12 Political Concerns in Transitioning Medical Care

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Establishment of Transition Clinics

The introduction of successful transition of pediatric patients to an adult setting is reported to start as early as 11 years. For children with congenital urological conditions (CUC), some recommend that children begin attending a joint pediatric and adult clinic at around the age of 13 [1]. While this model likely allows for introductions between patient and healthcare provider and a better understanding of the patient's history, health status and personal goals, the logistics of having two senior clinicians present at each visit for an extended period may be impractical in many systems. Reasons behind this will include a lack of personnel, space, reimbursement and financial support by the host institution. Furthermore, additional services such as neurosurgery, nephrology, orthopedics, and endocrinology, among others, may be unable to participate in multidisciplinary encounters. Support services such as social work can play an important role in transition of care and ideally, should be involved. Funding for such clinics may be particularly problematic. There are several potential barriers in setting up these clinics, for example, location, staffing, how will health care professionals from different institutions participate, and how is reimbursement divided. While this may not be a concern globally, these are questions faced by any healthcare professional seeking to start a transition program in the United States.

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Government Support

Successful transition of care for adolescents and the continuity of care for adults with congenital conditions is dependent on the availability of healthcare professionals to provide expert care. In addition to clinical expertise, the ability of these professionals to provide quality care hinges upon support at multiple levels, ranging from the unit and hospital in which he or she works. The influence of national specialty organizations, education and training committees, and the nation's health care system may significantly affect the success of a program. Additional support such as that afforded by charities and support groups are also important in the development of successful programs. Given the complexity of delivering such care, many countries, including the United States, continue to struggle with the development of programs to transition the care of patients with complex, long-term, congenital conditions. Additionally, care may be limited by restraints placed on health care professionals and institutional rules. For example, a pediatrician's license may limit his/her ability to care for people over the age of 18 or 21. Moreover, a pediatric hospital may not allow admission of patients over the age of 18 or 21. This age may even vary from institution to institution and country to country.

United States of America

The US population as of the 2010 census was 308.7 million. Almost one-quarter of Americans (74 million) were under the age of 18 at the time of the 2010 census [2]. In 2010, approximately 56.7 million people living in the United States had a disability. Approximately 8.4% of children under 15 had a disability, with half of these children having a severe disability and 0.5% of children under 15 requiring some assistance. The percentages of those with a disability, severe disability, and those requiring assistance increased with age [3].

As children with disabilities age, they are nearly twice as likely to be unemployed (41.4% employment rate) compared to their non-disabled counterparts (79.1% employment rate). Approximately 10.8% of adults between the ages 15 and 64 with severe disabilities were likely to experience persistent poverty over a 24-month period, which is twice the rate seen in adults with non-severe disabilities (4.9%) and almost three times as often as adults with no disabilities (3.8%). In 2008, the US federal government spent an estimated $357 billion on programs for working-aged people with disabilities, representing 12% of federal outlay. With advances in medical care, both the number and percentage of people with a severe disability continues to increase [3]. As an example, the economic burden of medical care for individuals with spina bifida is immense. In 2010, an estimated $1.79 billion were spent on emergency and inpatient services for people with spina bifida alone. This value does not include the cost of outpatient visits, surgery, medications, or the opportunity cost of missing work and/or school for the patient or caretaker [4].

In the United States, federal and state governments help provide health insurance and benefits to adults with disabilities through services like Medicare and Medicaid [3]. Medicare is a federally funded healthcare insurance typically for legal residents of the United States over the age of 65. Individuals over age 18 who have received Social Security disability benefits or have been diagnosed with end stage renal disease and been on dialysis for 3 months or have had a kidney transplant may also benefit from this insurance. Therefore, children with congenital conditions without renal failure will only be eligible for this form of insurance if Social Security deems physical and/or intellectual impairment are sufficiently severe that the individual cannot earn more than $1090/month from work and is not expected to earn that amount for at least 12 months [3].

