

What About The Caregivers? The Ethical Considerations for TAPS Screening And Follow-up Care.

Improving Twin Anemia Polycythemia Sequence (TAPS) screening guidelines can help prepare parents much earlier for the associated risks, treatments and required follow-up care over the course of a child's development.

Case Study

We examine the case of LK, a parent expecting monochorionic twins. During her pregnancy, she received care following standard guidelines for twin pregnancy (ACOG and SMFM). LK was not referred to a maternal-fetal medicine specialist during her pregnancy, nor did she receive doppler ultrasound of the mid-cerebral artery, despite complications such as cardiomegaly and size discordances between the twins. At 32 weeks, the twins were delivered due to fetal distress, and immediately diagnosed with Acute Peripartum Twin-Twin Transfusion Syndrome due to the presence of anemia and polycythemia in the babies.

Standard prematurity followups for two years were conducted, and despite passing newborn hearing screening, the former donor twin received cochlear implants after experiencing significant speech delays. The former donor also experienced developmental delays, requiring physiotherapy and occupational therapy. LK suffered significant financial expense due to limitations in insurance coverage, and the physical and psychological impacts were immense.

When LK spoke with a patient organisation about key findings in her case, she discovered that she potentially received an incorrect diagnosis before birth, and that Twin Anemia-Polycythemia Sequence (TAPS) was a likely cause of her donor twin's issues.

Impact on Families

No data exists on the impact of a TAPS diagnosis on families, however when we turn to our sister disease, TTTS, we see a documented risk of PTSD, depression and anxiety for parents and caregivers. There is a continual call to action for better follow-up care for children born pre-term.

With the recent discovery of increased risks of deafness and neurodevelopmental impairment for spontaneous TAPS donors, there is a need for more screening to enable better decision making. Raising a child with a disability comes with financial, social and emotional burdens, as well as an increased need for support for children and their families.

Evidence suggests that a TAPS diagnosis takes a toll on families similar to TTTS.



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Core Ethical Principles

Ethical Principle	Brief Definition	Application
Veracity	<ul style="list-style-type: none"> The principle of veracity guides professionals to deliver comprehensive, accurate, objective, and transparent information, emphasizing the value of honesty or truth-telling. Veracity also includes representing oneself in a truthful or honest manner (e.g., the abilities and knowledge surrounding care giving and health care practices). 	<ul style="list-style-type: none"> In L.K.'s case, she was never informed about the risks of TAPS, which is consistent among anecdotal parental reports. L.K.'s obstetrician cared for her based on previous experience and current guidance that limited the opportunity to provide transparent, comprehensive information to L.K. L.K.'s physician, in maintaining professional knowledge, ought to keep up with updated literature and clinical evidence to recognize TAPS as an underdiagnosed phenomenon.
Respect for Persons	<ul style="list-style-type: none"> Respect for persons emphasizes that persons should be treated with dignity and as autonomous agents. Additionally respect for persons guides practices that aim to protect persons with diminished autonomy. 	<ul style="list-style-type: none"> Becoming familiar with the literature, considering screening opportunities that align with MCDA twin determinations, and disclosing potential risks much earlier on in L.K.'s pregnancy would have prepared her for a tumultuous delivery and postnatal care experience. Preparing L.K. and her family and understanding their sociocultural, moral/ethical, and clinical values and needs from pregnancy throughout childhood aligns with the principle of respect for persons.
Autonomy	<ul style="list-style-type: none"> Autonomy is associated with the status we ascribe to rational beings as persons in the morally relevant sense. Recognition of autonomy is recognition of the inherent worth of individuals to be respected as persons and recognized for their ability to be self-determining. 	<ul style="list-style-type: none"> One important application of autonomy, and subsequently respect for persons, is in the informed consent process where L.K.'s autonomy should be recognized when making decisions through the delivery of accurate and comprehensive information. Autonomous goals may include shared decision-making that empowers families like L.K. and her children
Beneficence and Non-maleficence	<ul style="list-style-type: none"> The principle of nonmaleficence can be stated as such, "We ought to act in ways that do not cause needless harm or injury to others." We violate this principle when we intentionally do something that we know will cause harm to another. The principle can be violated even when we do not intentionally harm others. Under beneficence, we should act in ways that promote the welfare of other people. 	<ul style="list-style-type: none"> At L.K.'s 32nd gestational week, there were clear clinical issues including fetal distress and cardiomegaly, and twin identification as "monochorionic and diamniotic." A comprehensive, clinical examination was needed to confirm L.K. and her twins' health, consistent with the ethical principles of beneficence (to promote good) and nonmaleficence (to avoid potential harms). Unfortunately, no other diagnostic possibilities were presented to L.K., preventing her from making autonomous, postnatal decisions, and seeking support earlier to promote the needs of her twins (beneficence) and to reduce or prevent unnecessary harms (non-maleficence).
Justice	<ul style="list-style-type: none"> Requires that in the distribution of resources, a just or fair distribution of benefits and burdens should be made. Also requires that persons are treated fairly and with respect/without discrimination. 	<ul style="list-style-type: none"> While justice does not suggest all medical services be offered to parents such as L.K., it suggests opportunities ought to be afforded when relevant to the situation or case at hand. Under this principle, prenatal care is a relevant issue, especially regarding how parents are counseled prior to, during, and following diagnoses such as TTTS or TAPS; there ought to be fairness in the distribution of screening, treatment, and care-based opportunities centering on TAPS based on current and future evidence.

