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Multi-Disciplinary and Transitional Care for Children and Adolescents with Differences in Sex Development (DSD) and Congenital Adrenal Hyperplasia (CAH): Bridging the Gap

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Abstract

Differences in sex development (DSD), including congenital adrenal hyperplasia (CAH) are complex disorders requiring continuation of care from birth through childhood and adolescence to adulthood. Management of CAH/DSD includes several sensitive medical and social issues, starting with the dilemmas of deciding the gender of rearing, the need and timing of genital surgery/gonadectomy, gender identity, sexual orientation, and fertility potential. Thus, multidisciplinary team (MDT) and transitional care services are necessary for the proper management of CAH/DSD. MDT care is important to address age and gender-specific medical and psychosocial issues at different stages in life. In contrast, transitional care is important to minimize problems associated with abrupt 'transfer' of care from pediatric to adult services such as fragmented care and loss of follow-up.

Although the necessary expertise may exist, coordination between services to provide MDT and transitional care is not well established, especially in developing countries. Further, there is a scarcity of guidelines and research on multidisciplinary and transitional care in developing nations. Creating specialized centers of excellence with collaboration among the various specialties to provide holistic MDT and transitional care can help optimize care in lower-resource countries. This article discusses challenges faced in establishing multidisciplinary care and transitional care for CAH/DSD and suggestions to overcome them, with special emphasis on developing countries. This review is based on current literature, and our own personal clinical experiences in conducting transition care services for adolescents with CAH/ DSD over the past 2 years, at a tertiary care hospital-based university center in Sri Lanka, a lower-middle-income-country (LMIC) in South Asia.

Keywords: Transitional care, Differences in Sex Development, Congenital Adrenal Hyperplasia

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Introduction

Differences in sex development (DSD) are associated with a multitude of medical and psycho-social issues that evolve throughout a patient's life. DSDs encompass a wide spectrum of congenital conditions with atypical development of chromosomal, gonadal, or anatomic sex. DSDs are classified based on karyotype as 46XY DSD, 46XX DSD, and sex chromosomal DSD [1]. Congenital Adrenal Hyperplasia (CAH) is the commonest form of XX DSD in clinical practice, while XY DSD includes disorders of gonadal development, or androgen synthesis/action [1-3]. These disorders often have varying presentations as well as multiple manifestations at different stages of life, necessitating collaboration between different healthcare professionals [4]. Given the complexity of these disorders 'continuum of care' is important, and the concept of 'shared care' for managing individuals with CAH/DSD is accepted and recommended globally [5].

Individuals with CAH/DSD ideally require evaluation and management by a specialized experienced multidisciplinary team (MDT) [6]. As all healthcare institutions/centers will not be equipped with such teams to care for individuals with CAH/DSD, shared care between a central/ regional center of excellence and local centers is often a good way to provide optimal care. Individuals with DSD/ CAH also often require a 'transition of care' from pediatric to adult care services. During the transition, careful transfer of information and strategic planning will secure future compliance with medical care and help optimize the future health of these young individuals [7].

Multi-disciplinary care in DSD

The objective of MDT is to provide a common forum for a team of professionals from different disciplines to work together to deliver the best possible care to individuals with complex health needs [8, 9]. The importance of multidisciplinary care for individuals with DSD both in childhood and adulthood is been increasingly recognized [10]. Given the wide spectrum and complexity of manifestations in CAH/DSD, MDT involvement may be required at different levels, at different stages of life [11]. Generally, the team should include specialists in pediatric endocrinology, pediatric surgery/ reconstructive surgery or urology, pediatric and adolescent gynecology, and child and adolescent psychology/ psychiatry, with support from experts in clinical genetics, radiology biochemistry, and social work. As individuals reach maturity, specialists in adult endocrinology, gynecology, urology, reproductive health, and psychology/ psychiatry become vital to manage and optimize adult-life outcomes [4, 11]. As DSDs are relatively rare disorders, MDTs for DSD care could be established within one/ several tertiary care centers within the country/ region, depending on the needs of the country. These specialized teams will develop the necessary expertise collaborating regionally and internationally to develop best practices and provide a referral service for local hospitals within the region/ country.

