal maturation and fusion (Gunther, Diekema, 2006, p. 1014; Shim, 2015, p. 11; Singh, Sanyal, Chattopadhyay, 2010, pp. 3–8). The first high-dose estrogen therapy was instituted in 1956 in adolescent girls of tall stature, whose wish was to “minimize any further gain in height” (Gunther, Diekema, 2006, p. 1014). Ashley is the first patient with a profound developmental disability to have undergone the treatment, where the purpose was to attenuate her growth at a very early age.

Before starting high-dose estrogen therapy, Ashley underwent pretreatment hysterectomy which is a surgical excision of the uterus (Torpy, 2004, p. 1526). Her ovaries were left *in situ* in order to provide physiological hormone release and “some protection from osteoporosis” (Gunther, Diekema, 2006, p. 1015). The procedure had a prophylactic character. It was supposed to eliminate menses and to prevent development of uterine or cervical cancer, but it also allowed elimination of giving “concurrent progesterone during the treatment phase, potentially reducing the risks of thrombosis”

connected with estrogen institution (Gunther, Diekema, 2006, p. 1015; Rosendaal, Helmerhorst, Vandenbroucke, 2002, pp. 201–206). Moreover, it prevented the possibility of bleeding occurring (Ashley's Parents, 2007, p. 6). The risk of hysterectomy and long-term complications in Ashley was no higher than in a population of healthy pre-pubertal girls, with it being estimated as "minimal" (Gunther, Diekema, 2006, p. 1015).

The course of 400 µg transdermal estradiol per day took two years and six months. Estrogen patches were changed every three days and the girl's weight, height, bone age, hormones and thrombotic factors levels were monitored every three months (Ashley's Parents, 2007, pp. 4–7; Gunther, Diekema, 2006, p. 1014). Any long-term side-effects of estrogen therapy were difficult to assess because of the limited experience in the treatment of children of her age. According to the available research, these side-effects included "nausea, headache, and weight gain" (Gunther, Diekema, 2006, p. 1015). There was a report of hyperprolactinemia, which "is generally of no clinical significance and resolves after treatment" (Gunther, Diekema, 2006, p. 1015). Equally, one case of a girl with prolactinoma was reported, however there was no explicit medical evidence that this was an effect of the therapy (Gunther, Diekema, 2006, p. 1014). The main concern was focused on the elevated risk of thrombosis (Rosendaal et al., 2002, pp. 201–206). The effect of Ashley's high-dose estrogen treatment was a 20% in height and 40% in weight reduction. Her growth stopped at 153 cm and 29 kg respectively (Ashley's Parents, 2007, p. 8).

Additional procedures

Not only did Ashley undergo hysterectomy, but also breast bud removal and appendectomy were performed. The first procedure differs from the commonly known mastectomy performed in adult women. Breast buds are small and include milk glands, connective and adipose tissue (Javed, Lteif, 2013, pp. 9–10). Their removal involves making small incisions below the areolas, but both the nipples and areolas are left unaffected (Ashley's Parents, 2007, p. 10). Ashley's parents and physicians pointed out the following benefits of the procedure: 1) elimination of the source of discomfort while lying, or being secured with straps; 2) avoidance of the possibility of fibrocystic growth or breast cancer (both pathologies were reported in women from Ashley's family); 3) avoidance of "sexualizing" Ashley by her

caregivers, which may lead to sexual abuse when her parents are no longer able to take care of her or in the case of their death (Ashley's Parents, 2007, pp. 10–11). Appendectomy is a surgical removal of the appendix and was performed in order to prevent appendicitis (inflammation) that may lead to appendix rupture causing inflammation of the peritoneum. Peritonitis is a life-threatening state, which Ashley's parents were afraid of, thinking they may not be able to recognize its symptoms in time (Ashley's Parents, 2007, pp. 6–7). All of the surgical procedures were performed at the same time, limiting the surgery risk, pain and reducing the time of her convalescence to one month (Ashley's Parents, 2007, p. 10).

Objections against Ashley treatment

In 2006 the case of Ashley X and the above-mentioned treatment performed on Ashley was described in a medical journal (Gunther, Diekema, 2006). A year later, her parents started a blog *Pillow Angel*, describing their daughter's condition, treatment and the every-day life of their family. Making Ashley's case public initiated a debate among physicians and bioethicists that focused on analyses of the criteria and arguments used to evaluate the treatment from a medico-moral perspective. The discussion centered around providing ethical justification for this kind of treatment or expressing ethical disapproval and suggesting legal prohibition for the so-called "Ashley treatment." It also sparked a media firestorm and criticism of the decision made by her parents and physicians. Much of the criticism was a purely emotional reaction to this innovative and invasive therapy and "substituted rhetoric for argument" (Diekema, Fost, 2010, p. 31), using expressions such as "looping off her breasts," "mutilation" (Caplan, 2007), "butchery" (Picard, 2007). In other cases it took the form of an oversimplification: "she is being tube-fed, why not remove her teeth" (Picard, 2007), or was formulated as a slippery slope argument (Carlson, Smith, Wilker, 2012, p. 23; Clark, Vasta, 2006, pp. 7–9; Kerruish, 2016, pp. 77, 79). There were, however, some voices which in fact raised important questions and concerns. Many of them have been already referred to and analyzed in the subject literature, for example the argument of the quality of life and the objection of violation of dignity (Harnacke, 2016, pp. 141–150; Liao, Savulescu, Sheehan, 2007, pp. 16–20), the problem of the moral status of children with severe cognitive impairment,

such as Ashley (Jaworska, Tannenbaum, 2014, pp. 259–265), the principles of respect for persons, beneficence and justice (Clark, Vasta, 2006, pp. 1–12; Newsom, 2007, pp. 291–294).

