

# Transition of Surgical Care: Bridging The Gap Between Pediatric and Adult Services

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"Transition of care" is the process of transferring the care of patients from one discipline to another and from one age group facility to another. The main idea is to provide appropriate and continuous care without interruption. It is a purposeful, planned process that aims to address the medical, psychosocial, and educational/vocational needs of the adolescents and young adults.<sup>1,2</sup> In this model there is a gradual transfer of responsibility for the management of health-related issues to the patients themselves, making them independent in charge of their bodies and to other healthcare providers in collaboration.

Adolescence period is a rapidly changing state between childhood and adulthood where not only the physical changes occur, but also physiological and psycho-emotional development takes place. Gender differences become quite apparent at this stage, and physical growth follows a specific pattern, a hormone-driven process. The age duration of this period extends from 10 years to 20 years. Protective and supportive environments in the family, at school, and in the wider community are important because some adolescents are at a greater risk of developing mental health conditions due to their living conditions, stigma, discrimination or exclusion, or lack of access to quality support and services because of the medical ailments.

There are a number of congenital pediatric surgical conditions that require a lifelong care. Adolescents may face unique challenge by virtue of being placed between the family-centred, developmentally focused pediatric paradigm (that may undermine their physical independence and budding adult behaviours) and the

adult medical culture where respect of decision of an individual takes precedent over that of family, especially in the context of their social needs including reproductive health. All these affect their quality of life. Sudden shift from the pediatric to adult medical care may create a sense of uncertainty and dissatisfaction in adolescents.<sup>3</sup> This may result in anxiety that affect the continuity of medical care.<sup>4</sup> For a smooth and effective transfer of care for these adolescents, from pediatric to adult healthcare, transition programs are recommended worldwide.<sup>5</sup>

These programs mainly consist of three components: preparation (including policy-making and guiding patients and families, tracking progress, assessing readiness, and planning for the transfer), transfer to the adult facility, and finally, completion of the transition with integration into adult care.<sup>6</sup> This transfer needs to be a guided educational and therapeutic process. In order to achieve this goal, preparation starts in early adolescence (from 12 years to 18 years). During this period, the patients learn to function as adults and acquire the necessary skills and education to manage their illnesses independently. It is also important to make them understand and accept that the transfer of care to an adult facility will be a part of their life-long management processes. The second phase involves introducing adult care providers to the services, creating a new bond between the patients and the adult care providers. Adult surgeons also become familiar with the pediatric conditions, their specific needs, and management. This phase continues up to the age of 21 years in most of the cases. The third and final phase is the completion of the transition, where patients are handed over to adult service providers with the involvement of pediatric surgeons as supporters, when needed.

Transition of care programs are well-established in developed countries for various conditions. However, for surgical conditions, this transition is challenging, and data on the subject are limited.<sup>7</sup> Certain congenital surgical conditions require life-long management even after corrective surgeries.<sup>8</sup> This is not limited to their primary condition but also for the associated anomalies

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and related psychosocial issues. They may need follow-up with different surgical specialties.

In Pakistan, this concept is still nascent, and no such dedicated services are available. In fact, the definition of "pediatric age group" is also not agreed upon. The cut-off age of pediatric patients varies in different hospitals. Adolescent gynaecological clinics are established in few centres but by definition they do not fall into the transition of care program. At present there is an abrupt transfer of care from pediatric to adult services where the environment is quite frightening to many of the young patients. The bond of the pediatric patients with their treating surgeons is suddenly broken with this sudden transfer. However, many older age children feel shy while sitting among the small children in pediatric hospitals. Majority of the parents also refuse to take their children to the adult services, resulting in dropout from clinical care.

In context of Pakistan the important question is how to establish the transfer of care services that would be practical and contextual. The available resources, cultural norms and beliefs of the communities must be studied before embarking upon any such program. Creating awareness is the foremost step followed by in-depth studies to understand the perspectives of different stakeholders including policy makers and available resources.

Understanding the extent of the surgical needs of the children as they grow, construction of separate blocks for rendering such facilities, selection of children hospitals or adult care centres, provision of ancillary and supportive services are important. A strong collaboration to begin with is required between like-minded surgeons from different adult services. Guidelines may be developed based upon the burden of case-mix of surgical conditions for which services shall be required. Multidisciplinary teams shall be helpful in this context. Additional training may be required for the providers as they may face complex challenges in the management of such patients. Records keeping is important in order to audit the services provided and the future needs that may be incorporated.

Adolescence is a crucial age group, especially for the pediatric patients with the congenital surgical anomalies that require a life-long management. "Transition of care" programs may help in addressing the needs of these patients during an important period of their growth to adulthood. This is expected to improve their quality of life and reduce the burden on families as well.

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