

TRANSITION OF ALLERGY HEALTHCARE

John O Warner^{1,2}

Marta Vazquez-Ortiz^{3,4}

¹ Emeritus Professor of Paediatrics, National Heart and Lung Institute, Imperial College, United Kingdom

² Honorary Professor of Paediatrics, University of Cape Town, South Africa

³ Consultant in Paediatric Allergy, Imperial College NHS Healthcare Trust, United Kingdom

⁴ Course Director PG Cert, PG Dip and MSc in Allergy, Imperial College London, United Kingdom

Email | j.o.warner@imperial.ac.uk

ABSTRACT

Because allergic diseases are long-term conditions that commonly manifest first in early life and persist in various forms well into adulthood, the transition from paediatric to adult care is an inevitable requirement. To date there has been very little focus on the requirements and wishes of young people with long-term medical problems as they transition through health services. As a consequence, there is a paucity of guidance on the way in which their transition should be conducted to optimise the outcomes and experience of these patients. The burdens encountered by patients as they are expected to develop full independence and competence to manage their own condition are superimposed on a number of physical, psychological and social challenges. Their need to achieve educational and career goals while taking control of their allergies can be overwhelming. System specialist societies and health services are beginning to resolve this problem as outcome data show that young people are particularly vulnerable to adverse events. A disproportionate number of fatalities occur in young people with severe asthma and food-induced anaphylaxis. Recommendations on the structure of this transition are being developed by national and international allergy societies. However, regional differences in health service organisation and variations in political, sociological, environmental and financial structures mean that the transition can be optimised only through locality-based implementation. The planning must involve all stakeholders, of whom young people with allergic diseases are most important. A series of recommendations are presented here which incorporate those developed by the European Academy of Allergy and Clinical Immunology together with our own additions that respond to specific challenges raised by young people.

Keywords: allergic disease healthcare transition, asthma, food allergy, patient experience, patient outcomes

INTRODUCTION

Allergic diseases mostly arise in early childhood but as long-term conditions they commonly persist into adulthood. Therefore, many patients transition from paediatric to adult health services. In addition, the sequential development of different manifestations of allergy and/or the co-existence of more than one condition often result in patients consulting diverse system specialists. In both circumstances there is an urgent need to co-ordinate care so as to enable a smooth transition from one speciality to another.

Theoretically, linking different system specialist input through centralised allergy services should not be a problem. Allergists have the knowledge and skills to provide comprehensive management. However, the symptoms of potential allergic diseases can have many other causes and system specialists have the tools to ensure accurate diagnosis, meaning that collaboration is required. A centralised allergy service should provide a smooth transition through the medical disciplines, preferably by one-stop combined consultations. This will reduce the health and/or economic burden on patients, their families and health services.

However, transition from paediatric to adult care has proved to

be more difficult to achieve worldwide.¹ It occurs at a time in a young person's life when there are significant developmental changes. This can lead to medical vulnerability as they face physical, psychological and social challenges.² The young person is expected to develop full competence and autonomy to manage their condition independently while also achieving their educational and career goals.³ Parents who have previously taken the lead in exercising their responsibility for managing their child's allergic problems must metaphorically release the apron strings. This combination of challenges has the potential to compromise the healthcare of young persons. Among those with severe food allergy and/or asthma there are many examples of the deterioration of control during the teenage and early adult years, sometimes with catastrophic consequences.^{4,5} Indeed, adolescents with asthma and food allergy experience unexpectedly high mortality and morbidity compared to other age groups.^{5,6}

Because the evolution through to fully competent adulthood is a gradual process, the organisation of their transition must follow a similar path. It has been falsely assumed that reaching sensible adulthood and healthy behaviour is a linear process; however, sociological data suggest that it is a haphazard progression.⁷

Furthermore, gaining the level of health literacy and competence to make sensible decisions does not occur at a fixed age and may vary from time to time and between individuals throughout life.³ This leads to transition being a flexible process, one that starts in the early teens and continues until fully established competent adulthood. Depending on the young person's evolving maturity and competence, this will commence from around 12 years of age and continue well into their 20s as brain maturation is completed.