In the sections below, we will focus on four issues that bear great ethical importance, yet have received less attention so far. In our analyses, we shall concentrate on four conceptual and ethical dilemmas which cluster around: 1) the classification of that kind of treatment as therapeutic or non-therapeutic; 2) the process and criteria of medical decision-making on behalf of incompetent patients (surrogate/proxy decision making); 3) the child's right to an open future; 4) the criterion of best-interest and balancing benefits against risks and harms.

Classification of medical procedures: therapeutic versus non-therapeutic

One of the objections found in the subject literature considering Ashley treatment focused on its non-therapeutic character and questioned its medical necessity. To determine whether Ashley's treatment was therapeutic, we should first have a closer look at the classification of the medical procedures which Ashley has been subjected to, taking into account "the nature of the disease, the treatment proposed, and the goals of the intervention" (Jonsen, Siegler, Winslade, 2010, p. 16).

The primary aim of the therapy was to facilitate Ashley's daily and medical-care by administering high-dose estrogen therapy, which was to maintain a reduced body weight and height. Moreover, growth attenuation therapy administered together with hysterectomy, breast buds removal and appendectomy were intended to prevent scoliosis surgery, breast, uterine, or cervical cancer, to reduce the risk of inflammation of the appendix, as well as the pressure ulcers, bladder or lung infections that Ashley would be exposed to as a result of permanent immobilization (Ashley's Parents, 2007, pp. 4, 9–10; Gunther, Diekema, 2006; Kerruish, 2016, p. 73; Wrigley et al., 2017, p. 1181). It could be argued that the effects of Ashley treatment met the criteria of therapeutic treatment, such as: "maintenance or improvement of quality of life through relief of symptoms, pain and suffering"; "improvement of functional status or maintenance of compromised status";

“avoidance of harm to the patient in the course of care” (Jonsen, Siegler, Winslade, 2010, pp. 16–17).

In their criticism some authors claimed that Ashley treatment was not in fact of a therapeutic character and that there was no medical indication for it (Kittay, 2011, p. 618; Ouellette, 2010, pp. 966–967; Sobsey, 2010, p. 60). Consequently, they should be classified as non-therapeutic procedures, because they had no effect on the healing process or improving Ashley’s health. It has been also stated that the intervention was a result of the lack of an acceptance of the girl’s disability, and willingness to modify her body primarily for the benefit of caregivers (Carlson, Smith, Wilker, 2012, pp. 35–40; Ashley’s Parents, 2007, pp. 10–13; Kittay, 2011, pp. 618–619; Ouellette, 2010, pp. 973–974).

The term “medical indication” deals with the patient’s physiological or psychological condition determining what kind diagnostic, therapeutic or educational actions should be offered (Jonsen, Siegler, Winslade, 2010, p. 10). While evaluating whether there was a medical indication for Ashley treatment, we should take into account their positive and beneficial effects on her health condition, as Diekema and Fost say:

The tools of medicine are used commonly to treat disorders or conditions that are commonly defined as social. Consider laser treatment for facial hemangiomas, braces for crooked teeth, drug prescriptions for acne, and drugs to improve fertility. [...] The insistence on “medical” indications is not sufficient to help us distinguish why some interventions are appropriate and others are not. The relevant question is whether medical interventions were likely to be safe and effective in providing benefit to the patient and improving her quality of life.

(Diekema, Fost, 2010, p. 37)

Although we agree that the treatment offered to Ashley cannot be classified as curative (leading to an undeniable improvement of the condition), because of the nature of the disease, we think it can be called ‘supportive’ (and therefore therapeutic to some extent), since its main aim was to bring about a general relief in the disease and to slow down progression of coexisting diseases (Jonsen, Siegler, Winslade, 2010, p. 14).

Surrogate decisions for incompetent patients

In bioethics and medical ethics, the principle of respect for autonomy has become one of the key principles medical professionals are obliged to respect while providing care to their patients. Although there has been an overall agreement that respect for autonomy (basically understood as a capacity of self-determination and critical self-reflection) is central in any medical interventions, the notion of autonomy itself and the range of the respect for autonomy have become the subject of an ongoing debate and various interpretations (Dworkin, 1988, pp. 3–13; Mackenzie, 2015, pp. 277–290; O’Neill, 2002, pp. 21–27). It has been questioned whether personal autonomy is a value, whether it should be ascribed to persons or principles and whether it exists at all. Although these questions assume central importance, they fall beyond the scope of our paper. Therefore, for the sake of our argument, we will put them aside and adopt Gerald Dworkin’s idea that “the only features that are held constant from one author to another are that autonomy is a feature of persons and that is a desirable quality to have” (Dworkin, 1988, p. 6).

That concept resonates also in bioethics and medical ethics where the prevailing notion of autonomy refers to individual autonomy defined as “a feature of individual persons” and is equated with “*independence* or at least with a *capacity for independent decisions and action*” (O’Neill, 2002, p. 23). Beauchamp and Childress call it a decisional autonomy and associate it with an informed, free from any external or internal influence, competent decision that is related to legal competence and informed consent (Mackenzie, 2015, p. 278). Although Beauchamp and Childress’ notion of autonomy limits in fact a patient’s independence in decision-making process to her rights to either accept or refuse treatment offered by professionals, it has become a key principle in any medical decision-making.

