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Baishideng Publishing Group Inc
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Challenges of modern day transition care in inflammatory bowel disease: From inflammatory bowel disease to biosimilars

Ali Hakizimana, Iftikhar Ahmed, Rachel Russell, Mark Wright, Nadeem A Afzal

Ali Hakizimana, Rachel Russell, Nadeem A Afzal, Department of Paediatrics, University Hospital Southampton, Southampton SO16 6YD, United Kingdom

Iftikhar Ahmed, Department of Gastroenterology, University Hospital Southampton, Southampton SO16 6YD, United Kingdom

Mark Wright, Department of Hepatology, University Hospital Southampton, Southampton SO16 6YD, United Kingdom

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Correspondence to: Nadeem Ahmad Afzal, MBBS, MRCP, MRCPCH, MD, Department of Paediatrics, University Hospital Southampton, Tremona Road, Southampton SO16 6YD, United Kingdom. n.afzal@soton.ac.uk
Telephone: +44-238-1208711
Fax: +44-238-1204750

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Abstract

In this article we discuss the challenges of delivering a high quality Transition care. A good understanding of the adolescent needs with good communication between Transition care physicians and the patient is essential for good continuity of care. Despite availability of several guidelines, one model doesn't fit all and any transition service development should be determined by the local need and available healthcare facilities.

Key words: Transition; Adolescent; Inflammatory bowel disease; Biosimilar

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Core tip: Adolescent medicine is fast becoming a speciality in its own right. A good understanding of the needs of the adolescent patient is essential for delivering good quality care. Effective communication between Transition Care physicians as well as with their patient is the key to providing good continuity of care. Despite availability of several guidelines, one model doesn't fit all and any transition service development should be determined by the local need and available healthcare facilities.

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INTRODUCTION

I wish to start by first asking our readers a question, "When does an adolescent become an adult?"

Generally, an 18-year-old is considered to be a grown up adult and we will often use this "age cut off" to define many adult services including transition care and 18 would mark either the start or end of Transition care, depending on where you practice. Interestingly, the "Bank of America" and "United States Today" surveyed 2180, 18 to 26 year olds to find only 27% of the respondents characterised themselves as an adult and 1/3rd felt adulthood didn't begin until a person was at least 21 years old. The legal drinking age in United States is 21 years which might potentially influence the view. However, it is well known that acquisition of social and financial independence is considered to be important to become an adult, and this "adult age" seems to be ever increasing over the last few decades. This widening gap between adolescence and becoming an adult has now been linked with increasing mental health, behavioural and substance use issues (*e.g.*, smoking, alcohol and cannabis)^[1] which we may see in our practices and sometimes even in transition care.

Adolescents undergo biological, psychological and social development, whilst growing into adults. However, in teenagers with inflammatory bowel disease (IBD) these three milestones may be delayed. In addition, teenagers will often be taking regular treatments (oral medications and injections) possibly facing issues related to delayed puberty, worried about a shorter final height compared to expected, and then making matters worse when they may start comparing themselves with the peers.

The use of a sharp age cut off to define transition services suddenly appears woolly. Not unsurprisingly, only 5.6% of older adolescents/young adolescents on the verge of transfer to adult care met the gastrointestinal (GI) units benchmark in United States^[2].

There are other issues as well. With adolescents facing their own set of problems, practitioners in transition services need to be knowledgeable about these issues. Not just their understanding needs to be good, they also need to be able to relate and communicate well with the teenagers. The reality however is far from it. The Royal College of Paediatrics and Child Health (RCPCH), United Kingdom has launched a very interesting "young adult and transition project" with forum discussions and meetings including patient's stories including a blog by an 18 year old young man, Thine, who helped facilitate such an event^[3]. Thine with the group raised these poignant issues during discussion forums run on the day: (1)

middle aged doctors in particular compared to other age groups do not know how to communicate with young adults properly; (2) the doctors generally tend to communicate with parents rather than the patients; and (3) some felt that at the point of transfer to the adult services, they had not built up enough confidence to discuss issues openly and confidentially with their new adult consultants.

A number of adult gastroenterology physician surveys have been carried out to highlight the inadequate transition by paediatric gastroenterologists. Ironically, the response rate of adult gastroenterologists to these surveys has been extremely poor being as low as 30% which equally doesn't bode well for the interest or keenness of survey participants^[4-6]. Accepting all criticisms, with caveats, there is little doubt that IBD-transition care in today's age needs to improve.

These discussions highlight the importance of training practitioners in communication and transitional care practice.

WHAT IS TRANSITIONAL CARE?

