Ethical Case Commentaries

"Your time is up." Timing conflicts in transitional healthcare

Elena Nave[a,b], Matteo Cresti[c], Elisabetta Bignamini[a]

a Division of Pediatric Pulmonology, Regina Margherita Children's Hospital, A.O.U. Città della Salute e della Scienza di Torino, Italy
b Department of Life Sciences and Systems Biology, Turin University, Italy
c Department of Philosophy and Education Science, Turin University, Italy

Abstract

The objective of this clinical case commentary is to illustrate a specific limit in the timing of transition from pediatric to adult medicine in the healthcare context of severe, multiple disabilities. The discussed case regards a girl who suffers from permanent disability, whose pediatric care team has decided not to transition to an adult healthcare setting. A thorough analysis of the reasons justifying the pediatric team's choice underlines the fact that in this case (and similar cases as far as the clinical condition of patients is concerned), transition is not in the best interest of the patient because the conditions for transition are not met.

Conceptual and contextual premise

Clinicians specialized in pediatrics have to spend their caring time differently compared to their colleagues of other branches, mostly due to the peculiar status of their young patients. For example, this particularity is evident in two cases regarding decision-making: when the child is old enough to participate in choices regarding herself but not quite enough to express legally valid informed consent, or when the patient, because of the limits due to her medical condition or age, cannot be involved.

In the first case, clinicians should inform both the patient and her legal representatives (parents or guardians) in various manners, sometimes simultaneously, sometimes not. In the second scenario, physicians must communicate only with the child's legal representatives in order to obtain consent for treatment, in accordance with local legislation. However, in this last case, the moral consideration that clinicians need to keep in mind is that of including siblings and family members who have an emotional involvement in the decision-making process.

In fact, two different approaches to cure assessment coexist in the pediatric healthcare setting: patient-centered and family-centered [1–3]. Each of them is applied according to the contextual conditions that characterize each single case. The organizational model that we would implement here is a network model which contemplates cooperation between specialized centers, local institutions (health, social welfare and education) and local third sector associations. This model offers the possibility of "globally taking care of the patient" as it answers not only to the child's multiple needs (physical, psychological, social and ethical), but also to those of her siblings, parents, and sometimes even grandparents.

In this instance there are many different individual timeframes to be considered, overlapping and intersecting in the healthcare of minors, and each person involved in the decision-making process has their own particular one. Moreover, these timeframes frequently do not coincide, and their demands do not converge.

In the pediatric setting, it is possible to notice how differently children grow up and gain the competence to make choices. Some individuals are ahead of their time due to the chronic condition that afflicts them since birth, and they become precociously mature. Others, also due to the contextual conditions they are dealing with, struggle to become effectively competent and come of age while still incapable of making meaningful choices concerning their body and their own healthcare [4–6]. Others yet, permanently unaware, remain in a condition of complete dependence, incapable of expressing their will and perceptions, if not those relating to painful stimuli. As eternal infants, they can survive only through caregivers' choices and round the clock assistance.

In some cases the illness still allows decision-making abilities and moral autonomy to progressively unfold, enabling the patient to become a competent child. These skills nonetheless [7] require time and exercise in order to develop. This development depends on unavoidable subjective variability and, as far as the development of a child's competence is concerned, "contingencies such as experience and ability can be more salient than age" [8]. In any case, as we have already seen, the consideration of these aspects of development – moral autonomy and decision-making capacity – seems scarce and underestimated in transitional healthcare programs [9].

With this ethical case commentary we would like to point out another specific, critical aspect of transition healthcare programs for pediatric patients.

Currently, the institutional and bureaucratic organization of transition sometimes establishes a predetermined and unified time for the transition of pediatric patients to adult medicine. It usually begins in adolescence and continues in adult care settings when the patient has become a young adult.

This shift is standardized, it concerns all pediatric patients suffering from chronic or complex illnesses who are taken into care from the pediatric healthcare system, and it is planned and programmed independently of patients' and caregivers' actual needs, expectations and wishes [10, 11].

The understated problem is that in some cases the process of progressing awareness and growth of pediatric patients cannot occur. In some cases, the disease does not allow this process of change. Nothing has changed in the individual, not body size, not cognitive ability nor communication skills. There are illnesses and shattering injuries which cause severe intellectual disability, interrupting physical growth and producing permanent, severe and complex healthcare needs. In these cases the clinical itinerary is often characterized by acute events, forcing parents or guardians to face rapid deadlines and quick decisions.

In this analysis we want to consider a critical, challenging aspect of the transition process to adult care for a pediatric patient (whose initials are B.C.). She arrived at the Pneumology division because of an episode of acute respiratory distress related to her complex clinical condition.