The core composition of the MDT managing CAH/DSD can vary based on available expertise and can be further tailored individually for each encounter, based on the patient's age and needs. Initial management of DSD will focus on educating and counseling the family, establishing a diagnosis (including detection of life-threatening conditions such as adrenal insufficiency in salt-wasting forms of CAH), and appropriate sex assignment [4]. Decisions regarding the need and timing of genital reconstructive therapy in childhood, as well as the need for surveillance for gonadal malignancy and timing of gonadectomy where appropriate, will benefit from specialized MDT input [12]. Later in childhood and adolescence, focus is also given to disclosure, pubertal development, and gender identity, moving on to include sexuality, fertility, and monitoring for comorbidities [10]. Thus, the needs of those with DSD/ CAH will often require support from specialists in several fields, whose relative contributions may change over time.

Many families with CAH/DSD experience significant psychosocial problems [13]. Engaging with psychological care services could be helpful for parents: to face the unique challenges associated with the birth of a child with atypical genitalia, including coming to terms with the psychosocial issues they may face; and preparing them for meaningful discussions regarding gender of rearing [4]. A child psychiatrist/psychologist can also help the child to adapt to the multiple medical and psychosocial challenges they may face. During adolescence and adulthood, the involvement of a gynecologist/ urologist, specialist in sexual medicine, and adult psychiatrist/ psychologist is important to address issues related to gender, sexuality, sexual functioning, and fertility. There is also an important role for social and legal services in DSD care, in instances when a legal change of sex is required [10].

Upon reaching adolescence and adulthood, there is a fundamental shift from family-centered care to an independent individual approach. Continuous psychological support may be needed to help cope with disclosure and social and peer pressure. Irreversible procedures such as surgery for ambiguous genitalia and gonadectomy are best decided upon after comprehensive MDT discussion [7]. An in-depth understanding of the disorder is needed by parents and patients, to obtain informed consent. Certain surgeries may be contemplated by the individual given their cosmetic benefit, which could however compromise future fertility or sexual habits, and MDT discussion can be helpful in such situations [7]. Difficulty in understanding and accepting the condition, or any breach of trust with health care services could adversely affect the continuity of care and need special attention.

Transitional care in DSD

"Transition of care", in true terms, includes a series of actions designed to ensure continuity and coordination of care in a patient with a condition requiring long-term follow-up. It can be defined as a purposeful plan, a process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical conditions as they advance from a pediatric, family-centered health care provider to an adult, individual-focused one [14]. This is in contrast to the mere transfer of care, where there is abrupt termination of care by the pediatric team and commencement of care by the adult team. The National Transitions of Care Coalition, an organization dedicated to addressing issues related to the transition of care, defines it as "the care involved when a patient leaves one care setting and moves to another" [15]. However, in practice, what is generally happening especially in lower resource settings, is the 'transfer of care' of young patients with long-term medical conditions, from pediatric services to adult care services at a specific age defined by institutional protocols, e.g.: 14 years.

A well-structured transition of care from pediatric to adult care, however, is an important necessity in individuals with CAH/DSD for multiple reasons, especially since the age of transition often coincides

with that of puberty, which can be particularly problematic for young people with DSD. If the transition is not done in a coordinated manner, changing medical personnel can bring added pressure, and further compound difficulties faced by these young individuals.

Timing and process of transition

Ideally, the transition of care should be a gradual process, where the patient and family have sufficient time to develop trust in the adult healthcare providers. A timeline has been described for the transition of adolescents with DSD, based on recommendations from the American Academy of Pediatrics, which suggests that the process should begin with the introduction of the topic of transition, to the child and the caregiver, when the patient is around 12-13 years old [16]. By the age of 14-15 years, a transition plan, including the anticipated age of transition and the responsibility of each stakeholder in ensuring the completion of the transition process should be formulated. Review and modification to this transition plan can be done with the involvement of the patient when they are 16 -17 years old. Finally, the transition plan is implemented when they are 18-21 years old [16]. This timeline, however, may have to be modified or adjusted, according to the locality; for example in the UK, where the age for completion of transition is 18 years [7]. Further, transition may be more challenging for the family, in situations where the diagnosis of DSD is only made during adolescence and may require additional time for the family to adapt before starting the process [17]. A well-thought-out written transitional policy that gives due consideration to factors such as age, family support, emotional maturity, and coping capacity of the child, will help guide pediatric professionals on when to start the process [17].