The principle of respect for autonomy has become fundamental in the debate on informed consent that involves a patient’s voluntary, individual decision, one free from any influence. It goes without saying that in some cases such a decision cannot be met and surrogate (proxy) decision-making is needed in health care. These may include the case of emergency medical conditions, end-of-life decisions, withdrawal or withholding treatment, palliative care in the case of severely ill newborns or patients with neurodegenerative diseases, medical decisions for psychiatric patients or any incompetent patients.

Pediatric practice is unique for at least two reasons: 1) it covers also the cases of patients who have never been competent, or/and will never be, therefore no advance directives have been issued by the patient, and no patient life-values and wishes could be referred to while making a decision (as in the case of neonatology); 2) it decides about the future life of the child, its quality and length as well as it influences the range of the child's future possibilities, her flourishing and the right to choose and develop her own life-plan. In most cases decision-making process includes both parental informed permission and child's assent. Child should be provided with necessary information about planned treatment or medical procedures, but to a degree that is adequate to her age. It allows developing young patients' responsibility for their health, building trust-based patient-physician relationship, and in some way limiting parental right to make surrogate decisions (Kohrman et al., 1995). Undoubtedly, Ashley belongs to the group of incompetent patients whose capacities to make an individual, authentic decision have been nonexistent and to whom autonomy could not be ascribed in any sense. She has never had and will never have any capacity to make individual and voluntary decisions or to determine her life-path in accordance with her beliefs or values. Despite the fact that at the time of treatment she was almost seven years old, and children at her age can already reach a certain level of self-understanding and self-governing, her mental capacities had been fully impaired. This obviously made her unable to meet any requirements for a valid informed consent.

We agree with the opinion that the term "substitute" surrogate decisions applies mostly to adults who have lost the capacity to make autonomous decisions (Katz, Webb, 2016, p. e5); therefore, we will use the term surrogate decision or parental decision here. In pediatric practice a surrogate decision on any medical intervention that takes the form of informed "permission" rather than a "decision" (Katz, Webb, 2016, p. e2) should be weighed carefully. In Ashley's case it becomes even more complex since the treatment in question was innovative and highly invasive; moreover, its outcome was to shape her body and future life significantly.

In the case of incompetent patients who have left no advance directives, Beauchamp and Childress suggest taking into account three possible standards of making a surrogate decision: "*substituted judgement*, which is often presented as an autonomy-based standard, *pure autonomy*, and the *patient's best interest*" (Beauchamp, Childress, 1994, p. 170).

In the case of incompetent patients who have never been competent (such as Ashley), only the third, also defined as “acting so as to promote maximally the good of the individual” (Buchanan, Brock, 1990, p. 88) can be applied. It involves a calculus of weighing up the potential benefits and burdens of the treatment. This is also the very criterion which the Bioethics Committee of Seattle’s Children’s Hospital referred to. In justifying their approval for the treatment, they balanced the long-lasting benefits of the therapy against the risks and short-term suffering resulting from the planned surgeries. Other principles that could apply in this case include “harm principle, constrained parental autonomy, and shared, family-centered decision-making” (Katz, Webb, 2016, p. e5). Although we are aware of the difficulties concerning the best-interest criterion, especially the risk of taking it in a narrow sense, we are of the opinion that it is one of the crucial principles to be applied here. We also think that a broader approach of this notion, taking into account emotional, family and financial aspects should be adopted. We shall return to this issue later.

The right to an open future

The debate on children’s rights in modern democracies often concentrates on the conflict between the good and the right, using John Rawls’ terminology (Rawls, 1971, p. 31; Feinberg, 1986, p. 57) and refers to the autonomy of a child, her rights as well as to parental responsibility (Archard, 2004, pp. 53–69; Brake, Millum, 2014; Brighouse, 2002, pp. 31–52; Brock, 2005, pp. 377–398; Mullin, 2015, pp. 381–392). Children’s health care plays an important role in the debate since “we typically take children’s care concerns very seriously, and severely blame those who contribute to children’s ill health through negligence or abuse” (Mullin, 2015, p. 381). In formulating his concept of “the child’s right to an open future”, Joel Feinberg introduced a new perspective in the debate on the medical treatment of children (Feinberg, 1980b, pp. 124–153; 1986, pp. 325–326; 1992, pp. 76–97). The right to an open future comprises a set of rights and limits imposed on parents regarding what they can/cannot do to their children as well as what they should provide their offspring with. This notion has become of extensive interest among bioethicists and has already had a widespread impact on various issues concerning the health of children, such as genetic enhancement,

pre-implantation diagnosis, testing for late-onset genetic diseases, providing cochlear implants (Davis, 1997, pp. 7–15; 2001, esp. pp. 24–35; Kopelman, 2007, pp. 383–386; Millum, 2014, pp. 522–538; Nunes, 2001, pp. 337–349; Prusak, 2013, pp. 84–100). It could be claimed that Ashley treatment violates that right. Let us have a closer look at this objection.

Feinberg differentiates between: 1) “*A-C rights*” – the rights that are common to both children and adults, such as the right not to be killed, robbed or physically assaulted in any way, 2) “*A rights*” – the rights restricted only to autonomous adults, such as the right to religious preferences, and 3) “*C rights*” – the rights principally held by children, which comprise all the rights guaranteeing the maximum range of possibilities and choices awaiting the child in the future (Feinberg, 1992, pp. 76–78). An example of the kind of right that refers to our analysis is given by Gena Davis, who says:

A striking example is the right to reproduce. A young child cannot physically exercise that right and a teenager might lack the legal or moral grounds on which to assert such a right, but clearly the child, when she or he attains adulthood, will have that right. Therefore the child now has the right not to be sterilized, so that the child might exercise the right to reproduce in the future.

