Building the Multidisciplinary Transition Team

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The transition of a patient from paediatric to adult healthcare has emerged as a defined discipline within urology and is regarded as paramount in fostering high quality and efficient lifelong care with focussed, appropriate and specialist follow-up. Treatment of the urological condition must be paralleled with a focus on preventing ill health/complications and the promotion of healthy living with access to appropriate support [1]. In healthcare across the board we are now encountering a growing population of young adult patients who have benefitted from paediatric care that may include major reconstructive surgery in a range of specialties and who require reliable and accessible care into young adulthood and beyond by a practitioner with an appropriate level of expertise.

A major challenge arises in adolescent patients because the ongoing care needs when entering young adulthood can be complex and far-reaching. The patient with a congenital condition is on a lifelong journey, and their experiences in healthcare will play a large part in shaping their long-term outcome [2]. Effective transitional care is paramount, and it has been clearly demonstrated in many life-long conditions that seamless transition to adult healthcare carries significant benefits in health outcomes [3, 4].

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Transition Planning

When considering the basis of a transition team, a number of core principles should be considered. These ideals are outlined below:

Defining Adolescence

Adolescence is a crucial period of time in a young persons' life during which a complex series of biological, physiological and social changes take place simultaneously. Relationships and interactions develop while behaviours change as the brain matures, and the end point of the process is a young adult with a strong sense of independence, a passion for justice and righteousness. It is important to be able to help and guide all patients—especially those who are more vulnerable through this period of, often, turbulent change.

Adolescence begins at puberty (which in some young people may be as young as 10 or 11 years) and is often felt to extend well beyond the age of 20—with the brain continuing to mature until the age of around 25 years of age. It is difficult to apply hard boundaries to these age ranges, more often the upper age is defined by the readiness of the young person to fully embrace adulthood and all that adult life has to offer.

The National Institute for Health and Care Excellence (NICE) in the United Kingdom published a comprehensive guidance document in 2016 in which support for young people in transitional care is recommended up to the age of 25 years [5].

Defining Transition

It is helpful to consider transition as a series of steps rather than a one-off transaction or event. Moving healthcare delivery from paediatric to adult services may involve a change of geographical location and sometimes a change of specialist medical practitioner, as well as often involving a shift of emphasis from a family-centred decision-making approach to a more person-centred approach encouraging independent thinking and choices. The change in facility or personnel is the transfer. The assumption of responsibility by the young adult and their involvement in their own healthcare is the fundamental principle of transition.

Therefore, *transition* can be defined as the preparation, planning and support given before, during and after the process of *transfer* of care delivery [6]—including the safe and confidential transfer of health information documentation.

The Multidisciplinary Transition Team

The key elements of transition planning include;

- Communication and documentation
- Forward planning

- Transferable medical records
- Clear onward care plan, involving the young person in decisions at all stages
- Inclusivity; consider which key medical and supporting persons may be required
- Remain person-centred rather than focussed on process

A transition team may consist of as few or as many members as is deemed necessary based on local service arrangements and the particular care needs of the service. The underlying diagnosis and treatment will play a key part in the design of the service and the members required to deliver a successful MDT.

A minimum requirement or core team should be determined, and this should be applied consistently to all young people requiring transition. An example of a core transition team might include:

- Lead clinician
- Named specialist nurse
- Transition coordinator
- Clerical Secretary or personal assistant (PA) to handle administrative tasks
- Community services coordinator

Lead Clinician

The lead clinician will have full knowledge and understanding of the background diagnosis, treatment received to date, problems and challenges ongoing, and the future care needs. A discussion between the lead clinician and the young person with their family/advocate will reach an agreed stage whereby the process of preparation for transition will begin with an agreed future target date for the transfer of care.

The lead clinician may be a paediatric specialist, a specialist in adolescent and/or transitional care, or an adult specialist with an interest in ongoing care of patients with lifelong congenital conditions.

The availability of a specialist with the relevant expertise in caring for such patients varies greatly across healthcare systems, specialties and the specific arrangements in place in any local, regional or national setting will depend heavily upon appropriate service design.

A specialist receiving young adult patients with transitional care needs due to congenital lifelong conditions must have a good understanding of the relevant pathophysiology of the relevant anatomy and embryology, be able to be responsive to patient-specific care needs, and have the correct skills and equipment available to troubleshoot emerging problems in a timely manner.

For example a young person struggling with a complex situation such as catheterisation of a Mitrofanoff (continent catheterisable) channel with pain in their augmented bladder and blood in their urine should expect to receive attention without delay from a urologist fully capable of endoscopic evaluation using appropriate instruments and able to manage unexpected findings such as a bladder calculus.

Named Specialist Nurse

In many clinical circumstances, the appropriate person to act as a first point of contact is a named Specialist Nurse. Depending on local service planning a named nurse may be a dedicated full time Transition nurse, or otherwise may be an appropriate specialist nurse with responsibility for transitional care alongside the other aspects of their role.