Clinical case

B.C. is the second of two children, and she is the only sibling affected by a complex disease. She was born by a physiological pregnancy which ended with natural birth; at the age of 4 days she suffered a cardiac shock, which led to a diagnosis of complex heart disease. Following the consequent cardiac surgery, the patient suffered severe hypoxic-ischemic neurological complications (spastic tetraplegia and epileptogenic encephalopathy).

Therefore, her clinical condition not only poses a serious threat to her own survival, but also prevents her from developing the ability to attend to her own basic physiological needs; more so, it has affected her intellectual development and her perception of reality, which appear to be seriously impaired considering her chronological age.

B.C. had been repeatedly treated for several respiratory diseases and developed chronic respiratory failure that required long-term oxygen therapy. She has severe scoliosis, leading to severe posture problems and preventing her from sleeping without specific drugs and assistance. The patient's lack of sleep has a substantial and direct effect also on her mother's quality of life, who is her principal (if not only) caregiver. In fact, her father delegates the main responsibilities of the child's care to her mother and, substantially, the entirety of the burden of assistance. Her mother is instead reluctant to delegate B.C.'s assistance since she believes to be the only person able to guarantee the best possible care.

From a nutritional point of view she presents all the features of severe malnutrition; her past videofluorography (VFG) highlighted episodes of real tracheal aspiration of a pre/per deglutitory type (in B.C. the cough reflex is absent). This problem causes recurrent episodes of aspiration pneumonia.

B.C. lacks verbal communication skills and basic physical mobility, as she is not able to communicate verbally or through aids. According to her mother she can perceive pain and malaise which she expresses through crying, muscle stiffness, and tremor.

The first time we met her and her family, B.C. was 17 years and 7 months old. She arrived to our attention for a respiratory exacerbation, after an experience of transition to adult care which her cardiologist had promoted based on her age. Since a transition plan had not been devised to ensure the continuity and appropriateness of healthcare or of social support, her mother decided to return to the pediatric hospital looking for B.C.'s cardiologist to help with the present exacerbation.

The adult team pulmonologist who visited B.C. the day before her admission wrote that "no pulmonological complications were detected, but only problems related to her respiratory secretions".

At admission B.C. weighed 21 kg and has had continuous problems with her respiratory secretions. We started nutrition via nasogastric intubation (NGT) and discussed the possibility of percutaneous endoscopic gastrostomy (PEG). Her mother was very frightened at the idea that B.C. could not survive PEG surgery, so it took her a long time to decide to go through with the operation (almost three months).

Meanwhile, considering B.C.'s clinical status and the will of her parents, our staff decided to continue the follow-up in the context of the pediatric setting.

Ethical Comment

The case of B.C. is an example of an occasion in which the transition to adult medicine did not realize the best interest of the patient.

The primary purposes of transitional healthcare in the pediatric field have been thoroughly laid down in the literature [12–15]. For the most part, it has been designed to facilitate the transition of pediatric patients suffering from chronic illness both towards maturity and towards the healthcare system dedicated to adults [11].

Cystic Fibrosis is an excellent example in which transition healthcare is useful and effective [15, 16]. Indeed, in the past years it was exclusively considered a childhood disease because patients frequently did not survive long enough to reach adulthood, but scientific and technical progress has increased survival rates, bringing forth the development and expression of new adult-specific needs (self-determination, learning a profession, economic self-sufficiency, the exercise of sexuality, choices pertaining to responsible reproduction, urological-urinary discomfort, choices regarding drinking, smoking or enacting risky health behaviours, and so on) [17, 18].

When it comes to transitioning, patients are encouraged to move towards adult care also because most of the members of the clinical-care staff either cannot legally intervene on the body of adults or are not adequately trained to effectively satisfy their needs, nor does the pediatric setting foster the expression of their new health necessities. In the case of chronic conditions that do not severely compromise the development of intellectual and physical functions, it is in the patient's best interest to favor her own transition towards adult medicine, and it is consistent with a patient-centered approach to healthcare. Indeed, in this setting, the transition allows for better healthcare treatment and allows self-representation of the patient as an adult, as an autonomous and independent person.

The presence of severe multiple disabilities calls into question the possibility that transition to adult medicine, in some cases, is not indicated at all.

Patients with these problematic and incurable disorders do not go through the usual milestones that lead to adulthood: they cannot exercise any form of personal autonomy, their bodies do not grow and their abilities do not evolve. Their health is characterized by a delicate and precarious balance that it is not easy to understand and control, and tends to vary from one patient to another.

The cultural, social and familial environment plays a crucial role in the development of every child and is even more important for a child with disability [19, 20]. It can extend or reduce the functioning of children, improve or reduce their quality of life and contribute to giving a meaning to the existence of their impaired condition. Parents' involvement is crucial in a child's environment. Extensive literature has rigorously documented the average living conditions of these children's parents [21–23]. The mother is mainly reported as the principal caregiver and it is the continuous struggle of the family that literally allows the survival of these patients at their homes.