(Davis, 2001, p. 26)

Since some of the critical voices of Ashley treatment concentrated on violating her rights to make personal procreation choices (Carlson, Smith, Wilker, 2012, p. 37; Carlson, Dorfman, 2007, pp. 1–27; Coleman, 2007, pp. 725–726, 728; Kittay, 2011, pp. 620–623), we shall return to that particular right later.

Autonomy rights (“*A rights*”) can be exercised only by an autonomous person, therefore, they cannot be ascribed to children, who yet do not have the capacity of self-governing. However, as Feinberg proposes, all “*A rights*” have their corresponding rights called *rights-in-trust* that basically “can be summed up as the single »right to an open future«” and should be regarded as “future options kept open until he [a child] is a fully formed, self-determining adult capable of deciding among them” (Feinberg, 1992, p. 77). Simply put, the child’s right to an open future means respecting all the rights that will protect the child’s future. It is to safeguard the range of possible choices and preferences that will open up to the child once she becomes an adult. Simultaneously, it becomes a duty for a parent “to keep

as many as possible of a child's central life-options open until the child becomes an autonomous adult himself, and can decide on his own how to exercise them" (Feinberg, 1986, p. 69).

Although certain concerns arise as to whether and to what extent Ashley treatment has limited the possibilities of her adult future, and thus, has violated her right to an open future, none of the arguments seems to provide a justified ground to support such a claim. Let us analyze them now.

Feinberg supports his concept of the child's right to an open future by a *per analogiam* argument giving an example of a 2-month-old child whose legs were to be cut off before she acquired the ability to walk. It would be depriving her of an ability that is crucial for a person's development, and, consequently, it would limit significantly the set of options open to her when she achieves adulthood (Feinberg, 1992, p. 77). In Ashley's case this argument could be formulated in the following way: like for any adult woman, mastectomy (the breast bud removal) limits Ashley's ability to experience sexual pleasure, therefore, it limits her right to an open future, therefore, it is ethically unjustifiable. Even if we agree that it would decrease the sensual experiences for her, a more troubling and fundamental question arises, namely "how someone like Ashley would ever experience sexual pleasure without being exploited or sexually abused" (Diekema, Fost, 2010, p. 34). We could also claim that the sterilization that was performed has violated Ashley's reproductive freedom and her right to make procreative decisions in the future. As important as that right is, it has been formulated and intended for those who will have the capacities to make those kinds of decision as adults and will have the capacity to exercise their freedom. Ashley will never achieve even a minimum level of self-awareness to be able to exercise the right to have children.

As Joseph Millum rightly points out, Feinberg bases his concepts also on the argument from autonomy, that can be summed up as follows: the autonomy of a child as a future adult, who will be able to exercise certain rights, must be protected in advance, because the right to an open future derives from the right to autonomy for an adult person. Consequently, just as it *will be* impermissible to make decisions without a very good reason for children once they become autonomous persons, it *is* impermissible to make decisions without a very good reason for the children now (Millum, 2014, pp. 528–529). That chain of reasoning could be easily questioned since it seems that the conclusion is already included in the premise (a logical

fallacy). It is impossible to accept the conclusion of the right to an open future without a previous acceptance of the existence and legitimacy of that right. It becomes of great importance, as Millum states, to distinguish between “present and future autonomy” (Millum, 2014, p. 529), since without certain assumptions the latter does not derive from the former.

The objection towards performing mastectomy and surgery that led to infertility belongs to a large cluster of ethical concerns that could be labeled as the violation of bodily integrity (Carlson, Smith, Wilker, 2012, pp. 35–40; Coleman, 2007, pp. 726, 728). Also, growth attenuation treatment has been frequently classified as such (Coleman, 2007, p. 728; Kerruish, 2016, pp. 75, 77). It could be claimed that estrogen therapy that was intended to stop the growing process has violated Ashley’s right to grow and by reducing her height has significantly limited her future possibilities. Thus, it should be considered as harm (Kittay, 2011, pp. 619, 622–623). Even if we agree that this objection is true to some extent, two arguments could be given as a counterbalance. Firstly, it should be noted that Ashley’s case is no exception in pediatric practice and that the bodies of children are often violated while subjected to invasive surgical procedures, not to mention the cases of extreme body violation. Secondly, the harm done by the treatment violating Ashley’s body integrity could be balanced by the benefits of the procedures, namely that they will also enrich her future possibilities. Let us list some of them. Due to her reduced weight and height, her parents and care-providers will be able to carry her around and keep in motion easily, take her outside, expose her to the external world, all of which will contribute to a greater exposure to different sensations and result in expanding the range of experiences she might have. Moreover, as a result of being easy to lift, she can avoid discomfort associated with long immobilization, while the risk of developing pressure ulcers will be highly reduced. Also, it is important to note that the latest reports reveal that growth attenuation treatment has contributed to stopping the progress of spine scoliosis, which if progressed, would inevitably lead to invasive surgery. Ashley would most likely require posterior-only surgery, instrumentation and fusion, which involve considerable incision of the back and the implantation of hooks and rods allowing the correction of the scoliotic segment, control vertebral rotation and maintain normal sagittal alignment. This is associated with the “risk of spinal injury especially during derotation maneuvering” as well as “hook dislodgement and unloading” (Olgun, Yazici, 2013, p. 69). Finally, while it is true that

preventive mastectomy deprived her of some sexual pleasure, at the same time it significantly reduced the risk of developing breast cancer.

