JAHR | Vol. 10/1 | No. 19 | 2019

Preliminary Communication / Prethodno priopćenje
Received / Zaprimljen: 15. 2. 2019.
https://doi.org/10.21860/j.10.1.9

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Children's Autonomy in Medical Decision-Making

SUMMARY

Should children be allowed to express their opinion in regards to medical treatment or experiment? In the past, the practice seemed to assume that children are not matured enough to make decision affecting their well-being, their guardians therefore are given the power to decide for them. In this article the author will argue that this practice should be changed and children should be allowed to get involved. The author quoted findings of Grootens-Wiegers P., Hein I. M., van den Broek J. M. and de Vires M. C. in regards to children's ability from developmental and neuroscientific aspects that children actually start knowing their like, dislike, good and bad… from a very young age. Though these processes are gradual, the finding tells us that children are not as immature as we used to think. The author thus argues that children's autonomy must be respected in some way when medical decision is to be made. At least, they must be told what options are available and seek their opinion.

Keywords: children's autonomy, decision-making, educational psychology.

Introduction

Can children make decisions on their own regarding their health care or participation in clinical trial? The common understanding is that children do not quite know what is good for them, because they are not mature enough, therefore the decision relating their health care or participation in clinical trial needs the consent of their parent or guardians.

Educational psychologist, however, suggested that we must let children develop their own decision-making ability as early as possible, because that will help them mature and also become responsible citizens as they grow: "Childhood is a time of increasing independence. As children grow and develop they become more able to do things for

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themselves, to express themselves and to explore their world independently" said Dr. Sue Grossman, an education professor of University of Eastern Michigan[1].

In modern medical ethics, autonomy has been regarded as one of the four principles that we must respect in any human medical procedures. If this principle is universally valid, children should be allowed to make decision related to their wellbeing as long as they comprehend the procedures and effects. The "father knows better" approach in traditional family has been questioned since children in modern time mature much faster than we usually recognize. Recently, various international laws and guidelines took note of this reality and accentuate the importance of respecting the early-maturing-autonomy of children regarding their medical treatments and research participations. For instances, the American Academy of Pediatrics (AAP) supports individualized decision-making about life-sustaining medical treatment for all children regardless of age[2]. The new law in Victoria, Australia requires physicians to honor advanced directives written by children from March, 2018[3], and the Article 12 of the UN Convention on the Rights of the Child states that "Children shall be provided with the opportunity to be heard in any judicial or administrative proceedings affecting the child directly"[4].

Encouraging children's autonomy

Sue Grossman described that a class interaction that allowed children to choose and play as they like has the following positive results: a feeling of control, building self-esteem, cognitive development, moral development, accepting responsibility, minimizing conflict, maximizing learning…etc., if we encourage children to choose and make decision about daily activity to benefit their life development, why should we deny and deprive them their right to express themselves in the matter relating to their health care?

Prof. Grossman concluded in her remark: "The wise teacher understands that children make choices all day long, whether adults want them to or not. They choose to obey, ignore, or defy rules and directions and determine for themselves whether to speak kindly or angrily to others. They decide whether school or child care is a good

1 Grossman S: Offering Children Choices: Encouraging Autonomy and Learning While Minimizing Conflicts in *Early childhood NEWS* -- The Professional Resource for Teachers and Parents. www.earlychildhoodnews.com/earlychildhood/article_view.aspx?ArticleID=607

2 American Academy of Pediatrics. Committee on Bioethics, Guidelines on forgoing life-sustaining medical treatment. Pediatrics: 1994:106(5): 1151-3.

3 Bioethics Today, Nov 16, 2017 posted by Cassandra Rivais, J. D., MS on Enhancing pediatric decision-making: Australian Law allows children to complete advanced directives. www.amc.edu

4 UNICEF. Convention on the Rights of the Child. United Nations. Treaty Series 1577.3 1989.

place to be. Our task is to provide children with appropriate, healthful options and help them to make and accept their choices. In this way, we are developing confident, independent children who feel in control of themselves"[5].

On the webpage of Australian Government Department of Education, Employment, and Workplace Relations (DEEWR) (2009) is stated that 'Children develop their emerging autonomy, inter-dependence, resilience and sense of agency', responsibility confidence. If we want children to reach these outcomes, we need to provide them with opportunities to develop and to explore their world, to ask questions and to express ideas[6].