In B.C.'s case there is a clear conflict between the needs of the patient and her caregivers/family on one side, and the needs of the institutions on the other. In fact, the family asks that the pediatric center continue to take care of the child because of the human relationships already established, the expertise of the clinicians, and their knowledge of the condition of the patient.

Since the clinical condition of the patient does not meet the criteria for an effective transition, the requisites necessary in order to transition to adult medicine are not respected. As already remarked, patients like B.C. do not acquire those characteristics for which the transitional programs have been designed: in fact, there will be no change in her perceptive, cognitive, psychological and social state. She will never become competent, develop the need for independence from her parents, nor will her conditions ever require a specialist in adult diseases. This clinical case, therefore, suggests that patients in similar health conditions generally do not need a transition to adult medicine. Moreover, the analysis of this case highlights the problem that a rigid organization of transitional health does not meet patients' and caregivers' needs.

The transition of patients with severe disabilities represents an extraordinarily delicate and challenging circumstance for them and their parents. The transition implies the need to carry out certain bureaucratic procedures, the need to rely on new specialists and to attend unknown health facilities.

Within the pediatric context, parents of children with severe disabilities find competent interlocutors who are especially skilled in becoming the parents' co-partners in the management of their children's conditions.[1] Pediatric care is calibrated to meet the specific needs of children, their family and their caregivers. It has long been known that children are not tiny adults [24], thus the specialization of pediatric sciences is based on the clinical and physiological parameters of those who go through infancy, childhood, and adolescence. According to us, children like B.C. permanently remain in the condition of infancy.

The transition is justified when the model of pediatric care, with all its specificities, no longer represents the adequate answer to the patient's needs. The transition is not justified when the patient maintains her physical pediatric characteristics [25].

In B.C.'s case the achievement of the chronological threshold of adulthood does not bring forth new meanings, needs or changes. According to a family-centered and patient-centered care approach, no transition would be in her best interest. The pediatric staff is the most qualified to follow her because her body has remained the specific one studied by pediatricians, and the whole system of pediatric care is organized to support her parents in decision-making processes, in in-home health assistance and in psychological and social needs. In cases like this, reasons to justify transition are not found.

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[1] Certainly, another way to face the problem could be to train adult physicians to be able to communicate with these patients, their families, and other people involved. This solution brings benefits to clinical practice because it makes physicians more communicative. Nevertheless, it faces problems of effectiveness, namely that adult physicians will face a small amount of these severely disabled patients, and it implicates a high cost with few benefits. These patients, like B.C., remain "children" (both physically and mentally) as long as their entire life, and for this reason they should be treated by pediatricians; also, this solution may be better from a resource-allocation point of view. These few patients can continue to be treated by pediatricians, instead of investing resources to train adult physicians which involves the use of resources that could be spent more effectively.

Conclusion

In this commentary we discussed the case of a girl who is now 18 years old, an age that would require her a transition to adult medicine. She has a complex disease, cardiac and respiratory problems, as well as neurological impairment. These problems result in a condition of severe multiple disability and total dependence on caregivers. Although health institution bureaucracy imposes a transition to adult medicine, this transition is not morally justified. There are two central and acclaimed reasons to transition from pediatrics to adult medicine: first of all, the expertise of physicians specialized in adult medicine allows for greater effectiveness in caring for patients who are no longer infants; secondly, the successful completion of the development of patients' moral autonomy allows them to make competent decisions regarding their own health in an adult healthcare setting. However, in this case, these conditions do not occur.

The patient's physical condition is more similar to that of a child, as she weighs only 21 kg and has severe neurodevelopmental impairment. In this case an effective transition to adult medicine was not possible, not only because of the severity of B.C.'s clinical status which hinders her from reaching desired healthcare transition outcomes [26], but also because of the lack of understanding of her family's challenges (emotional, behavioral, social and spiritual) associated with transition. Moreover, B.C.'s short life expectancy calls into question the usefulness of supporting the effective implementation of a transition plan to adult medicine in this specific case.

The best interest of such patients it to remain in pediatrics structures, where they can receive proper treatment and where clinicians are trained to interact with patients who are not (or not yet) fully competent, interfacing with different subjects: both the patients and their parents or guardians.

In this case and similar ones we suggest that transition should not occur. The bureaucratic system in countries imposing transition only based on age criterion should be modified in order to allow parents and patients proper care. In sum, our opinion is that the guide to transition shouldn't be a general and bureaucratic concept of time, but rather the individual time of each patient, taking into consideration their needs and development.

Correspondence
Elena Nave
PhD in Philosophy – Bioethicist
Division of Pediatric Pulmonology
Regina Margherita Children's Hospital
A.O.U. Città della Salute e della Scienza di Torino
Piazza Polonia 94
IT-10126 Turin

E-mail: elena.nave[at]unito.it

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