Although philosophers offer various definitions of parental rights and obligations and their application range, there has been a general consensus as to parental responsibility for their children's health. Child-centered theories ascribe parents the rights only as a consequence of their responsibilities. Parental responsibilities are considered morally prior to parental rights, as David Archard states "the parental right to rear derives from and is conditional upon the fulfilment of the duty of moral parenthood" (Archard, 2004, p. 152). The extreme account of this concept assumes that parents are obliged to provide as many skills and possibilities to their children as possible and to maximize children's well-being. It might be claimed that in the case of children whose needs go beyond standard ones, and who because of their disease require more care and attention, children's needs and interests should be prior to those of their parents. This opinion has been expressed also in Ashley's case by Dick Sobsey who advocates for "special protections of these universal rights for children with disabilities, calling for measures to ensure the fullest possible »individual development« of children with disabilities" (Sobsey, 2010, p. 59). While we generally agree with this viewpoint, we believe that an extremely maximized version of this rule means accepting the claim that the interests of children, especially with disabilities, should override any interests of their parents. Such a demanding obligation (or sacrifice even) will be, however, difficult to implement since the "fullest" range of possibilities and options may simply appear impossible to provide. We agree with the opinion expressed by Archard that "to require that parents shall do everything they possibly can to promote their child's development and welfare treats them as no more than altruistic paternalists, devoted agents of the good of their offspring" (Archard, 2004, p. 150). Thus, an optimum range of possibilities that parents are obliged to provide will suffice. It should be also noted that in Ashley's case her interests and those of her parents do not stand in conflict, but they intertwine to such an extent that at times they cannot be clearly separated from each other. We shall return to this issue later.

Best interest and balancing benefits against risks and harms

The best-interest criterion has been commonly accepted as the most preferable one in the process of medical surrogate decision-making on behalf of incompetent patients who have left no advance directives or when the surrogate has no knowledge of the patient's life and moral preferences. Some bioethicists argue in favor of this principle even if advance directives are left, and endorse "adoption of a »present best interests« principle mandating systematic assessment of an incompetent patient's contemporaneous interests" (Dresser, 1986, p. 374). In the cases of patients suffering from severe mental retardation whose mental capacities are extremely limited, and moreover, will never be increased, an important question arises, namely, whether they have any interests at all. It could be argued that patients with irreversible brain damage, or severe mental dysfunctions who will never be cured have no interests, as Feinberg says "without awareness, expectation, belief, desire, aim, and purpose, a being can have no interests; without interests, he [a person] cannot be benefited; without the capacity to be a beneficiary, he [a person] can have no rights" (Feinberg, 1980a, p. 177).

Despite the fact that Ashley's mental capacities remain severely compromised and her mental life is extremely poor, we can still argue that patients such as Ashley do have some interests. Yet, they differ significantly from the interests that autonomous and self-aware persons have. In the case of fully competent patients, or even those with limited competency, the notion of interest can include "*desires* and *aims*, both of which presuppose something like *belief*, or cognitive awareness" (Feinberg, 1974, p. 52) since they have capacity to "exercise some measure of control over and take responsibility" for their lives (Brock, 2007, p. 133). Undoubtedly, Ashley has no desires or aims. Ashley's (and Ashley-like patients') interests are unique also in another important aspect. Due to the fact that she has never been competent and had no interests in the past, her interests are concentrated on, and limited to, the present. In Ashley's case it is difficult to say that she has any future interests. Nevertheless, if we take into account the concept of welfare interest that could refer to her overall well-being (Dresser, 1986, p. 384) and the possibility of expanding the range of experiences she might have in the future, they should not simply be put aside or ignored.

In Ashley's case the notion of interest should be tailored to her exceptional existential status. Referring to Ronald Dworkin's concept of

“experiential” and “critical” interests (Dworkin, 1993, pp. 201–208), it could be argued that Ashley, and Ashley-like patients, have experiential, yet not critical interests. Critical interests refer rather to critical judgements than experiences and could be defined as those that make one’s life meaningful and successful, and allow exercising a life-plan, etc. Experiential interests are basically about interests in having desirable experiences, feeling pleasure, joy, and not having undesirable experiences such as pain, suffering, boredom, shame or sadness. It is quite obvious that they are strictly tied to the present. We think that Ashley, and Ashley-like patients, have interests, although they are generally limited to the present and to the experiences they may have. They include having interests in meeting their basic needs and present desires, being fed and avoiding hunger, being warm, having peace, being cared for and being safe, minimizing pain and maximizing pleasure (Kerruish, 2016, pp. 73, 77, 79).

Balancing the benefits and risks/harms a certain medical procedure may cause is an important element of implementing the best-interest principle in the evaluation as to whether the procedure should or not be performed. Since we have already described the expected benefits and potential risks or/and harms of Ashley treatment, we shall be brief here.

The expected benefits of Ashley treatment may include: 1) easier care (transporting, feeding, changing clothes/diapers, etc.); 2) reduced risk of pressure ulcers and infections resulting from permanent immobilization; 3) protection against discomfort associated with large breast size (common in her family) and using straps in the stroller to stabilize her body during any transport; 4) protection against menstrual pain; 5) reduction of cancer risk; 6) the possibility to experience more due to her being carried around easily – simply put she would be exposed to a greater range of experience than if she were permanently immobilized; 7) protection of the axial skeleton and avoidance of spinal surgery resulting from progressing spine scoliosis. After the estrogen therapy finished, the scoliosis still developed, deforming Ashley’s body and causing internal organs relocation. In October 2008 it reached 56 degrees and since then it has remained stable. Stopping further progression of spinal deformation is thought to be the effect of growth attenuation (Ashley’s Parents, 2007, p. 10).

