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SPECIAL ARTICLE

Rapid genomic testing in critically ill pediatric patients: Genetic counseling lessons from a national program

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ABSTRACT

Genetic counselors (GCs) face unique challenges in the acute care setting. Acute care environments—such as neonatal and pediatric intensive care units—are characterized by urgency, complexity, and rapid decision making. These settings require GCs to navigate a delicate balance between addressing the immediate clinical needs of patients and providing comprehensive genetic information to families, while demanding adaptation of existing skills for practice.

Rapid genomic testing (rGT) is increasingly becoming standard of care in acute care. GCs are well placed to support families through the rGT process. Despite this, there is a lack of consistency in the provision of comprehensive acute care genetic counseling globally and a subsequent need for professional guidance in this area.

The Acute Care Genomics study piloted a national approach to delivering rGT for infants and children admitted to intensive care units in Australia with suspected genetic conditions between 2018 and 2022. GCs from across Australia were involved in both pre- and post-test counseling for the families of these critically unwell children. Based on our collective experience of delivering this national rGT program, this article provides a discussion of common challenges for health professionals new to delivering rGT in intensive care. We share some practical solutions and make recommendations for supporting families in this area of practice.

Introduction

Genetic counselors (GCs) face unique challenges in the acute care setting. Acute care environments—such as neonatal and pediatric intensive care units (ICUs)—are characterized by urgency, complexity, and rapid decision making. These settings require GCs to navigate a delicate balance between addressing the immediate clinical needs of patients and

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providing comprehensive genetic information to families, demanding adaptation of existing skills for practice.[1-4]

Genomic testing is increasingly becoming standard of care in the acute care environment, and rapid results can be returned to families within days.[5] Rapid genomic testing (rGT) has clear diagnostic and clinical utility for critically unwell children with rare conditions, and its implementation is supported by a number of health care systems.[6,7] Despite this, a recent scoping review identified gaps in care for patients undergoing genetic and genomic testing in ICU settings, demonstrating a lack of consistency in the provision of comprehensive acute care genetic counseling globally and highlighting a subsequent need for professional guidance in this area.[8]

Significant research supports our proposal that GCs are well placed to support families through the rGT process.[2,3] Many have argued that rGT is distinct from other types of genomic tests because of its high clinical utility and early implementation in the diagnostic trajectory.[9] When rGT is first proposed, parents are typically in the midst of contemplating a myriad of other decisions for their critically unwell child, and they may not differentiate between these decisions and the decision about rGT.[4] Research in the United States suggests the need for greater involvement of genetics specialists in the ICU, highlighting the potential benefits of having a dedicated acute care GC who is able to see families and provide on-the-job training to nongenetics specialists.[10] GCs can facilitate informed consent for rGT while utilizing an empathic, family-centered approach. Importantly, research shows that integration of GCs in the acute care setting supports parents' decision making and assists to reduce parental anxiety and decisional conflict.[11] Despite the described benefits, minimal guidance has been provided for genetic counseling practice in this context to date.

The Acute Care Genomics (ACG) study piloted a national approach to delivering rGT for infants and children admitted to ICUs in Australia with suspected genetic conditions between 2018 and 2022.[5,12] The study recruited from 17 hospitals in all states and territories, including all children's hospitals in Australia, and delivered testing to 450 critically infants and children with an average time to report of <3 calendar days and average diagnostic yield of 54%.[5,12] A multidisciplinary working group established the patient selection criteria and standard operating procedures for the clinical and laboratory pathways to ensure consistency across sites. The program developed online test ordering and consent materials to improve efficiency and plain language genomic reports to facilitate results communication.[13] All but one of the hospitals had onsite clinical genetics services, with genetics services to the Royal Darwin Hospital in the Northern Territory provided remotely by the Victorian Clinical Genetics Services. Genomic testing was performed at 3 laboratories, with 89% of tests delivered by the Victorian Clinical Genetics Services. The program funded the cost of testing and funded fractional GC time at the 6 largest recruiting clinical genetics services (equivalent to 1.5 positions nationally) with the intention of developing the role of GCs as part of delivering rGT. GCs were involved in both pre- and posttest counseling for 88% of the families as part of the program, and the mean number of consultations was 2.0 (range 1-6) per family.[12] The 35 GCs involved in the program built a community of practice and led research in exploring the psychosocial, counseling, and ethical dimensions of rGT in neonatal and pediatric intensive care.[2,3,7,9,13-17] Based on our collective experience of delivering this national rGT program, we provide here a discussion of common challenges for health professionals new to delivering rGT in intensive care. We share some practical solutions and make recommendations for supporting families in this area of practice.