YOUNG PEOPLE'S EXPERIENCE OF TRANSITION

Poor patient experience during transition can have a significant adverse effect on outcomes.^{8,9} The only way this experience can be improved is by listening to the views and the lived experiences of young people as they progress through transition.^{10,11} In designing the solutions, healthcare professionals must work with young people to incorporate an understanding of the wide range of influences on health.¹² The author, Dr Warner, has been involved in a qualitative study that is focused on young people with sickle-cell disease (SCD) as they transitioned from paediatric to adult services; the insights provided by the young people have implications for all long-term conditions.¹³ The design of the research programme should be replicated for allergy to understand the disease-specific issues. The SCD study highlighted the fact that health professionals frequently fail to recognise that young people actually have expertise in understanding their medical condition, a matter flagged for other chronic conditions.¹⁴ If the voices of those with severe disease such as asthma are not heard, including their health-related needs and priorities, they may delay seeking medical attention, and that could lead to adverse outcomes.⁴

Several other important messages have emanated from the SCD study. Young people reported a relatively smooth transition from paediatric to adult specialist care. However, they were dissatisfied with non-specialist services and encountered significant problems in accident and emergency, and also in general adult medical settings. While this was partly disease-specific in relation to pain relief, the lack of appreciation of a young person's knowledge of their own condition was upsetting. They felt out of place and unwelcome in adult wards compared to the welcoming friendly atmosphere in paediatric settings. Poorer accommodation in adult compared to paediatric settings has even been a concern expressed by 15–17-year-olds (and their parents) admitted to trauma centres.¹⁵

Dr Warner's awareness of this came very early in his career when an 18-year-old long-standing patient of his with severe asthma attended his first adult out-patient clinic. While he was in the waiting-room, an elderly patient with chronic respiratory disease sitting next to him fell asleep on his shoulder and dribbled onto his jacket. He fled from the clinic, luckily finding Dr Warner in an adjacent out-patient clinic. Dr Warner was able to use this event to persuade his adult chest physician colleague to start joint transition clinics. However, similar experiences have commonly led to young people adopting strategies to avoid attending hospital with potential adverse outcomes from delays in receiving appropriate treatment.¹³ A Swedish survey of young adults with severe asthma revealed similar concerns that their views were not being considered in planning management.¹⁶

A lack of engagement by adult services and the reduced frequency of consultations had the potential to lead to the same response as SCD patients who disengaged from follow-up as a result. Patients not being heard has been a theme in a few publications.^{13,17}

DESIGNING TRANSITION PROGRAMMES

Irrespective of speciality, previously, most attempts to optimise young persons' transition have involved a 'top-down' approach where the process is formulated by health professionals in the absence of research evidence. It is disappointing that most guidelines for transition have been developed without the involvement of those who have first-hand experience of the process. For instance, a Delphi exercise formulated after a systematic review of the published literature involved health professionals, parents and carers, but not the young people themselves beyond stage 1 of the process. The most important desired outcome highlighted in this study was enhancing quality of life (QoL).¹⁸ How this can be achieved optimally will require prospective studies involving different transition programmes. A systematic review of publications by the European Academy of Allergy, Asthma and Immunology (EAACI) focused on the challenges faced by young people with allergic disorders.¹⁹ Psychological problems and poor QoL associated with inconsistent treatment adherence (the term used in the study) were common themes for all the allergic conditions. Asthma and food allergy had the greatest adverse effects. Favourable influences arose from effective communication and supportive healthcare providers. However, to date, no studies have followed allergy patients through their transition and evaluated their experience. A systematic review of publications focused on interventions during transition identified that a limited improvement in QoL was achieved following general education interventions and peer-led camps, but only studies in asthma had acceptable statistical validity.²⁰ This has stimulated both the EAACI and the British Society for Allergy and Clinical Immunology (BSACI) to create task forces to develop guidelines for the transition of young people with allergic diseases.^{21,22}

Among the many conundrums being considered by BSACI, the transfer of care for those in the midst of oral allergen immunotherapy (OIT) has been a particular concern. While paediatricians have become very familiar with food-allergy diagnosis and management, it is relatively new to adult specialists. Indeed, many adult allergy services do not have the facilities for or experience of delivering OIT. This is a theme noted by other disciplines, notably by hepatologists for patients with childhood onset of hepato-biliary disease, many of whom received transplants in early childhood for conditions unfamiliar to adult clinicians.²³ It is notable that, as with allergy, it is specialist societies in the international system who are taking the initiative to develop recommendations regarding the transition from youth to adulthood.²³

PRINCIPAL COMPONENTS OF A TRANSITION PROGRAMME

While a plethora of articles outlining the problems and making suggestions on the structure of transition do exist, they all agree that much experience and outcome research is still required. No study has to date identified the optimal approach by prospective

study. Furthermore, the absence of those with lived experience of planning the programmes will inevitably lead to programme failure. The optimal approach to implementation must be to co-design the transition process with patients and their parents and/or carers together with health professionals, all as equal partners. The EAACI guidelines on transition were formulated after a thorough literature review and involved diverse health professionals and representatives of patient organisations but not the patients themselves.²¹ Having included patients could well have added several other components to the recommendations. A cross-sectional European survey among young people with asthma and/or allergies and their parents endorsed the guideline recommendations prior to publication.²⁴

The key evidence-based recommendations of the EAACI were divided into general and allergy-specific.