Medicaid is a social health care program that provides free or low-cost health coverage for low-income people, families with children, pregnant women, the elderly and people with disabilities with resources insufficient to pay for health care. This program is funded jointly by state and federal governments. Currently, each state individually manages and determines who is eligible for the program and which services are covered [5]. Total Medicaid spending in 2016 was over $550 billion dollars [6]. The income limit to qualify for Medicaid differs by state. For example, in New York and California, the Medicaid income eligibility limit is $28,179 for a two-parent household and $16,642 in a one-parent household. In Indiana, the Medicaid income eligibility limit is $28,383 for a two-parent household and $16,763 for a one-parent household. In addition to Medicaid, Children's Health Insurance Program provides low-cost health coverage to children in families that earn too much money to qualify for Medicaid. Other public health insurance programs cover nearly half (44%) of children with special health care needs [7].

With the passage of the Patient Protection and Affordable Care Act (ACA) in 2010, often referred to as ObamaCare, children can stay on their parents insurance through age 26 and those with pre-existing conditions can obtain insurance coverage during open enrollment [8]. When data was last measured in 2010, prior to the full enactment of ObamaCare, the uninsured rates were no different in adults aged 15–64 with severe disabilities (21.0%), non-severe disabilities (21.3%) and no disability (21.9%). However, those with severe disabilities were less likely to have private insurance (40.2%) compared to those with non-severe disabilities (65.2%) and no disability (71.1%). Overall, almost half (48%) of adults with severe disabilities received government health coverage [3].

The future of the ACA remains an issue of intense debate in the United States. Shortly after passage, there were several challenges to the constitutionality of the ACA. In *National Federation of Independent Business v. Sebelius*, the Supreme Court ruled that the ACA's individual mandate was constitutional when viewed as a tax and that individual states had the right to opt out of the ACA's Medicaid expansion without losing preexisting Medicaid funding [9]. Several states have opted out of the elements of the ACA for which they had discretion. In *King v. Burwell*, the Supreme Court ruled that federal subsidies could be used in the 34 states that did not set up their own insurances exchanges, prompting *United States House of Representatives v. Price* in which the House sued the administration alleging that the money for premium subsidy payments to insurers had not been appropriated, which is required for federal spending [10]. The uncertainty regarding continued subsidy payments prompted some insurance companies to raise premiums.

In addition to judicial challenges to the ACA, there have been legislative repeal efforts. Since passage of the ACA, there have been unsuccessful repeal efforts in the 111th, 112th, 113th, 114th, and 115th Congress. In 2017, the American Health Care Act was introduced to partially repeal the ACA, which was passed in the House of Representatives [11]. The Senate attempted to pass multiple amendments to this bill, including the Better Care Reconciliation Act of 2017, the Obamacare Repeal Reconciliation Act of 2017, and the Health Care Freedom Act of 2017 [12–14]. So far, all specific bills were defeated in the Senate. There remains significant uncertainty about the future of the ACA under the current Trump administration.

Those with disabilities, especially severe disabilities, are significant consumers of the health care system. This usage will continue to grow as people with severe disabilities have improvements in survival. As children with disabilities mature into adolescents and adults with anomalies and disabilities, transition of care becomes important. Neither the American Pediatric Surgical Association (APSA) nor the Society of Pediatric Urology (SPU) has a statement regarding the transition of care of patients from pediatric to adult providers. Pediatric general surgeons surveyed revealed that nearly all (95%) treated patients up to 22 years of age, and many cared for older patients. Institutional limitations and lack of a qualified adult surgeons were cited as the most common barriers to transition [15]. In a similar survey amongst pediatric urologists, 2/3 reported caring for adult patients, while more than 80% felt that a pediatric or adult urologist with an interest in transitional care would provide optimal care. Nearly 70% of pediatric urologists surveyed reported that they would refer mature complex genitourinary patients to a urologist with an interest in adolescent/transitional urology, if one were available [16].