Preparation of the patient should be commenced at least a year before the actual transition takes place, and the patient should be gradually prepared to commence assuming some responsibility for his/her own care. Stepwise gentle disclosure of the nature of the condition, and an explanation of the treatment needed will help facilitate this process [7]. Adolescents with DSD have shown a willingness to be more involved in decision-making, especially about their sexual health [18]. Meeting members of the adult team whilst still being managed by the pediatric team, and enabling communication with the pediatric team, even after the transition is complete can help smooth and non-threatening continuation of care. Patient registries can be useful to monitor the transition of care and ensure that no child is left behind [10].

Challenges in providing MDT and transitional care

While the importance of MDT and transitional care services for the management of DSD is well recognized, gaps in care still exist, even in developed countries [19]. The complexity of the underlying DSD, which can often pose diagnostic as well as complex management issues, is often an inherent challenge to healthcare teams dealing with DSD [7]. Some other issues which have been reported to contribute to the hesitancy of pediatricians to facilitate timely transition include inadequate collaboration between pediatric and adult care professionals, emotional effects of severing the patient-doctor relationship between the pediatric team and children/families whom they have cared for many years and reduction of research opportunities due to low number of patients and negative economic impact [7, 20]. Poorly managed transition, however, will result in fragmented care and unmet patient needs [7]. A well-structured transition process should enable both the patient as well as adult health provider to be well-informed regarding problems encountered in early life, which can have important long-term health consequences. Otherwise, patients may default follow-up, if the attention received during the pediatric and adolescent period, is not continued in busy adult clinics, where metabolic and reproductive health needs specific to DSD may be overlooked. However, few developed countries have a national framework for the transition of care of pediatric patients with DSD to adult services [10, 19].

The situation is less satisfactory in developing countries, where, while expertise may exist, coordination between services to provide MDT and transitional care is often not established. Indeed, the need for 'MDT and transitional care' is often under-recognized by healthcare providers in developing countries [20]. This could be dictated by logistical factors, including the existence of separate tertiary care hospitals for adults and children, lack of interconnectivity between central and peripheral hospitals, and lack of integrated electronic patient health records. Shifting patients from pediatric to adult care services in developing countries, thus often occurs as an abrupt transfer of care, instead of as a smooth transitional process, due to limited opportunities for combined and shared care. Separately functioning hospitals can also cause unwillingness or inertia by patients, to change from the health care institute that they have visited throughout childhood and adolescence, into an entirely new center. Lack of established protocols to guide healthcare providers, scarcity of relevant research as well as financial restraints in developing countries, could also be contributory factors [7]. Due to the above restraints and challenges, MDT care and transitional care for individuals with DSD are yet to be established in many developing countries. However, multidisciplinary management of DSD, with emphasis on early detection and management, (even with minimal facilities for molecular genetic diagnosis) can lead to improvement in the quality of life of young people with DSD in developing countries [21].

Clinical experience in establishing MDT and transitional care services in lower-middle-income countries.

We have established and conducted MDT and transition care services for adolescents with CAH/ DSD, in a tertiary care hospital-based university center in Sri Lanka, a lower-middle income country. During the process of initiating and continuing these specialized clinical services, we experienced many challenges. Yet the process was an enriching learning experience, and remarkably satisfying in terms of delivering a structured and smooth transition for the

young adolescents with CAH/DSD.

An important fact to highlight from our experience is that many practical difficulties can arise at the outset when a novel clinic with the participation of multiple specialties is been established in low-resourced settings. Some logistic challenges we encountered included: finding adequate physical space and scheduling times convenient to all regularly (considering the large numbers of patients seeking care at the limited tertiary care centers) and documentation and record keeping (which is mostly done manually yet). Finding appropriate local health services to refer young adults for long-term follow-up was difficult, due to the lack of specialized medications and resource personnel in many local settings. However, older adolescents and young adults with upcoming major academic examinations/ and occupational responsibilities found it difficult to travel to tertiary centers regularly. Finding solutions to these practical concerns was challenging, and compounded by the lack of guidelines to direct the process. However, the enthusiasm of these young individuals and their families, to actively participate in the MDT/ transitional care clinics despite difficult social circumstances, was rewarding. We made improvisations based on the individualized medical and social needs of each patient, and witnessed gradual familiarization and trust building between the young people and families and the adult care teams, facilitating a smooth transition of care.