Working in the ICU

Many GCs have never experienced working in the ICU before their involvement in delivering rGT. The often-confronting nature of seeing critically unwell children may influence their interactions with patients and families if not adequately prepared. It is more usual for GCs to see families in the ambulatory setting, often toward the end of their diagnostic journey. This is typically in a controlled environment, at a scheduled face-to-face appointment, and often after having had at least 1 interaction with the family via telephone. In contrast, the ICU setting is complicated by a variety of factors, including the involvement of many other health professionals, the unpredictable and sometimes chaotic physical environment, which often lacks privacy, and other clinical priorities for the patient and family.[2,4,17]

In the acute care setting, GCs often meet families during their child's first few days of hospital admission (Box 1). This adds complexity to rapport building because parents are often under the extreme stress of having a critically unwell child and are equally unfamiliar with the ICU environment. Families may have competing priorities, including making various other important medical decisions for their child. This may mean parents are distracted, unsure of the GC role in their child's care, and/or not fully engaged in the pretest counseling and consent discussion. As a result, some parents may need multiple discussions over the course of several days to help them understand the implications of rGT. In some cases, one or both parents may not be present for such discussions. Furthermore, the birthing parent may still be an inpatient in another hospital (in the neonatal ICU environment especially). As in the outpatient setting, there may also be complex family circumstances where separate pretest counseling discussions with parents are required. These myriad of distracting factors and the high variability in patient and family circumstances makes truly tailored pretest counseling particularly important in this setting.

The ICU environment is also relevant in the context of GCs working with ICU staff. Unlike the outpatient setting, where GCs often work in familiar multidisciplinary teams,

Box 1. provides an example amalgamated from the experience of the GCs involved in the ACG study. Pseudonyms are used throughout.

Box 1: Case study

Finn* is the second child to nonconsanguineous parents Sally* and Brett*. They also have a 2-year-old son Henry* who is well. Finn was admitted to the neonatal intensive care unit (NICU) on his first day of life because of multiple congenital abnormalities, including Tetralogy of Fallot, diaphragmatic hernia, hypospadias, and dysmorphic features.

Finn's parents wanted to do whatever they could to help him while trying to understand more about his condition. Sally had an amniocentesis during the pregnancy with Finn because of detection of a diaphragmatic hernia at the 20-week morphology scan. Chromosomal microarray analysis (CMA) was performed at the time and was nondiagnostic. Finn's parents thought that this meant he was cleared of having any genetic condition.

After receiving clarification of the difference between CMA and genomic testing, Finn's parents provided consent for rGT. Three days later, rGT identified a pathogenic variant in *TAF1*. This causes a very rare condition associated with severe to profound intellectual disability, bilateral hearing loss, vision loss, and dystonia. The genetic counselor (GC) and clinical geneticist talked through the result before meeting with the family. It was discussed that this result would be a devastating diagnosis for Sally and Brett and would likely come as a shock to them. A clear role for the GC was defined, as the family would no doubt require a great deal of psychosocial support after the diagnosis.

The genetics team then discussed the result with the family, explaining that the condition is life limiting. Sally and Brett expressed they felt devastated and had difficulty processing the diagnosis. Together, they asked for any information about this gene to be made available to them. The GC spoke with Sally and Brett on multiple occasions to provide them with scientific articles about TAF1 but also to link them with the small number of affected families around the world online.