As to the risks and harms that could result from Ashley treatment, they may include: 1) violation of bodily integrity; 2) exposure to stress and temporary pain associated with surgery, hospitalization and estrogen therapy;

3) exposure to postoperative complications and the use of high doses of sex hormones (Gunther, Diekema, 2006, p. 1015).²

Although the overall well-being of Ashley (her physical comfort, being free from pain, her emotional state, all of which are related to the possibility of experiencing and expanding the range of sensations as much as possible) should be of primary concern while making the decision to expose her to a set of invasive and experimental medical procedures, the family situation and the financial aspect should not be ignored. Some bioethics claim that while making surrogate medical decisions for incompetent patients, other, external factors, apart from those related to the patient itself, should be taken into account (Dresser, 1986, pp. 393–404; Singer, 2007). Also, the authors of the report, called *Appleton Consensus* (Stanley, 1989, p. 132), which describes international guidelines on making decisions for incompetent patients who have never been competent, point out several crucial aspects determining medical decision-making in such cases. The authors claim that while assessing the quality of life of incompetent patients, one should not only balance the benefits and risks/costs for the patient, but also carefully examine the interests and burdens of all other people involved in the treatment and care-providing. These may include the interests of the surrogate or family, of the physician and care-givers, of the health care institution, and of society. In Ashley's case, it can be noted that the interests of both the patient and her parents are closely related. This becomes most visible with the example of growth attenuation treatment. Some critics say that the treatment is solely in the interest of Ashley's parents, whose primary motivation was to make things easier for themselves (Coleman, 2007, pp. 722–728; Kerruish, 2016, p. 76; Sobsey, 2007, pp. 1–8; 2010, pp. 59–60). We argue, however, that it is beneficial also for Ashley.

Due to Ashley being smaller and lighter, it is easier for her parents to carry her around and keep in motion, to take care of her basic bodily needs, such as diaper changing, changing her position at night, but at the same time it exposes her to a greater range of sensations from the outer world and reduces discomfort and pain resulting from permanent immobilization. Instead of being transported by means of mechanical equipment, she may be carried, held in someone's arms and cuddled by her parents. The parental

² We list here only those we consider ethically important. For others, see for example: Gunther, Fost, 2010, pp. 30–44.

touch is a vital element of her well-being and feeling safe. This also gives her the chance to experience more sensations and pleasure, as explained above, than if she were tied to her bed. It appears then that the expected benefits of the therapy for parents directly affect the quality of life of the child and *vice versa*. In other words, they intertwine, they are interdependent and quite often inseparable (Kerruish, 2016, pp. 71, 73).

Concluding remarks

After years of ethical debate, Ashley's case still remains controversial. It involves important ethical issues concerning the complexity of performing invasive medical procedures on children and incompetent patients who have never been competent. While any invasive medical procedure in such cases should be carefully evaluated from a medico-moral perspective, in Ashley's case (and Ashley-like patients') the preventive nature of the procedures, their expected effects, the process and elements of surrogate decision-making, the right to an open future as well as balancing benefits and harms should become crucial factors. It becomes undeniable that the procedures Ashley underwent were innovative and highly invasive, however, they also were intended to increase the comfort of her life in the future and minimize the risk of cancer or spine surgery. Being smaller and lighter, she can be carried around easily by her parent, which contributes to her feeling and experiencing more than if she were permanently immobilized and transported by means of mechanical equipment. In fact, the treatment did not limit the range of possibilities in her future life, but rather expanded the range of sensations and experiences she might have. It is also important to note that Ashley treatment is beneficial not only for Ashley, but also for her parents. Ashley and her parents' interests intertwine and are inseparable; therefore we conclude that the treatment was in both parties' interest.

References

- Archard, D. (2004). *Children: Rights and Childhood*. 2nd ed. London–New York: Routledge.
- Ashley’s Parents (2007). *The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels”*. Retrieved from: <http://www.pillowangel.org/> (22.12.2018).
- Beauchamp, T.L., Childress, J.F. (1994). *Principles of Biomedical Ethics*. New York: Oxford University Press.
- Brake, E., Millum, J. (2016). Parenthood and Procreation. In: *The Stanford Encyclopedia of Philosophy*. Retrieved from: <https://plato.stanford.edu/archives/spr2018/entries/parenthood/> (20.04.2019).
- Brighouse, H. (2002). What Rights (if Any) Do Children Have? In: C.M. MacLeod, D. Archard (eds.), *The Moral and Political Status of Children* (pp. 31–52). Oxford: Oxford University Press.
- Brock, D.W. (2005). Shaping Future Children: Parental Rights and Societal Interests. *Journal of Political Philosophy*, 13 (4), 377–398.
- Brock, D.W. (2007). Patient Competence and Surrogate Decision-Making. In: R. Rhodes, L.P. Francis, A. Silvers (eds.), *The Blackwell Guide to Medical Ethics* (pp. 128–142). Malden, MA: Blackwell Publishing.
- Buchanan, A.E., Brock, D.W. (1990). *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge University Press.
- Caplan, A. (2007). *Is Peter Pan Treatment a Moral Choice? Debate over Stunting a Disabled Child’s Growth Pits Comfort against Ethics*. Retrieved from: http://www.nbcnews.com/id/16472931/ns/health-health_care/t/peter-pan-treatment-moral-choice/#.XMmxv9jgqpo (6.03.2019).
- Carlson, D.R., Dorfman, D.A. (2007). *Investigative Report Regarding the “Ashley Treatment”*. Retrieved from: https://www.disabilityrightswa.org/reports/investigative-report-regarding-ashley-treatment/investigativereportregardingtheashleytreatment_may2007/ (2.04.2019).
- Carlson, D., Smith, C., Wilker, N. (2012). *Devaluing People with Disabilities Medical Procedures that Violate Civil Rights*. Retrieved from: <https://www.ndrn.org> (20.04.2019).