Suggestions to overcome the challenges

There is now an increased interest in improving holistic care in DSD worldwide. Regular MDT discussions to deliver coordinated care to patients with DSD are recommended by international guidelines [22]. Studies have shown that well-structured transitional programs which ensure that adolescents move seamlessly from pediatric to adult care, help to improve quality of life and provide good disease control [23, 24]. Creating highly specialized centers that can address the complex needs of individuals with rare diseases such as DSD/ CAH from childhood to adulthood is recommended as one way to achieve these goals [22].

Based on available literature and our personal clinical experiences, we suggest creating specialized centers for DSD care, with the involvement of various specialties from both pediatric and adult care services is the most feasible way to optimize lifelong care for individuals with DSD, especially in developing countries, where necessary expertise may often be limited to a few major cities. These centers can liaise with local healthcare teams to provide comprehensive and sustainable long-term care throughout the country. Considering the benefits of structured, well-planned MDT and transitional care for individuals with DSD, initiative must be taken to establish proper systems to optimally mobilize available resources and expertise.

National Policy and Research

National guidelines on transitional care should be formulated in consultation with the relevant professional bodies. Guidance may be obtained from established protocols in Western countries, with appropriate changes as necessary to adapt to cultural needs and available resources. Healthcare professionals should be made familiar with the process of transition. For this, education on transitional care needs to be introduced into both undergraduate and postgraduate medical curricula, while continuous medical education programs should be utilized to increase awareness among medical professionals.

When considering rare conditions such as DSD, the establishment of a national/ regional registry for patients will be useful, to ensure that no individuals are 'left out', ensure surveillance and audits of the process, and facilitate follow-up. This will also facilitate further improvement of care. It is important to promote locally and regionally relevant research on DSD, focusing on both medical and psychosocial health. Practical difficulties faced can be identified and rectified through these processes.

Transitional clinics

Practical methods to conduct transitional care as either dedicated transition clinics or as routine clinics need to be considered. Identifying the optimal physical space to conduct these clinics and obtaining relevant personnel to organize and coordinate the participation of pediatric and adult health care teams and patient/family needs careful consideration. A successful transition needs active involvement from both pediatric and adult healthcare teams. It is important to have an insight into the phenomenon of transition initially. Positive interpersonal connections between teams need to be built. Attitudinal changes are required, and professionals must come to a common platform for the holistic management of the patient.

The composition of the transitional care team needs to be collectively decided. Based on our experience we suggest that if the patient is residing far away from the center, the local healthcare setting to be involved in routine regular follow-up care in adulthood. If this is the case, the best local center to collaborate with for shared care needs to be identified, in discussion with the patient, as a change of residence could also occur around this time, for higher education or career needs or based on adult relationships/marriage. Local health care could be provided by a general physician or if available endocrinologist of the closest hospital with the plan of reviewing the patient 6-12 monthly at the specialized center, and routine follow-up and medication if any to be provided at the local center. Any problems and issues which may occur when establishing a new service should be periodically reviewed and the process revised and improved as relevant, with increasing experience to improve service provision.

Process and timing of transition

Given that each adolescent will have different social circumstances and needs, individualized decisions regarding the optimal timing of the transition are better taken in discussion with the patient and family rather than routinely adhering to a set age for commencing transition. Individuals with DSD should be followed up at a pediatric clinic until puberty is

established and secondary education is completed.