1. How the World deals with the minors in terms of their autonomous decision-making?
   Independence contributes to the development of self-esteem, identity, and wellbeing. Doing something for yourself produces a powerful sense of achievement and success. The world is indeed moving toward this respect of children's autonomy, for instance, Grootens-Wiegers, and Hein et al indicated in their paper published in BMC Pediatrics, 2017, 17:120 that in Holland children from the age of 16 may take treatment independently and children from the age of 12 are allowed to give informed consent for research participation[7].
   In the USA a minimum of 7 years of age is defined for asking assent as opposed to legal consent from children[8]. In Taiwan, a common practice involving children older than 7 in clinical trial needs the PI to add consent form written in Tsuyin system that they learn in kindergarten and grade 1 and 2 of how to read. They should also co-sign the consent form in addition to their guardians.
2. The opinion of scientific study on children's decision-making capacity such as neuroscience, developmental psychology, ethics:
   The recent findings of the studies of neuroscience, psychology and bioethics have argued that children in modern time have developed faster than the previous centuries, thus their maturity and capability to make decision cannot use the outdated standard to judge from. Weithorn and Campbell have found in their studies that "children as young as 9 years old have the capacity to make

5 Sue Gross. Childhood News, 2008. http://www.earlychildhoodnews.com/earlychildhood/article_view.aspx?ArticleID=607] (accessed: 15 December 2018).

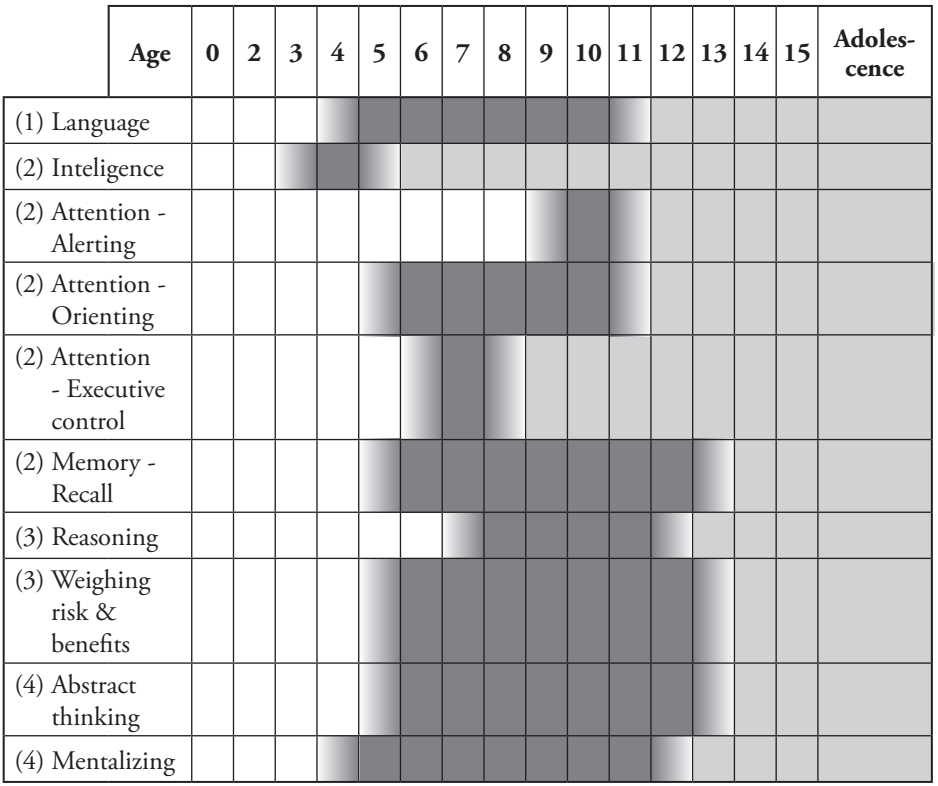
6 Australian Government Department of Education, Employment and Workplace Relations (DEEWR) (2009). Belonging, Being & Becoming: The Early Years Learning Framework for Australia. DEEWR: Canberra. ACECQA (2011). Guide to the National Quality Standard. ACECQA: Canberra.

7 http://bmcmedethics.biomedcentral.com.

8 Children's Assent - National Cancer Institute: children's assent to clinical trial participation 2005. www.cancer.gov/about-cancer/treatment/clinical-trials/patient-safety/childrens-assent.

informed choice"[9]. Mann and Harmoni concluded that children at age 14 or 15 are as competent as adult[10]. Hein and Troost demonstrated that children older than 11.2 years may be competent to consent to clinical research[11].