The American Society for Adolescent Medicine defines transitional care as "purposeful planned movement" of adolescent and young adults with chronic physical and medical conditions from child-centred to adult-orientated health-care systems^[7].

This definition lays down underpinning principle for transitional care from paediatric to adult services, which is "continuity of care". This has been further explained by Haggerty *et al*^[8] defining three types (concepts) of "continuity".

First is continuity of use of information on past events to make current care appropriate *e.g.*, a practitioner should be fully aware of previous treatments, any drug reactions, non-response and surgery before prescribing new treatments. Without this information incorrect or ineffective treatments may be prescribed to the patients.

Second is adopting a consistent and coherent approach to patient's changing needs *e.g.*, childhood to adulthood. Adolescence brings a significant change in the life of an individual which comes with its own challenges, further amplified in patients with any chronic illness such as IBD. Patient with chronic illness may be affected by delayed biological and sexual maturation^[9].

Third is an ongoing therapeutic relationship between patient and providers, which gastroenterologists and practitioners view as regular clinical appointments by the similar teams in a transitional clinic. Both paediatric and adult practitioners should be present in such a clinic. A handover clinic where a patient may only be seen once by paediatric and adult teams before moving on to adult services shouldn't really be labelled as "transitional clinic".

VARIATION IN TRANSITION GUIDELINES IN DIFFERENT COUNTRIES

Guidelines regarding the protocol for transitional care vary between regions. These variations perhaps not only reflect our own differing views about transition and adolescent growth but are also dictated by available healthcare systems. Despite this observed variation, there tends to be a general consensus regarding major aspects of transitional care.

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition guidance

Guidelines for the United States and Canada are outlined by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN). In its recommendations the NASPGHAN acknowledges the difference in the health care services of the two countries (United States and Canada) and adopts its approach accordingly. NASPGHAN places emphasis on promoting independence for the adolescent patient, they recommend that the Paediatric Gastroenterologist should begin to see their adolescent patients without their parents to resemble the relationship they will have with adult physicians. A discussion regarding the subject of transition of care to adult gastroenterologist and its benefits is also recommended to take place with both the patient and their family. The importance of a skilled adult physician with experience in caring for young adults is also highlighted by the NASPGHAN. Moreover, the importance of sharing medical records is stressed to reassure the family that both the paediatric and adult services are working together to deliver high quality care for the patient. With regards to the timing of the transition, the NASPGHAN provides separate recommendations for the United States and Canada. Since patients over the age of 18 years cannot be admitted to paediatric care in Canada, the transitional process needs to occur earlier in adolescence and must be completed by the age of 18. Meanwhile in the United States, many young adults are under the medical insurance of their parents and insurers require that hospital admission occur at the location where the insurance holder resides. This raises different challenges in the transitional process as many young adults will be at college during this period which may be preferable by many as they may be more independent at an older age. We need comparative studies to see which system works better for our patients. Despite this, a lot of the care occurs over the telephone though, which may pose its own difficulties for the gastroenterologist and patient^[10].

As adults we would often take our spouses or on occasions even our parents or family members for our appointments. We, in Southampton (United Kingdom) therefore don't believe in a solitary patient attendance at a clinic in the absence of their parents. We believe

this should be patient choice and not made obligatory in guidelines. At the same time we also encourage patients to show responsibility in communication and not look at their parents for each piece of information.

European Society for Paediatric Gastroenterology Hepatology and Nutrition guidance

European guidelines have been set by both the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) and the European Crohn's and Colitis Organisation (ECCO). Compared to NASPGHAN guidance, ESPGHAN appears to place more emphasis on recognising the psychosocial factors involved in the care of adolescent patients. Their guidelines state that the "time of transition should be individually adapted according to psychosocial readiness" and emphasize for this to occur between the ages of 16 and 18 years old. Furthermore, joint clinics where the adolescent is seen with both paediatric and adult gastroenterologist are encouraged by the ESPGHAN^[11].

NICE guidance in the United Kingdom

In the United Kingdom, NICE has issued guidance on transition from children's to adult's services for young people in 2016^[12]. This document defines the importance and principles of transition care laying emphasis in the period before, during and after transition. The guide discusses adoption of person centred approaches which are developmentally appropriate for each individual giving adolescents options to have a choice about their transition care. NICE introduces the concept of a "named worker" depending on each individual young person's needs. A named worker could be anyone ranging from a nurse, youth, education practitioner, health professional, GP, Specialist nurse, transition worker or an adviser. The NICE guidance also defines the role of this person which is essentially not only to support the teenager and family but also to help pursue appropriate care.