- Chen, W., Shieh, C., Swanger, S.A., Tankovic, A., Au, M., McGuire, M., Tagliati, M., Graham, J.M., Madan-Khetarpal, S., Traynelis, S.F., Yuan, H., Pierson, T.M. (2017). GRIN1 Mutation Associated with Intellectual Disability Alters NMDA Receptor Trafficking and Function. *Journal of Human Genetics*, 62 (6), 589–597. DOI:10.1038/jhg.2017.19.
- Clark, P.A., Vasta, L. (2006). The Ashley Treatment: An Ethical Analysis. *Internet Journal of Law, Healthcare, and Ethics*, 5 (1). Retrieved from: <http://ispub.com/IJLHE/5/1/8005> (24.03.2019).
- Coleman, G. (2007). The Irreversible Disabling of a Child: The “Ashley Treatment”. *National Catholic Bioethics Quarterly*, 7 (4), 722–728.
- Davis, D. (1997). Genetic Dilemmas and the Child’s Right to an Open Future. *HastingsCenter Report*, 27 (2), 7–15.
- Davis, D. (2001). *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children’s Futures*. New York: Routledge.
- Diekema, D.S., Fost, N. (2010). Ashley Revisited: A Response to the Critics. *The American Journal of Bioethics*, 10 (1), 30–44. DOI:10.1080/15265160903469336.
- Dresser, R. (1986). Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law. *Arizona Law Review*, 28 (3), 373–405.
- Dworkin, G. (1988). *The Theory and Practice of Autonomy*. New York: Cambridge University Press.
- Dworkin, R. (1993). *Life’s Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. New York: Alfred A. Knopf.
- Feinberg, J. (1974). The Rights of Animals and Unborn Generations. In: W.T. Blackstone (ed.) *Philosophy and Environmental Crisis* (p. 43–68). Athens: University of Georgia Press.
- Feinberg, J. (1980a). *Rights, Justice, and the Bounds of Liberty: Essays in Social Philosophy*. Princeton: Princeton University Press.
- Feinberg, J. (1980b). The Child’s Right to an Open Future. In: W. Aiken, H. LaFollette (eds.), *Whose Child? Children’s Rights, Parental Authority, and State Power* (pp. 124–153). Totowa, NJ: Rowman & Littlefield.
- Feinberg, J. (1986). *The Moral Limits of the Criminal Law: Harm to Self*. New York–Oxford: Oxford University Press.

- Feinberg, J. (1992). *Freedom and Fulfillment: Philosophical Essays*. Princeton: Princeton University Press.
- Gilbert, S. (2009). Children's Bodies, Parents' Choices. *Hastings Centre Report*, 39 (1), 14–15.
- Gillam, L.H., Hewitt, J.K., Warne, G.L. (2010). Ethical Principles for the Management of Infants with Disorders of Sex Development. *Hormone Research in Paediatrics*, 74 (6), 412–418. DOI:10.1159/000316940.
- Golden, G.S. (1987). *Textbook of Pediatric Neurology*. New York: Plenum Publishing Corporation.
- Gunther, D.F., Diekema, D.S. (2006). Attenuating Growth in Children with Profound Developmental Disability. *Archives of Pediatrics & Adolescent Medicine*, 160 (10), 1013–1017. DOI:10.1001/archpedi.160.10.1013.
- Harnacke, C. (2016). The Ashley Treatment: Improving Quality of Life or Infringing Dignity and Rights? *Bioethics*, 30 (3), 141–150.
- Javed, A., Lteif, A. (2013). Development of the Human Breast. *Seminars in Plastic Surgery*, 27 (1), 9–10. DOI: <http://dx.doi.org/10.1055/s-0033-1343989>.
- Jaworska, A., Tannenbaum, J. (2014). Person-Rearing Relationships as a Key to Higher Moral Status. *Ethics*, 124 (2), 242–271.
- Jonsen, A.R., Siegler, M., Winslade, W.J. (2010). *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 7th ed. United States: McGraw Hill Medical.
- Katz, A.L., Webb, S.A. (2016). Informed Consent in Decision-Making in Pediatric Practice. *Pediatrics*, 138 (2), e1–e16. DOI:10.1542/peds.2016-1485.
- Kerruish, N. (2016). Growth Attenuation Therapy. *Cambridge Quarterly of Healthcare Ethics*, 25 (1), 70–83. DOI:10.1017/s0963180115000304.
- Kittay, E.F. (2011). Forever Small: The Strange Case of Ashley X. *Hypatia*, 26 (3), 610–631.
- Kohrman, A., Clayton, E.W., Frader, J.E., Grodin, M.A., Moseley, K.L., Porter, I.H., Wagner, V.M. (1995). Informed Consent, Parental Permission, and Assent in Pediatric Practice. *Pediatrics*, 95 (2), 314–317.
- Kopelman, L. (2007). Using the Best Interests Standard to Decide Whether to Test Children for Untreatable, Late-Onset Genetic Diseases. *Journal of Medicine and Philosophy*, 32 (4), 375–94.