An article on Medical decision-making in children and adolescents: developmental and neuroscientific aspects published online on May 8, 2017 has this interesting observation: children as young as the age 4 have their intelligence being developed and continue till their adulthood. Memory, the ability to recall, can already be seen at the age of 6[12]. My own personal experience tells me that the earliest event I could recall took place when I was between 4 and 5 years of age and those events are still remembered even today. This personal experience shows that the ability to recall



9 Weithron L. A., Campbell S. B.: The Competence of children and adolescents to make informed treatment decision. Child Dev. 1982:53:1587-98.

10 Mann L., Harmoni R., Power C. Adolescent decision-making: the development of competence. J. Adolesc. 1989;12: 265-8.

11 Hein I. M., Troost P. W., Lindeboom R. Accuracy of MacArthur Competence Assessment Tool for measuring children's competence to consent to clinical research. JAMA Pediatr. 2014;129168]:1147-53.

12 Petronelta Grootens-Wiegers, Hein I. M., van den Broek J. M. and de Vires M. C. Medical decision-making in children and adolescents: developmental and neuroscientific aspects; BMC Pediatrics. 2017;17:120. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5422908/.

actually developed a little earlier than this article has stated. Reasoning develops at the age of 8. Abstract thinking starts at the age of 6. Let me quote the chart that the authors of this article provided[13]:

The chart (quoted from Wiegers and Hein...et al) illustrates that children begin to develop their understanding and ability from as young as the age five or six and continue till their adolescence and beyond.

What can be the signs that a child of a certain age is sufficiently competent?

In medical practice there is no clear-cut point whether a child of a certain age is regarded as capable of making decision. In MacArthur Competence Assessment Tool, Appelbaumn P. S., and Grisso T. have argued that a certain level of competence is required for medical decision-making and listed four standards: expressing a choice, understanding, reasoning, and appreciation.[14]

- Expressing a choice: this refers to the ability to express a choice. This implies that someone can communicate a preference of treatment or research participation. The required neurological skill is being able to communicate. From the age of 5, children have reasonable understanding of language continuing to the age of 9 and throughout adolescence.
- Understanding: this is about the ability to understand the information in regards to the proposed medical treatment or research and to comprehend the fact that a choice needs to be made. The authors have indicated that maturity in orientation and in attention develops around the ages of 7-10 and then goes on to slightly increase during adolescence. Children at the age of 10-12 appear to have similar recall abilities compared to adults.
- Reasoning: this pinpoints to the ability to reason about risks, benefits and possible consequences of the proposed treatment or research options. This moves a step further from factual understanding. Children at the age of 6 to 8 already demonstrate the ability for logical reasoning. Risk identification develops strongly between the ages of 6 and 10.

13 Petronelta Grootens-Wiegers, Hein I. M., van den Broek J. M. and de Vires M. C. Medical decision-making in children and adolescents: developmental and neuroscientific aspects; BMC Pediatrics. 2017;17:120. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5422908/.

14 Appelbaum P. S., Grisso T. The MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) Sarasota: Professional Resource Press; 2001.

- Appreciation: the appreciation of nature of a situation implies that someone will not only understand the various options, but also the relevance of these options for the personal situation. Between the age of 3 and 4, children already start to recognize their own beliefs and desires that contribute to the development of personal norms and values.

These standards may give impression that children are actually still in developing stage not mature enough to acquire fully developed abilities, but the authors found that children actually acquire these abilities already in early age though these abilities continue to develop.

A reminder and a case: Elsa's story

One thing we must keep in mind that humankind, including adults and children, has the tendency that at one time we demonstrate sufficient competence for decision-making in a certain situation, and can also lack the adequate competence in another. Children who have shown to be reasonable conversation-partners during their treatment can temporarily become noncompliant in adolescence. Wiegers and Hein shared a story about Elsa: "Elsa is a 16-year-old adolescent who was diagnosed with diabetes type I at the age of 4. The first year after the diagnosis, her parents did all the diabetes care. The insulin pump Elsa was wearing had a safety lock to prevent accidental use. Elsa was able to express how she felt and when she was 7 she was able to measure her blood sugar. At 8, she could instruct the pump to give the insulin dose needed during the meals. At 10, Elsa showed profound insight in how to adjust her insulin pump setting. She was so well informed and experienced to take care of herself. Then she went to secondary school at 12, things started changing. She did not tell her friends of her diabetes and even tried to deny her condition at school and often took off the pump such as during physical exercise at school. Elsa was a very friendly person showing remorse and promising improvement. At age 14, she had to be admitted to ICU due to severe dysregulation of her diabetes. At 16 the same thing happened after drinking large amount of alcohol …"[15]