At Southampton Children's Hospital, we annually run 12 transition clinics; 6 are IBD transition and the other 6 hepatology transition clinics. The clinics are attended and supported by the paediatric and adult teams which comprise of consultant, specialist nurses, dieticians and psychology support. The care plans are agreed in advance to ensure smooth transition with the specialist nurses working as a key worker for patients and families. Due to our strong network links, we also successfully transition patients to other local GI services carried out in transition clinics in individual hospitals in the Wessex Network (12 hospitals with 8 regional clinics).

CHALLENGES FACED BY PROVIDERS - FROM BIOSIMILARS TO IBS

Innumerable challenges are faced by Transitional Care

providers. It is not possible to go through each individual scenario and therefore will mention 3 common issues faced in our current transitional practices.

Use of biosimilars

Improvements in diagnosis and development of new treatments has provided the modern day clinician with many treatment options. These options can help to tailor and optimise care to each individual patient. Monoclonal antibodies have revolutionised treatment of inflammatory bowel disease. Various monoclonal antibodies aim to target cytokines in the inflammatory cascade, suppressing these target molecules and help treat disease. A number of agents are now available on the market, which can be administered *via* various routes ranging from infusions in hospitals, to the use of subcutaneous injector pens in the community or home. In Southampton we discuss all available options with our patients, giving them the choice of treatments. Patients with their families proactively decide about their treatments. Although no data is available to prove this approach, we feel this not only empowers patients to take active control but also helps in better compliance.

A more recent development, evolutionary rather than revolutionary, is the use of Biosimilars for treatment of inflammatory bowel disease. NHS England describes Biosimilar as a biological medicine which is highly similar to another biological medicine already licensed to use^[13]. Biosimilars are cheaper and a Royal College of Physician audit shows that if Biosimilars are used in all recruited patients the NHS United Kingdom would make a significant annual cost saving^[14]. This is a huge cost saving which could potentially be invested in other services. In Southampton, our adult GI services developed a business case modelled on 150 IBD patients treated with a mean of 400 mg remicade every eight weeks for one year with a range of savings in drug acquisition costs. A potential saving of up to £812000 per annum with a 50% discount in drug costs if all patients agreed to change to Biosimilar infliximab was identified and this was invested into other parts of the GI service improving overall care^[15].

Switching from one monoclonal antibody to a biosimilar is a very hot topic, a quite common issue faced in transition care and there remains a considerable variation on adoption of this practice. The British Society of Gastroenterology was the first to advocate such practice^[16] however more cautious approaches have been adopted by other societies. Several to date studies on clinical efficacy, safety and immunogenicity of biosimilars do not show any issues^[17-19]. To date very limited paediatric data is available^[20] on use of biosimilars. As antibodies may develop within 2-3 treatments, ECCO advise against a switch due to non-medical reasons particularly within the first 6 mo of starting treatment^[21].

Another option is to avoid switching and this is possible by commencing treatments after discussion and a joint agreement is reached between the paediatric and adult teams. We prefer this approach in Southampton and often make these decisions in our regular 2 weekly joint adult and paediatric IBD meetings. Letters detailing treatment plans are then sent to local hospitals and patients who feel confident and assured by the conjoined management.

IBS in IBD

Irritable bowel syndrome is present in 14% of high school and 6% of middle school students^[22]. Little is known about IBS in teenagers with IBD though and studies are needed to understand this. We often face this issue in our practices and perhaps we can help bridge these gaps by sharing evidence from each other's practices. For *e.g.*, while adult colleagues are more knowledgeable in management of IBS in IBD, paediatric gastroenterologists are very experienced in use nutrition as sole treatment or supplement in Crohn's disease (CD).

Abdalla *et al.*^[23] in a large 6309 participant study showed 20% of IBD patients may have concurrent IBS making it 1 in every 5 patients. IBS-IBD patients are more likely to be women, less likely to have graduated college and a comparatively lower QOL. Also these patients account for a relatively higher number of clinic visits when compared to non IBS-IBD patients. Despite no studies, in Southampton transition clinics we often recognise these issues in adolescents and teenagers.

It is not always easy to differentiate IBS symptoms from active IBD disease and patients may therefore often undergo repeat endoscopies. Use of tests such as faecal calprotectin may have a useful role particularly when normal calprotectin has been previously documented in an IBD patient.

Liver disease in IBD

At first presentation of paediatric IBD, liver enzymes are abnormal in 6.9% of all patients, more commonly in patients with UC than CD. Spontaneous normalisation of liver function tests occurs in about 40% patients within the first 3 mo^[24]. Developing PSC is worrying but is fortunately less common in paediatrics with an incidence rate of 0.23/100000 compared to 1.11/100000 in adults^[25].