As urologists, we have used our own specialty as an example to represent the challenges faced, in this field. When thinking of this one should consider that there is no adult equivalent of bladder exstrophy, posterior urethral valves or hypospadias (to suggest some examples)—hence these are often less familiar to adult practitioners. As more patients with complex genitourinary disease and reconstruction grow, approach adulthood and survival to old age, the United States will develop a growing need to formalize an approach to transition care from pediatric to adult providers. Formalization of the process remains difficult for several reasons. There are many components necessary for transition beyond governmental support and insurance previously described. While it is unclear how many "adolescent urologists" or "congenital urologists" are necessary, Woodhouse estimates the need to be one "congenitalist" for four million people [17]. Currently, most "congenitalists" are part of the division of pediatric urology or adult urology at their respective institutions. To date there are no formal training programs for adolescent or congenital urology. Training in general urology may not adequately prepare a urologist to care for an individual with a chronic CUC. Currently, in the United States, there seems an increased willingness of those trained in pediatric urology, reconstructive urology and/or female pelvic medicine to care for these individuals. Additional training beyond a general urology residency in both adult reconstructive techniques and pediatric urology and knowledge of transition processes would be optimal. However, the American Board of Urology (ABU) mandates that an individual must dedicate

75% of his/her effort to pediatric urology in order to be eligible for a certificate of added qualification in the discipline. This may thwart residents interested in "congenitalism" from pursuing additional training in pediatric urology for fear they may not be recognized as having this additional expertise particularly if they are devoting more than 25% of their time to the care of adults, albeit with congenital conditions. Development of training programs for "congenitalists" requires the interest of practicing urologists as well as the support of specialty governing bodies such as the ABU and Royal College of Surgeons.

The specific needs of adults with CUC almost always outweigh those of a child who presents to a pediatric urology clinic with the same congenital disorder. This can be attributed to a "longer history", increasing needs or worsening of the disease process. For example, concerns associated with sexuality and fertility arise, and renal or bladder function may worsen. Colleagues within the division may not appreciate longer patient encounters and more tedious and complicated surgeries given the patients extensive surgical history. This may be viewed negatively by departmental colleagues, as peers can see more patients over the same period of time and in turn generate more income for the group.

The American Academy of Pediatrics, American Academy of Family Medicine, and American College of Physicians-American Society of Internal Medicine released a consensus statement describing a framework to ensure a smooth transition to healthcare [18]. Unfortunately, applications of these principles and adoption of transitional programs have been observed in multiple fields throughout the United States. Due to similar problems and obstacles observed in children with congenital urologic diseases, anorectal malformations, Hirschsprung disease, HIV, allergic disorders and immunodeficiencies, type 1 diabetes, hypercholesterolemia, inflammatory bowel disease, sickle cell disease, congenital heart disease, autism, rheumatic conditions, transplant recipients, and children with other chronic diseases requiring hospitalization, research into optimal transition plans have been described [19–31].

As part of its work, the National Alliance to Advance Adolescent Health, sponsor of Got Health, and the American Academy of Pediatrics have actively worked to support the delivery of transition services in both primary and specialty care settings. As reimbursement for such services remains difficult, they have developed a transition payment tip sheet that includes CPT codes and alternative payment methods to support the delivery of recommended transition services. These include pay for performance, capitation, bundled payments, shared savings arrangements, and administrative or infrastructure payments. Details are available at www. gottransition.org.

Canada

In sharp contrast to the American healthcare system, a group of socialized health insurance plans provide coverage to all Canadian citizens. Health insurance in Canada is publicly funded and administered locally with guidelines provided by the federal government. This is available to all citizens regardless of medical history or personal income. Private health insurance plans are also available to supplement primary health coverage. While private clinics do exist, they are not legally allowed to provide services covered by the Canada Health Act [32]. Private clinics may decrease wait times for certain services and are a subject of controversy, as some feel this leads to discrepancies in health care delivery based on income. In 2001 health care expenditures in Canada were $100 billion. In 2015, approximately 10.1% of Canada's gross domestic product is spent on health care (approximately 16.9% in US) [33].

The Canadian Pediatric Society has provided a mission statement on the transition of care from pediatric to adult practices. Health care goals include involvement of the adolescent in the management of the condition, adolescent and family understanding of the condition, understanding of personal potential, completion of adolescent developmental tasks, and attaining self-esteem and self-confidence [34].