What can we learn from this case? This story tells us that children as they grow even from a very young age know their needs and desires and can make a choice. Children can be autonomous like adults perhaps from the age of 10 or 12, depending on their mental development. The situation however, can have an impact on them (as well as

15 Petronelta Grootens-Wiegers, Hein I. M., van den Broek J. M. and de Vires M. C. Medical decision-making in children and adolescents: developmental and neuroscientific aspects; BMC Pediatrics. 2017;17:120 https://bmcpediatr.biomedcentral.com/articles/10.1186/s12887-017-0869-x.

on any adult) as what happened to Elsa when she started the secondary school – the peer pressure, the self-image, the need to socially and emotionally belong.

Children are capable of being autonomous, depending on different individuals. But they, as well as adults, need support and counsel when the situation changes. This proves that children need to be given education and support to exercise autonomy depending on the situation at times.

Elsa's story reminds us that everyone, including adults, has their vulnerability and weak points in life, but children's autonomy should still be sought and respected depending on their mental, emotional and social developments. When required, counsel must be given regardless of children or adults.

A game to determine whether a child reaches autonomous capacity to make a decision.

I would like to share four standards trial for consideration. These four standards are as aforementioned: expressing a choice, understanding, reasoning, appreciation.

This trial is like this: questions are asked and evaluated for each of the decision-making capacity standards. Each standard is awarded 25 points from the evaluation. Any child who scores above 80 points is regarded as competent, 60 as conditional, below 60 indicates that parental proxy/guidance is necessary.

Sample questions: Each standard can have 5 questions with each worthy 5 points: If the answer is quick and definite, 5 points are given; when participant hesitates, 3 points; turning to parent for guidance, 1 point:

- Expressing a choice: do you prefer to have a shot or to take a drug? If taking a shot, the medicine will immediately start to work, but you will feel a slight tingling pain. If you can swallow the drug, no pain is felt and that can also help you. What do you prefer?
- Understanding: The drug you will take tastes bitter, would you take it or not and why? Another question is like this: Would you go outside to play when the storm is sweeping and why?
- Reasoning: If you cross the street when the red light is on, you may be hit by the coming car. You are in a hurry, but the red light just appears, would you go across and why?
- Appreciation: You need to ask your father for a favor, but he has just had a fight with your mom and is very upset, what would you do?

Conclusion

Autonomy is one of the most important principles of medical ethics. Do we grant this right to children under the legally recognized adult age? If no, this right is not universally valid. People will argue that we usually use the best interest standard for decision-making in children because they are presumed to lack the capacity to discern. But as children get older and acquire cognitive skills, and experience emotional maturity, their individual views deserve our attention even though they are still regarded as children for being under the legal adulthood.

In a human research experiment involving children, parents are approached for consent but more and more countries will require children to express their assent and co-sign the ICF before the experiment is approved to go ahead.

For a good bioethics, children must be involved and their opinions heard in medical treatment or experiment: "Our self-education…already has made considerable progress, but we have to go further, so that the guiding rule for our action may be the bio-ethical demand: Respect every living being on principle as an end in itself and treat it, if possible, as such"[16].

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Autonomija djece u donošenju medicinskih odluka

SAŽETAK

Treba li djeci dozvoliti da izraze svoje mišljenje o liječenju ili sudjelovanju u kliničkom ispitivanju? U prošlosti se pretpostavljalo da djeca nisu dovoljno zrela da donose odluke koje utječu na njihovu dobrobit, stoga se skrbnicima davala moć odlučivanja umjesto njih. Autor će tvrditi da bi se ta praksa trebala promijeniti i da bi djeci trebalo omogućiti da se uključe. Autor navodi P. Grootens-Wiegersova, I. M. Heinova, J. M. van den Broekova i M. C. de Viresova istraživanja u pogledu sposobnosti djece, od razvojnih i neuroznanstvenih aspekata da djeca zapravo počinju spoznavati ono što im se sviđa ili ne sviđa, dobro i loše... od vrlo rane dobi. Iako su ti procesi postepeni, istraživanje nam govori da djeca nisu tako nezrela kao što smo prije mislili. Autor, stoga, tvrdi da se dječja autonomija mora na neki način poštovati kada se donosi medicinska odluka. Barem im se mora reći koje su opcije dostupne i tražiti njihovo mišljenje.

Ključne riječi: autonomija djece, donošenje odluka, obrazovna psihologija.