Introduction

Does the duty to ill or disabled children who would have died without modern interventions extend to the time of transition to the adult system or beyond?

For individuals with medical conditions that span from adolescence into adulthood, issues of transition from paediatric to adult care gain particular importance. As adolescents develop physically, emotionally and cognitively, their medical and psychosocial needs also change, often as their legal status changes.

These particular adolescents are different from adolescents who have been treated, cured and subsequently discharged from paediatric settings. Their differences ethically support provision of different types of care from other adolescents, care that includes adequate transition into the adult system and consideration of continuing to provide care in paediatric settings.

Ethical Issues in the Transition to Adult Care

John is a 17 year old with severe cardiac disease resulting from chemotherapy when he was 3 years old. Without chemotherapy he would have died. Because of it, he has a disabling condition. He has just learned that he will have to leave the paediatric setting when he is 18 and feels worried and unprepared for this. His program does not have a formal transition process. John has frequent appointments with paediatric cardiologists and sub-specialists, nurses, social workers, dieticians and others. He has heard for years that the adult system isn’t very good, he might have to go to more than one hospital for care, social workers aren’t readily available and it will be “like a factory.” He knows that the people at the children’s hospital have saved his life more than once, but isn’t sure that the adult providers will be aware of his needs or recognize when he is in trouble.

Ethical Elements

- Duty to provide appropriate transition care for young people whose lives have been saved by our health care systems
- Duty to transfer the trust that young people and their parents have for pediatric providers to their new adult providers by using a graduated system of transition;
- Truth telling - Paediatric providers must consider how, when and how much information to provide paediatric patients about perceived inadequacies in the adult system, specifically around the unique needs of newly transferred young adults. Harms can be avoided when information about the adult system is provided in a developmentally appropriate way, accurately and with enough time to provide adequate support and transition to the new system.

Jeanne is a 22 year old being treated at a paediatric hospital for a hemoglobinopathy, as there is a long waiting list for the adult program. At a regular appointment, the nurse starts to measure her, and Jeanne says, “I’m 22. I stopped growing 5 years ago.” Jeanne is about to graduate from college, and plans to take a year off before finding a job. No one has thought to tell her that her parents’ health coverage will no longer apply to her once she has graduated, and that she needs to find a job with good benefits.

Ethical Elements

- Duty to treat young adults who are still being cared for in the paediatric system in a developmentally appropriate and respectful manner consistent with their age
- Obligation to understand and address increased financial burdens of adults living with illness

Manuel is a 17 year old with autism. He is able to attend school and functions quite well. The paediatric clinic where he gets his asthma care has adapted to his needs—he is always taken right into a quiet room, is seen by just one professional at a time and they speak with him in a calm voice. Manuel and his parents have been told that they will be leaving the paediatric setting in 6 months. The asthma program at the nearest adult hospital says that he isn’t sick enough for them. His family doctor says that Manuel disrupts the waiting room. His paediatrician says that if he can’t admit Manuel to the paediatric hospital, he will need to get his care from another doctor. Manuel’s parents want his stay extended in the paediatric system. They are told that this can’t happen, and that they should find a place for him to get care as an adult.

Ethical Elements

- Conscientious decision-making about age of transfer, particularly in special populations such as those with autism, developmental delay and extremely rare childhood onset diseases for which there is little expertise in the adult care system
- Duty to advocate for patients’ needs, including providing information and support to adult healthcare systems

Saima is an 18 year old with lupus. Her mother always comes into the room with her for appointments, answers all the questions and makes all the decisions. Saima knows that she has lupus, but doesn’t seem interested in any of the details. Her medical information is sent to the adult lupus clinic when she leaves the paediatric system. At the first visit, her mother is firmly asked to stay in the waiting room. She is very angry about this and insists that Saima change to a different clinic, even though Saima is happy with the new clinic. Her mother doesn’t want to have the transfer summary sent to the new doctor, as she doesn’t want the paediatrician to discover they aren’t taking his advice about adult care.

Ethical Elements

- Duty to promote self-management and autonomy
- Reduce harms - Ensure adequate information flows to the adult system so that health is not compromised and the young person is offered reasonable choices based on their individual health status. The patient and family should be informed of the importance of information transfer.

CONCLUSION

Technological and therapeutic advances in modern paediatric care have resulted in a new generation of adolescents surviving with chronic illness and disability. Those active in the transition field believe that provision of appropriate transition interventions will lead to improved survival of adolescents with chronic conditions.

Transition initiatives should consider ethical issues that exist for many patients, as highlighted in these case examples. Such issues are often as diverse and complex as their medical counterparts.

Attention to the ethical issues surrounding these complex cases has the potential to positively influence a successful transition, thereby improving health outcomes for an already at-risk population.