Transitional care meetings should ideally commence a few years or at least six months before transfer to adult care. Individuals should be gradually allowed to develop responsibility regarding their condition. Patients should be gradually introduced to the concept of transition, and what it entails, before meeting the adult medical team at transition care meetings. This will help the patient and family to accept the idea and develop trust in the process. This will help minimize misinterpretation of transfer to adult services as a detachment by the previous medical care team, once adult age is reached. During the initial transition clinic, the patient and family will usually be seen jointly by pediatric and adult endocrinology teams, with other specialties joining at subsequent clinics as needed. If the patient is planned to be followed up by a clinician at a local center for routine follow-up in adulthood, ideally, that clinician will also be invited to participate in a subsequent meeting, to meet the family and be involved in the final plan, using an on-line platform when feasible. Patients will be gradually educated that there will be changes in management goals when an adolescent with DSD enters adulthood. The change in focus of care from achieving optimal growth, puberty, and psychosocial development to optimizing reproductive and metabolic health, including psycho-sexual and fertility issues that may emerge over time should be explained, emphasizing the need for continued specialized adulthood medical care.

In the presence of adult and pediatric endocrinology teams, a secondary look at the patient will be worthwhile. Re-appraisal of the initial diagnosis, especially when definitive genetics are not available can be done. The patient should be re-evaluated, and a comprehensive plan should be formulated. This should include future metabolic and fertility issues, parameters to be monitored, management of emergencies, and handling of drugs. This information should be given to the adult center of follow-up as well as the patient. In certain conditions, especially when a young adult has fertility wishes, an accurate genetic diagnosis may be mandatory. This message also should be conveyed to the individual and family, for them to make informed decisions.

Following the transition, the pediatric team can continue to be involved for a few years, if so requested by the patient, as they will be more familiar with the clinicians who managed them during the long years of childhood and adolescence. All decisions taken should be formally documented for future reference. To empower individuals with DSD, provide written instructions and reading material during transitional meetings. Obtaining feedback from the individual and family, re-evaluating the process regularly, and conducting audits and longitudinal research on long-term outcomes and quality of life, will all assist in uncovering gaps in care and improving the health care delivery.

Telemedicine

With advancing technology, telemedicine can be a very useful tool if used effectively to improve MDT and transitional care for DSD. Virtual platforms can be considered, especially in more complex situations, where specialists from multiple disciplines may need to be involved, and the physical presence of all parties concerned is difficult to arrange [8]. New care models need to be developed and explored, including the use of telemedicine for MDT and transition care clinics which will be convenient as well as cost-effective for all parties [8]. However, the availability of facilities, patient acceptance, and effectiveness will need to be assessed when establishing such care systems.

Table 1: Guide for establishing transition-of-care services for adolescents with chronic diseases

Steps to establish transition-of-care services for adolescents with chronic disease
National policy and research
Establish national guidelines on the transition of care (professional medical bodies)
Introduce the concept of transition into undergraduate and postgraduate curricula
Establish disease-based national/ regional patient registries to monitor the process
Conduct continuous educational programs on the importance of healthcare staff
Promote locally and regionally relevant research
Establishing transition-care clinics
Identify relevant pediatric and adult care teams
Identify appropriate space and staff to coordinate
Establish positive communication and collaboration between teams
Review and improve the process over time
Process of transition
Introduce the concept of transition to adolescent and family
Empower the adolescent to take responsibility gradually
Introduce the adult-care team at a joint meeting
Re-appraise diagnosis, current and future issues with adult-care teams
Discuss new goals of management with adolescents and family
Formulate a clear follow-up plan over several meetings
Monitor the process of transition based on feedback, audits, and long-term outcomes
Timing of transition
Individualize timing of transition considering patient's age, maturity, social needs
Commence the transition process a few years before the anticipated age of transfer of care Combined follow-up by pediatric/ adult care teams until puberty completed

Conclusion

Understanding that individuals with DSD/CAH are a group of individuals who need lifelong, careful follow-up to optimally adapt to a normal life, will help establish better management. Literature regarding DSDs and transitional care is scarce, especially in developing countries. A multidisciplinary approach with shared decision-making should be done from early diagnosis and continued during and after the transition to adult care. Guidelines for proper transition should be established and a smooth process should be planned to ensure patients are neither disappointed nor dropped out of medical care. Creating centers of excellence for DSD/CAH care to create collaborations among the various specialties may offer the best possible care to individuals with DSD, whose care can then be shared between the centers and local healthcare teams.

Nomenclature:

DSD Differences in sex development
MDT Multi-disciplinary team

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