- Liao, S.M., Savulescu, J., Sheehan, M. (2007). The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making. *Hastings Center Report*, 37 (2), 16–20.
- Mackenzie, K. (2015). Autonomy. In: J.D. Arras, E. Fenton, R. Kukla (eds.), *The Routledge Companion to Bioethics* (pp. 277–271). New York: Routledge.
- Millum, J. (2014). The Foundation of the Child’s Right to an Open Future. *Journal of Social Philosophy*, 45 (4), 522–538. DOI:10.1111/josp.12076.
- Mullin, A. (2015). Children, Parents, and Responsibility for Children’s Health. In: J.D. Arras, E. Fenton, R. Kukla (eds.), *The Routledge Companion to Bioethics* (pp. 381–392). New York: Routledge.
- Newsom, R.W. (2007). Seattle Syndrome: Comments on the Reaction to Ashley X. *Nursing Philosophy*, 8 (4), 291–294.
- Nunes, R. (2001). Ethical Dimension of Paediatric Cochlear Implantation. *Theoretical Medicine and Bioethics*, 22 (4), 337–349.
- O’Neill, O. (2002). *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press.
- Olgun, Z.D., Yazici, M. (2013). Posterior Instrumentation and Fusion. *Journal of Children’s Orthopaedics*, 7 (1), 69–76. DOI:10.1007/s11832-012-0456-5.
- Ouellette, A. (2010). Shaping Parental Authority over Children’s Bodies. *Indiana Law Journal*, 85, 956–1001.
- Partsch, C.J., Sippel, W.G. (2001). Pathogenesis and Epidemiology of Precocious Puberty. Effects of Exogenous Oestrogens. *Human Reproduction Update*, 7 (3), 292–302. DOI:10.1093/humupd/7.3.292.
- Picard, A. (2007). It’s Wrong to Keep Disabled Girl as an ‘Angel’. Retrieved from: <https://www.theglobeandmail.com/life/its-wrong-to-keep-disabled-girl-as-an-angel/article20391949/> (19.04.2019).
- Prusak, B.G. (2013). *Parental Obligations and Bioethics: The Duties of a Creator*. New York: Routledge.
- Rawls, J. (1971, reprint 2005). *A Theory of Justice*. Cambridge, MA: Harvard University Press.
- Rosendaal, F.R., Helmerhorst, F.M., Vandenbroucke, J.P. (2002). Female Hormones and Thrombosis. Arteriosclerosis, Thrombosis, and Vascular Biology. *The American Journal of Heart Association*, 22 (2), 201–210. DOI:10.1161/hq0202.102318.

- Shim, K.S. (2015). Pubertal Growth and Epiphyseal Fusion. *Annals of Pediatric Endocrinology & Metabolism*, 20, 8–12. DOI: dx.doi.org/10.6065/apem.2015.20.1.8.
- Siddiqi, S.U., Van Dyke, D.C., Donohoue, P., McBrien, D.M. (1999). Premature Sexual Development in Individuals with Neurodevelopmental Disabilities. *Developmental Medicine & Child Neurology*, 41 (6), 392–395. DOI:10.1111/j.1469-8749.1999.tb00624.x.
- Singer, P. (2007). *A Convenient Truth*. Retrieved from: <https://www.nytimes.com/2007/01/26/opinion/26singer.html> (18.03.2019).
- Singh, D., Sanyal, S., Chattopadhyay, N. (2010). The Role of Estrogen in Bone Growth and Formation: Changes at Puberty. *Cell Health and Cytoskeleton*, 3, 1–12. DOI:10.2147/chc.s8916.
- Sobsey, D. (2007). Growth Attenuation and the Indirect Benefit Rationale. *Ethics and Intellectual Disability*, 10 (1), 1–8.
- Sobsey, D. (2010). Ethics or Advocacy? *The American Journal of Bioethics*, 10 (1), 59–60. DOI:10.1080/15265160903460962.
- Spriggs, M., Savulescu, J. (2006). The Ethics of Surgically Assigning Sex for Intersex Children. In: D. Benatar (ed.), *Cutting to the Core: Exploring the Ethics of Contested Surgeries* (pp. 79–96). Maryland: Rowman & Littlefield Publishers.
- Stanley, J.M. (1989). The Appleton Consensus: Suggested International Guidelines for Decisions to Forego Medical Treatment. *Journal of Medical Ethics*, 15 (3), 129–136. DOI:10.1136/jme.15.3.129.
- Torpy, J.M. (2004). Hysterectomy. *The Journal of the American Medical Association*, 291 (12), 1526.
- Wrigley, R., Kerruish, N., Hofman, P.L., Jefferies, C., Pollock, A.J., Wheeler, B.J. (2017). Growth Attenuation Therapy for Children with Severe Physical and Cognitive Disability: Practice and Perspectives of New Zealand Paediatricians. *Journal of Paediatrics and Child Health*, 53 (12), 1180–1185. DOI:10.1111/jpc.13629.

Abstract

In our paper we present and analyze the case of Ashley X as well as the treatment she underwent as an example of invasive medical procedures performed on children. The case still remains controversial, and the treatment consisting of growth attenuation, hysterectomy, appendectomy and breast buds removal has both its opponents and proponents. In our paper we have a closer look at some arguments important for ethical analysis of Ashley's case and treatment. First, for a better understanding of the case we present her medical condition. Secondly, we refer to the classification of therapeutic versus non-therapeutic medical procedures. Thirdly, we examine the issue of surrogate decisions for incompetent patients. Finally, we analyze two vital ethical arguments: a) the right to the open future and b) the criterion of best-interest.