After relaying the diagnosis to the family, the genetics team informed the ICU, cardiology, and other treating teams. Initially, there were conflicting opinions on what to offer this family. Some teams were supportive of a surgical repair for the cardiac abnormality, whereas others felt offering the family a palliative approach may be more beneficial. A clear role for the GC during these discussions was to advocate for the family but also to ensure the treating teams were aware of the complexities of this condition and its effects on Finn and his quality of life.

Ultimately, both scenarios were discussed with the family at length with the understanding that they would be supported in whichever decision they made.

A week later, after numerous discussions, a meeting with the family and other medical teams was held. Finn's parents and treating team decided to redirect his care toward palliation and not proceed with cardiac repair. Finn was eventually discharged home with supportive care. He died at 5 months of age, surrounded by his family.

GCs may not have established relationships with ICU staff, and a major role of the GC is therefore to establish trust with these health professionals. Furthermore, nongenetics health professionals may be unfamiliar with the role and unique skillset of the GC or the utility of rGT for their patient,[2] and a face-to-face education session with ICU staff may therefore be helpful in introducing the genetics team to the ICU team and explaining their key roles, responsibilities, and scope of practice. Conversely, GCs may benefit from education sessions delivered by those who have experience working in the ICU. Strategies such as these ensure that GCs are included in the process of rGT in a way that most effectively supports patient and family care. The importance of advocating for the families, particularly when families have declined rGT or need additional time to make a decision, is an essential role of the GC in the acute care setting and relies on establishing rapport with the rest of the treating team.

Having genetics involved in the care of an inpatient may also provide benefit in the form of a positive feedback loop. Evidence from GCs working in an inpatient setting suggests that working closely with members of the inpatient care team may lead to an increase in genetic diagnoses, which further increases non-genetics specialists' understanding of the utility of genetic testing, thereby leading to an increase in referrals to genetics.[18] The longer GCs work in an inpatient setting, the more referrals they are likely to receive and the greater benefit patients experience from genetics care, leading to GCs feeling they are valued members of the multidisciplinary team.[18]

Managing expectations

A major role for GCs in the acute care setting is to manage both clinician and family expectations around rGT to ensure the technology is used responsibly and effectively.

Family expectations

Previous research emphasizes the importance of setting realistic expectations for clinical and personal utility of rGT with parents.[14] Because of this, some have suggested that pretest counseling for rGT should focus on promoting these realistic expectations of the test, as well as discussing the broad goals of testing, parents' hopes and values, potential impact on parent-child bonding, and clarifying misunderstandings.[9]

One of the first conversations GCs should have with parents in the ICU environment is about the limitations of prior genetic testing that may have been performed, particularly antenatal screening and testing. GCs have an

important role in providing education about the different types of genetic and genomic testing and normalizing potential parental (and professional) misunderstanding, given the complexity of testing options available.

The next step in managing parental expectations is to discuss the limitations of rGT itself. These conversations include informing parents of the chance that no diagnosis will be made, or that a variant of uncertain significance may be found, leading to more uncertainty in an already uncertain environment. It should also be clearly communicated during pretest counseling that a rGT result may have no impact on treatment or management for the patient,[1] and that a nondiagnostic result does not exclude the possibility of a genetic cause.[19]

Discussion of the potential implications of all possible outcomes of rGT is one of the most important facets of pretest counseling. It is important to make families aware that many genetic conditions may lead to intellectual or physical disability or be life limiting.[2] Most genetic conditions do not have a cure, and it is of utmost importance to prepare families for the possibility of receiving a devastating diagnosis for their child. Furthermore, some genetic conditions may be so rare that there is little information about how to provide treatment and management for the condition. Pretest counseling for rGT in acute care should also include making parents aware that results may change the professional recommendations of the child's care team.[4] In our experience, most families decide to consent to rGT despite its limitations and the potential for a devastating diagnosis.[5,12]