They have outlined several strategies to help transition. At teenage visits, they recommend part of the visit occurring without parents to give the patient an opportunity how to discuss their problems, ask and answer questions, and advocate for themselves. Educational material dealing with youth issues and youth living with health conditions are provided to patients and the patients are recommended to attend peer-support meetings in person or online. Similar parental and sibling support groups also exist. The hospitals arrange family and teen education days to allow teens to meet each other, gather information, and discuss transitioning to the adult system. Finally, a formal acknowledgement of "graduation" in the form of a certificate from the pediatric staff given to the patient marks a rite of passage, while a letter to the patient and family about the new facility and staff can allow the patient and family know what to expect in the adult setting [34].

United Kingdom

Most healthcare in the United Kingdom (UK) is provided by the National Health Service (NHS). Within the UK, each country has some variability in healthcare policy and delivery, but the general system is similar. The NHS is a free service to all residents of the UK and is financed from mandatory national insurance taxation paid by employees directly from their salaries and supplemented by an obligatory contribution from employers. Self-employed persons pay the full contribution themselves. The onus is on the employer to deduct contributions from its employee's wages. Dependents, those with special needs and the unemployed are exempt from contributions. In England, the NHS accounts for most of the Department of Health's budget (£110 billion in 2013–2014) [35]. The total expenditure on healthcare as a proportion of GDP in 2015 was 9.8%, which was less than comparable economies such as Canada (10.1%), Belgium (10.4%), Denmark (10.6%), Netherlands (10.8%), France (11.0%), Germany (11.1%), Sweden (11.1%), Switzerland (11.5%), and the USA (16.4%) [33].

The Department of Health in the United Kingdom has clear guidelines recommending pathways to facilitate optimal transitional care across all specialties [36]. In addition, there are government initiatives to establish centers of expertise to develop clinical care, including better transition, to support clinical research and expand education and training programs for healthcare professionals [36]. Specific guidelines for the transition of patients with HIV are available from the Children's HIV Association [37]. Neither the British Association of Paediatric Surgeons (BAPS) nor the British Association of Paediatric Urologists (BAPU) have a statement on transitioning of surgical patients with complex congenital problems. Similarly, there is not a clear defined pathway of transition from child and adolescent mental health services to adult mental services, with half of trusts reporting children with attention deficit hyperactivity disorder were prematurely discharged from service due to a lack of suitable adult services. Additionally, there was a reported lack of written transition protocols, care pathways, commissioned services and inadequate information sharing between services [38].

There are several prominent multidisciplinary transition clinics in the UK. The adolescent urology department in University College Hospitals (UCHL) in London works closely with the Great Ormond Street Hospital's Department of Paediatric Urology where there is a transition clinic. Patients are brought to UCHL and seen by clinicians in the multidisciplinary adolescent unit, where there are joint clinics and joint operating sessions with adolescent gynecologists. There is a lifelong commitment to patients, and there is no further transitioning process. Similarly, the Adult Transition Urology Clinic (ATUC) in Glasgow, Scotland was established as a joint effort between Royal Hospital for Sick Children and Southern General Hospital. In this clinic, a pediatric urologist and adult urologist see patients concomitantly. Other specialists, e.g., adolescent gynecologists, will participate if needed. A survey of the 26 out of 30 patients who attended the clinic and completed transition over 4.5 years was conducted and completed by 19 patients. It revealed that 95% thought the clinic was useful and 89% would recommend it to others. Those involved in the clinic recommended 18 as the ideal transition age. They further recommend written information be provided to patients to help address patient needs and concerns as well as allowing the patient to decide when and if they should transfer their care to the adult setting, as one in five patients did not feel comfortable in the adult setting [39].