Recommendations

1. Chorionicity should be established early in multiple pregnancies
2. Clinical indicators for monochorionic twins should be carefully evaluated and complications should be well-known among trained providers
3. Screening for TAPS and TTTS should be done at the start of the second trimester
4. Prenatal counseling should be offered and accessible to all families prior to, during, and following screening protocols
5. Screening should not be cost prohibitive and offered to all families with monochorionic twin pregnancies
6. Transparent treatment options and associated benefits/risks should be disclosed to parents/guardians for informed decision-making
7. Treatment options should be based on the needs of the patient and should not be withheld based on disability bias
8. All monochorionic twins born with TAPS should receive hearing tests at birth and receive monitoring during developmental stages
9. Neurodevelopmental testing and monitoring should occur at birth with follow-up at developmental stages
10. Management plans for parents should be established by coordinated care providers and specific to the individual needs of the patient

Relevancy to Healthcare Professionals

An ethical examination of current screening practices and case-based examples provide additional support for the importance of better clinical screening processes, patient advocacy and communication among providers and families.



References

1. Tollenaar, L.S.A., Lopriore, E., Slaghekke, F., Oepkes, D., Middeldorp, J.M., Haak, M.C., Klumper, F.J.C.M., Tan, R.N.G.B., Rijken, M. and Van Klink, J.M.M. (2020), High risk of long-term neurodevelopmental impairment in donor twins with spontaneous twin anemia-polycythemia sequence. *Ultrasound Obstet Gynecol*, 55: 39-46. <https://doi.org/10.1002/uog.20846>
2. European Foundation for The Care of Newborn Infants (EFCNI). European Standards of Care for Newborn Health [Internet]. [cited 2022 Dec 4]. Available from: <https://newborn-health-standards.org/>.
3. Shahat ARS, Greco G. The Economic Costs of Childhood Disability: A Literature Review. *International Journal of Environmental Research and Public Health*. 2021; 18(7):3531. <https://doi.org/10.3390/ijerph18073531>
4. Beauquier-Maccotta B, Chalouhi GE, Picquet AL, Carrier A, Bussières L, Golse B, Ville Y. Impact of Monochorionicity and Twin to Twin Transfusion Syndrome on Prenatal Attachment, Post Traumatic Stress Disorder, Anxiety and Depressive Symptoms. *PLoS One*. 2016 Jan 11;11(1):e0145649. doi: 10.1371/journal.pone.0145649. PMID: 26751570; PMCID: PMC4709103.

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