Addressing possible outcomes of rGT during pretest counseling fosters a trusting relationship with the families. Pretest counseling for genomic testing is well recognized as being essential for facilitating informed consent, and GCs have been recognized as well placed to provide this service.[6] Previous research suggests that parents can be comfortable with the amount of information provided and the opportunity to ask questions at pretest counseling, while simultaneously not needing to understand every detail of genomic testing.[14,20]

As well as the complexities discussed above, there are expectations of the logistical aspects of rGT that GCs are well placed to manage with families. These include sample collection requirements and timeline expectations. Sample requirements are typically minimal (1 ml), and children admitted to ICU will have vascular access so that a blood sample can be taken easily without causing any further discomfort or pain. It is also important to set expectations for families around when results from rGT will be available. Some GCs maintain daily contact with families to ensure they know when to expect results, whereas others give estimates of time frames at the time of consent. In all cases, we recognize the need for a very clear and concrete plan of how results will be disclosed, and by whom. Ideally, a geneticist and GC should both be involved in the results discussion, and it should ideally take place in person. However, telehealth technology can be utilized in cases which 1 or both parents are not present in the NICU. Follow-up post-discharge should be scheduled because this provides a further opportunity to address the families' information and psychological needs outside of the acute environment.[7,16]

Health professionals' expectations

There are many competing agendas in the acute care environment and a variety of pressures from various medical practitioners when offering rGT to families. Because rGT is still seen as a new and exciting technology, many medical professionals are keen for families to consent to rGT to assist the care team in managing the complex needs of the critically ill child. In our experience, there is sometimes an over-reliance on rGT technology and a lack of understanding of its limitations. Additionally, some families have personal reasons for declining the use of rGT. Managing health professionals' expectations, both regarding the ability of this technology and the potential for families to decline its use, is therefore equally as important as managing families' expectations.

One of the primary challenges in managing health professionals' expectations is setting realistic turnaround times for rGT results. Clinicians often face immense pressure to make quick decisions for their patients. To address this, laboratories and sequencing facilities must establish clear and achievable timelines for delivering results. It is essential to communicate that, although rGT is faster than traditional methods, it is not instantaneous, and certain factors can affect the timeline, such as sample quality and the complexity of the analysis. Open and transparent communication is key to aligning expectations. GCs working in the acute setting are well placed to facilitate this clear communication between all medical professionals and laboratories involved. To do this, GCs may use electronic communication to update the treating team and ensure good dialog with the testing laboratory. Multidisciplinary team meetings can also serve as a forum to update treating teams on testing progress.

Helping to set realistic expectations with ICU clinicians also benefits families. Research at the beginning of rGT implementation suggests a steep learning curve for nongenetics health professionals in this setting, with a mismatch in perceptions and expectations between medical professionals and parents.[15] ICU staff are not always aware of the complexities of genomic sequencing, analysis, and results. Some ICU staff can rely heavily on a genetic diagnosis being made for the patient, with consequences such as delaying decision making for procedures until genomic results are available. Furthermore, although a GC may be responsible for formally discussing rGT with families, parents will also take into account other health professionals' opinions about rGT in their decision making.[4] Because of this, it is essential that all members of the treating team hold realistic expectations of rGT.

To facilitate appropriate use, nongenetic health professionals should receive training and support in rGT.

Previous research has demonstrated a need for education of ICU staff in rGT.[1,3,10] Such education benefits families by allowing all health professionals to accurately answer bedside questions regarding rGT as they arise.[4] Additionally, although it is important for ICU staff to understand variant interpretation and the laboratory processes of rGT, education about the ethical and counseling considerations is equally as important.[4] Building upon this, close collaboration with the local genetics team in managing patients undergoing rGT, and case review meetings provide invaluable opportunities for experiential learning in the long term.