Children with liver and IBD may be seen in both IBD and Hepatology transitional clinics making an already complex management even more difficult. Without good communication this may cause confusion. In Southampton we successfully adopted a model where the paediatric gastroenterologist responsible for patient's care leads and oversees management in each individual transition clinic. These patients will eventually be followed up more in the clinic where there is more disease burden but keeping the other specialists

informed about any change of treatments at all times.

DISCUSSION

Where do we stand with regards to transitional services today?

Although we have started to understand the need of Transition care but we certainly are still not doing well and there is still a long way to go. The Royal College of Physicians conducted a National IBD audit showing only 53% of healthcare providers provide a transitional care service for young people with only 46% provide regular transitional care in hospitals in United Kingdom. On a positive note this is an improvement from previous years^[26]. With available services the Royal College of Physicians recommends Transition care providers to having a clear written policy and protocol for transition care. The audit findings are again quite pessimistic, revealing only 36% of services having a specific transition policy.

This issue is not exclusive to the United Kingdom, a national survey of Paediatric care providers in the United States also highlighted room for improvement in providing transitional services. Although slightly better than the United Kingdom, 68.1% of providers reported providing support for transition. Again, only half of participants reported being familiar with the transitional guidelines^[27].

There is no disagreement that gastroenterologists should be knowledgeable about transitional care. In a survey of 383 adult gastroenterologists, 96% held the belief that it was important for an adult physician to have knowledge of the medical aspects of adolescent health care however only 73% felt that they had adequate knowledge. Again worryingly only 46% of adult physicians felt they were competent to deal with adolescent developmental and mental health issues^[6].

One of the criteria used for successful transitioning is acquisition of "medical knowledge" and independence of adolescent patients with regards to their treatments. As high as 69% of surveyed adult gastroenterologists surveyed expected patients having knowledge of their medications as an expectation in delivering transitional care^[6]. This expectation is perhaps unrealistic particularly when adult IBD patients don't retain such knowledge about their treatments. A study on adults with regards to knowing information about their IBD medications found that although 97% of patients could recall the names of their medication; this figure dropped significantly with regards to recalling their dose (63%) and even lower regarding knowledge of the side effects of their medication^[28].

Transition care providers report that unsuccessful transition care resulted where they were unable to communicate effectively with their patients^[29]. As also mentioned at the start of this article, this remains a key hurdle in providing even the best of services to our patients. More focus is needed to train the practitioners

in better communication with patients and families. Despite being a people contact profession, we as doctors are never trained in communication skills during our medical training years. We are expected to automatically learn on the fly. This method certainly works well for some but not for all of us. We feel communication should be an essential part of the curriculum especially for students aiming to pursue branches of medicine where there is first contact with patients.

CONCLUSION

We continue to face a number of challenges with regards to delivering transitional care. These range from no services to poor delivery and on occasions not helped by unrealistic expectations of the practitioners. Lack of insight and knowledge of transition care providers is a significant issue. Adolescent medicine is fast becoming a speciality of its own and these issues could be addressed by better training opportunities for the transition care providers. Health Units successfully running transition processes could share their experiences positively in possible unit to unit peer review visits, a process which was once run by the Royal College of Physicians. It is also about the time we recognise the role of patients who can help in development of our services. In the absence of a joint concerted effort, of us all working together we continue to fight a losing battle risking compromised care with poor continuity and confidence for our young IBD adolescent patients. At national level Paediatric gastroenterologists join and contribute to Transition care forums and activities in the British Society of Gastroenterology. Perhaps it is time now for us to invite adult gastroenterology colleagues to paediatric gastroenterology meetings. This will not only improve communication but also help to increase our understanding of common issues faced in Transition care. We will have a better chance to iron these issues managing these challenges together.

In Southampton we do not find a regular 3-4 monthly clinic to be adequate for delivering the needs of what we recognise as a "quality transition care". In addition to the clinic, the two teams meet in a two weekly joint paediatric and adult IBD meeting to discuss difficult and complex cases. Alongside this we recognise the important of gastroenterology teams meeting patients and families and now hold a regular open transition meeting in Southampton. This has turned out to be an excellent resource not only to enhance patient education but also giving patients a chance to meet members of the Adult and Paediatric IBD teams. These are a couple of examples which have helped improve delivery of transition care in Southampton and are by no way meant to be proscriptive for everyone to follow. One model doesn't

fit all and any transition service development planning should be determined and dictated by the local need and available healthcare facilities.

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