Australia and New Zealand

Adolescents make up more than 10% of most general practitioners practice in Victoria, Australia. These providers reported having an incomplete understanding of developmental aspects of adolescence and reported concerns about their knowledge of and competence in delivering adolescent health care. They perceived a range of barriers to effective health care provision, including issues of confidentiality, communication and cost and desire changes in the Medicare card and rebate systems to ensure improved access to affordable, confidential care for adolescents [40].

Since 1999, a Private Health Insurance Rebate has supplemented the public health plan. For this rebate, the government funds up to 30% of any private health insurance premium covering people eligible for Medicare. Including these rebates, Medicare makes up about 43% of the total Commonwealth health budget [41]. In 2016–2017, Medicare expenditure was $22.0 billion [42]. Expenses are expected to increase by 2.5% to 2020-2021 reflecting higher demand for health services. Medicare and Private Health Insurance Rebate expenses comprise 41.2% of total estimated health expenses for 2017–2018 [43].

In Australia, there are some good examples of successful transition programs. A "transition support programme" for young adults aged 15–25 with Type 1 diabetes was developed in Sydney to assist young people as they move from pediatric to adult health services. This allows them to remain under a system of care including a diabetes specialist, primary care physician and diabetes educator with the hopes of improving specialist clinic attendance after leaving pediatric services, improving glycemic control, and reducing hospital admissions for reasons related to Type 1 diabetes, like diabetic ketoacidosis [44].

The Australia and New Zealand Association of Paediatric Surgeons Inc. (ANZAPS) does not have a written policy on transitioning of pediatric patients with complex congenital conditions. However, hospitals are addressing the issue of transition at the hospital level. The Royal Children's Hospital in Melbourne has developed an adolescent transition program that is equipped to introduce transition programs into every specialty at RCH. They have a separate transition department that identifies a transition lead in each department and tries to establish a transition service and clinic. In New Zealand, Starship Children's Health in Auckland, New Zealand has developed web tools outlining the transition process. They have devoted clinics to transitioning of patients with diabetes and congenital heart conditions and are currently working on clinic for other specialties [45].

Cultural Issues

Cultural differences in religion, family structure, expected early adulthood experiences, relationship to health care providers, health literacy, and goals for independence exist across various countries and ethnicities [46, 47]. This becomes compounded when language differences exist between provider and patient. However, even when a language barrier can be bridged with an interpreter, cultural variations can still interfere in the relationship between a patient and medical provider [47].

One of the major differences between cultures is a young adult's experience as they develop from late teens to early adulthood. This developmental time period has been termed "emerging adulthood." In China, for example, much of the population is rural and poor, and only 20% obtain any post-secondary education. However, as China's middle class continues to grow, it can also be expected that many life experiences associated with the transition from childhood to adulthood experienced in western societies will be experienced by a growing proportion of young Chinese [46].

In Latin America, like China, only those in wealthier families experience emerging adulthood. In more economically developed countries, emerging adulthood is experienced across a range of social classes. In one such country, Argentina, young adults resemble their counterparts in the United States in many ways but are found to have more enduring family ties and stronger family obligations [46].

Emerging adulthood is widespread across Europe. Many Europeans spend their young adult years studying, traveling, and socializing before settling into the commitments of adulthood. However, this varies somewhat across Europe, as southern Europeans are accustomed to living with their parents during young adulthood [46].

In western societies, numerous factors, such as healthcare systems, the availability of healthcare professionals, social services, support groups and family structure and support can influence the success of transition. Families are crucial in transition planning and implementation. Numerous family variables, such as living arrangements, extended family support, education, income, and marital/familial support impact health care transitions [48].

Familial support has been linked to traits such as emotional resilience and independence in adolescents and young adults with chronic illness [49]. When parental and child views differ with regards to a patient's increasing maturity or perceived readiness for more independence in their own healthcare, transition planning and implantation may be negatively affected [49–52].

Even after patients are old enough to assume legal responsibility for making their own medical decisions, parents and close family members will often provide emotional and financial support during transition and beyond. However, many patients with congenital abnormalities also have varying levels of cognitive impairment. Parents, or other close relatives, often continue as legal decision makers when the patient is unable to assume the responsibility. As such, reliance on emotional and financial support from parents may be more important for young people with disabilities compared to their non-disabled peers [53].