Importance of emotional well-being

Emotional well-being is a necessity for all GCs and should be a priority for anyone considering working with families in the ICU. GCs working in the inpatient setting report increased responsibility, time commitments, the need for flexibility, and added psychological burden.[18] Genetic counseling for rGT can be extremely rewarding; however, it involves providing emotional support, complex information, and guidance to families facing one of the toughest challenges of their lives. GCs with young children may experience transference and counter-transference in this setting. Burnout is particularly important to be aware of for GCs with inpatient roles.[18] As GCs increasingly engage with families navigating rGT, it is imperative that they prioritize their own well-being through self-care practices. Acknowledging the importance of emotional well-being not only benefits GCs personally but also contributes to their ability to provide effective patient care.[18] Resources such as supervision, mentoring programs, and personal counseling/psychotherapy should all be considered to assist in promoting well-being.

Recommendations

For those GCs and health professionals whose role it is to discuss rGT with families in an acute care setting, we recommend the provision of specialized professional development. This education should focus on acquiring the knowledge and skills required to work in the unique acute care setting to build competence and confidence. Training provided through structured short courses or online training modules coupled with onsite orientation of the acute care workplace may benefit those who are less familiar with this work environment.

Because of the complexity of issues associated with counseling within the acute care environment, we suggest dedicated mentoring by those who have prior experience working in this area. Sharing of learned experience by ICU specialists, nurses, clinical geneticists, and other GCs could provide invaluable insights to those less experienced.

Supervision is a mandatory requirement for all practicing GCs in Australasia.[21] Reflective practice within supervision provides an opportunity for GCs to deeply reflect on the complex issues encountered within the acute care setting. Furthermore, it can be a useful tool to foster strength and resilience to better equip genetics professionals to work in an environment that is not only overwhelming for families but also confronting for unfamiliar health professionals themselves.

From a more practical perspective, we also recommend the development of tools related to rGT, such as standard operating procedures, template letters, standardized reports,[13] and flow charts, to prevent delays, ensure consistency, and increase efficiency.

Finally, other health professionals should be utilized to support GCs working at the top of their scope of practice in intensive care. Genetic counseling assistants, as are present in many genetics departments, should partner with GCs to take on lower-scope tasks as appropriate. For example, sample coordination, multidisciplinary team communication, and follow-up reminders are all administrative burdens that can be relieved by such support staff.

Conclusion

The delivery of rGT in the acute care setting represents an emerging area for genetic counseling practice. GCs are well placed to support the information and emotional needs of parents[1] and play an important role in advocating for parents and families, as well as assisting them to understand and adjust to the results of rGT in this setting.[19] Furthermore, GCs' skills allow them to help parents cope with the implications of rGT, regardless of the diagnostic outcome.[19] Importantly, not only are GCs sufficiently skilled and adaptable, but they are also ready and willing to contribute to the delivery of rGT in acute care and to lead the genetic education of other ICU health professionals.[3]

The Acute Care Genomics study recruited nationally across Australia, and although some conclusions can be drawn as to how to prepare the international GC workforce for the implementation of rGT, careful consideration should be given as to how rGT may be implemented in different health care settings. Appropriate funding for GC time needs to be factored into service delivery models when designing rGT programs, and this will be dependent on approaches to reimbursement. Establishing communities of practice and GC networks across multiple centers facilitates role development; sharing of expertise, resources, and experience; and ensures consistency. Ideally, multiple GCs working within a given setting would be available to manage rGT cases as they arise to address logistical issues and help manage the risk of emotional burnout for lone practitioners. However, this may not be possible in many settings, and clinical geneticists, ICU clinicians, nurses or other specialists trained in rGT may provide redundancy.

With rGT increasingly routinely available in routine care, we can now draw on extensive research and experience to further develop the role of GCs as part of the multidisciplinary teams delivering these services.

Data Availability

No specific data sets were generated or analyzed for the purpose of this publication.

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Author Contributions

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Ethics Declaration

The Australian Genomics Acute Care study has Human Research Ethics Committee approval (HREC/16/MH/251). Parents provided informed consent for participation in the study after genetic counseling.

Conflict of Interest

The authors declare no conflicts of interest.

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