GENERAL

1. Start transition early (11–13 years).
2. Use a structured multidisciplinary approach.
3. Ensure adolescents and young adults (AYA) fully understand their condition and have resources they can access.
4. Ensure active monitoring of adherence.
5. Discuss any implications for further education and work.

ALLERGIC DISEASE-SPECIFIC

1. Simplify medication regimes and the use of reminders.
2. Focus on areas where AYA are not confident and involve peers in training AYA patients.
3. Identify and manage psychological and socio-economic factors that have an impact on disease control and QoL.
4. Enrol the family in helping AYA to undertake self-management.
5. Encourage AYA to let their friends know about their allergies and asthma.

The list is predominantly top-down, and the AYA descriptor in these recommendations might be problematic. In some countries and cultures, 'adolescence' is viewed as a pejorative term; there the preference is for the over-riding term, 'young people'.

Several other key components of successful transition must also be included. They arise from experience in working with young people in clinical practice during the development of the Royal College of Paediatrics and Child Health allergy care pathways and subsequently the SCD study.^{13,25} The message repeated by young people in all settings was this: 'listen to our views and expectations. Respect our developing autonomy and avoid beneficence (paternalism) at all costs. Give us time to get used to adult services by maintaining contact with the paediatric team throughout the transition period.'

The difficulties arising during contact with non-specialist services must be anticipated. If the young person always has a facility to contact a specialist health professional (an allergy nurse specialist often being the most favoured) urgently when things go wrong, these problems will be overcome.

Our suggested additions to the recommendations are these:

1. Ensure the young person's views about their allergic condition and its management together with their expectations are heard and incorporated into the management plan.
2. Reach an accord (mutual agreement) with the young person on their treatment programme. This has the best chance of achieving concordance (the preferred term compared to compliance or adherence, both of which imply paternalism).
3. Establish how the young person would like the agreed management plan to be presented: detailed or simplified; hard copy or on-line; or on their smart phone, etc.
4. Ensure that the young person has a named familiar health professional they can rapidly contact if they encounter problems.
5. Be sensitive to and avoid using words considered to be pejorative by young people.
6. Understand the dynamics in the young person's family, their social network and future life aspirations. These will all influence the way in which you handle such issues as parental over-protection, risk-taking behaviour, lifestyle, career aspirations and environmental threats to health.
7. Work towards having facilities specifically set aside for young people for both in- and out-patient settings.
8. Work towards establishing a combined multi-disciplinary paediatric and adult allergy team with, where appropriate, shared facilities such as for OIT.

LOCAL CONTEXT

While there are basic principles to which transition programmes must adhere, the local context must be considered. This includes structural, cultural, environmental, political, financial and sociological variations. Several countries, including South Africa, have a paucity of adult allergy services. Until this shortfall is corrected, paediatric allergy services may need to continue clinical support well beyond the normal transition age. Transition programmes will therefore vary from one region to another and are best designed by local teams involving all stakeholders – most notably those young people with allergic conditions. There are still many unmet needs and therefore standardised experience and outcome measures will be needed to evaluate transition programmes. This will facilitate comparisons that will help to identify those components which result in the greatest success.

CONCLUSIONS

A high proportion of children with asthma and allergic diseases will require ongoing care well into adulthood. The transfer of young people from their paediatric allergy team to adult allergists has only recently been a focus of attention. Indeed, this is true for all long-term conditions, and health services worldwide are struggling to devise optimal transitions.²⁶ There are many gaps in the evidence regarding what constitutes the optimal pattern of transitional care. Specialist allergy societies have created task forces to make recommendations predominantly based on literature reviews and expert opinion; however, the key stakeholders, namely, young persons undergoing transition, have rarely been involved. To incorporate the specific needs of those undergoing such transition, we must understand more about the lived experiences of young people with allergic

diseases. Standardised experience and outcome measures will be required to facilitate prospective research which compares different transition programmes in order to optimise long-term outcomes.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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