State agencies assume the role of guardian and act in lieu of the parents and/or close relatives in some children with disabilities. The rates of disability of children in foster care are high. Approximately 14% have a disability usually involving a cognitive or psychological condition [54]. In addition, many former foster children live in poverty, with many former foster youths homeless, poorly educated, or unemployed. Further, studies have shown that 30% of former foster youth had difficulties accessing healthcare due to inadequate finances or insurance, while 40% had worries about their health care. Fortunately those with more severe disabilities may receive ongoing support from various social service agencies, however, there remain serious deficiencies in how foster care programs manage the transition from child to legal adult with respect to health care services [55–57]. Some critics have recommended extending childhood Medicaid coverage to age 21 in an effort to assist young people leaving the foster care system [58].

Range of Services

The range of services differ largely between institutions based on institutional support, the training of the physicians providing care and the availability of subspecialty services. In the United States, there is no formalized training for those interested in treating adult patients with congenital disorders for most specialties. In addition, there is no agreed upon process for transition. As such, the services provided at each institution and by each service are highly variable.

The Canadian Pediatric Society recommends a multidisciplinary approach integrated into existing specialty clinic settings that provide a stepwise plan of increasing responsibility for self-care. Transition services may include individual counseling, psychoeducational groups, joint transition clinics, educational materials, and online tools [34].

In the United Kingdom, there are government initiatives to establish centers of expertise to develop clinical care, which includes transitional care. There are several prominent multidisciplinary clinics across the country. Similarly, hospitals in Australia are focusing on developing multidisciplinary clinics to treat common diseases.

Supporting Organizations

There are numerous international, national and local support groups for various diseases. Individuals and families affected by rare medical conditions often look to nonprofit support organizations and advocacy groups to understand how the condition may affect their lives, for medical information about the condition, treatment options, latest research, and other resources.

Advocacy groups often help people connect with each other online via Facebook, blogs, listservs, etc. and may provide opportunities to meet in person at local meetings, summer camps or yearly conferences. These supporting organizations provide medical information in easy-to-understand terms and often have a list of helpful resources, such as financial assistance resources, sources for special medical equipment, and advice on dealing with school or health insurance issues [59]. Many groups will work closely with centers of excellence and can be involved in the training of specialists. They can often help patients and families find specialists with experience diagnosing and treating rare medical conditions [60].

Advocacy groups often help advance medical research by maintaining rare disease registries to collect information about individuals with specific medical conditions or referring patients to appropriate registries [59, 61]. Often these groups will keep information about the progress of research and will help raise money to offer grants to medical researchers and pharmaceutical companies who are developing new treatments [59–61]. Perhaps most importantly, advocacy groups help educate the public and medical community about the condition and may take issues to local, state, and federal governments to help pass legislation that will improve the lives of those affected by rare and genetic conditions [59, 62].

Many advocacy groups focus on one rare condition or a group of closely related conditions. These groups may join together to create umbrella groups to tackle larger issues, such as advocating for legislation to help or protect all individuals with rare conditions. Examples include NORD (National Organization for Rare Disorders), Genetic Alliance, Global Genes, and EURORDIS (European Rare

Disease Organisation). Umbrella organizations have helped pass the Orphan Drug Act, GINA (Genetic and Information Nondiscrimination Act), and the European Union Regulation on Orphan Medicinal Products.

The National Alliance to Advance Adolescent Health, sponsor of Got Health, and the American Academy of Pediatrics has actively worked to support the delivery of transition services in both primary and specialty care settings. As reimbursement for such services remains difficult, they have developed a transition payment tip sheet that includes CPT codes and alternative payment to support the delivery of recommended transition services. These include pay-for performance, capitation, bundled payments, shared savings arrangements, and administrative or infrastructure payments. Details are available at www.gottransition.org [29].

In summary, optimizing transition services is necessary. Beyond the willingness of healthcare professionals to care for these patients, political support at all levels will be needed for continued success and further improvements in care.

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