However the role is defined within a particular unit, the named nurse should have a comprehensive knowledge of the full range of the relevant congenital conditions and should be familiar with the details of each individual young person entering the period of transition to adult care.

The named nurse should be present at transition clinic appointments and be integral in care planning for each young person.

Transition Coordinator

In some larger paediatric hospitals, where transitional care occurs across multiple specialities, a transition coordinator plays a vitally important role in keeping care coordinated and aligned. They can facilitate transition planning and moving ahead at an appropriate pace, ensuring that appointments are made at convenient times for the young person and their family. The aim of this is (aside from excellent care) to minimise wasted Hospital resources through missed appointments and to maximise the effectiveness of the transition/transfer process. Document handling and storage, availability of case notes and care pathways at forthcoming appointments, may be enhanced through the effective use of a transition tracking database system managed by the transition coordinator and good administrative support.

Administrative Support

An efficiently managed transition/transfer system is greatly enhanced by the involvement of an administrative focal point such as clerical secretary or personal assistant (PA) who works closely with the lead clinician, specialist nurse and transition coordinator. A clear understanding of the care pathway being used and the ability to monitor progress of each young person during their individual transition journey is pivotal to success. The integration of a secretary/PA in the transition team to maintain clear and accurate administrative tasks is vital.

Community Services Coordinator

In many cases, where a child has successfully accessed a range of hospital or community services throughout paediatric care the same services may not be so easily or readily accessible after transition to adult health care. An example may be

psychological support or mental health services. Many young people with complex health conditions experience anxiety and stress as a result of their health or in association with a chronic condition. In many areas, good access to child and adolescent mental health services exist and a period of stability is reached during adolescence. After transfer to adult services, access to good quality and regular mental health care can be challenging and consequently mental health is at risk of deterioration. A coordinator of services based in the community can be very helpful in bringing together all of the surrounding elements of care needed for an individual in a way that seeks to avoid the interruption of care and further helps to streamline the transition period [7]. Such community-based services may include physiotherapy and occupational therapy, psychology, obtaining pharmacy prescription items, access to family doctor appointments, continence services, supplies of medical equipment such as catheters and vocational help such as assistance in accessing college education.

Inclusion of Additional Resource

The wider multidisciplinary approach in urology (as an example) might include involving the following disciplines in care planning (while not necessarily being present at each transition clinic or meeting);

- Nephrologist
- Endocrinologist
- Orthopaedic Surgeon
- Neurosurgeon
- Gynaecologist
- Psychologist
- Pain specialist

This serves to demonstrate the breadth and depth required to form the whole multidisciplinary team. Clearly, not all specialties are needed for all cases but all need to be available when required. Different diagnoses and specialties will, clearly, require different input.

Conclusion

Both transition and transfer remain developing areas in healthcare for long-term conditions. Careful transition planning, the use of a core team and a wider multidisciplinary group are key in helping young people to navigate the complex landscape of healthcare systems in which it can be difficult to achieve seamless flow and continuity. We must strive to improve not only the transition process but also the overall care systems in which young people and adults with long term healthcare needs exist. Quality metrics are required in order to understand how and why some

adolescents still fail during the transition/transfer process. To access adult healthcare appointments may not be the most important goal for all young people; becoming a fully independent adult with employment prospects, feeling valued, and in meaningful relationships is, for many, the desired endpoint of their journey into young adulthood [8]. Appropriate healthcare needs to play its role in supporting that for our patients.

Irrespective of the detail of the transition system in place, the safe, meaningful and effective onward delivery of care between two very different healthcare environments (paediatric and adult care) is paramount. From good quality care comes trust and a more enriched relationship between young adult patient a doctor. If we hold the welfare of our young patients at the centre of multidisciplinary transition planning, the process cannot go far wrong.

References

1. Michaud PA, Suris JC, Viner R. The adolescent with a chronic condition. Part 2: healthcare provision. Arch Dis Child. 2004;89:943–9.
2. Borer JB. Current approaches to the urologic care of children with spina bifida. Curr Urol Rep. 2008;9:151–7.
3. Kraynack NC, McBride JT. Improving care at cystic fibrosis centres through quality improvement. Semin Respir Crit Care Med. 2009;30:547–58.
4. Sawyer SM, MacNee S. Transition to adult health care for adolescents with spinal bifida: research issues. Dev Disabil Res Rev. 2010;16:60–5.
5. National Institute for Health and Care Excellence. Transition from children's to adult services for young people using health or social care services. NICE guideline [NG43]. 2016. https://www.nice.org.uk/guidance/ng43. Accessed 19 Oct 2018.
6. Sawyer SM, Blair S, Bowes G. Chronic illness in adolescent—transfer or transition to adult services? J Paediatr Child Health. 1997;33:88–90.
7. Okumura MJ, Saunders M, Rehm RS. The role of health advocacy in transitions from pediatric to adult care for children with special health care needs: bridging families, provider and community services. J Pediatr Nurs. 2015;30(5):714–23.
8. Okumura MJ. The transition journey: time to systematically address transition planning to adult health care. Pediatrics. 2018;142(4):e20182245.