Getting transition right for young people with diabetes

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Summary

Effective transitional care is now nationally and internationally accepted as integral to quality care for young people with chronic conditions such as diabetes. Although published guidance has been available for many years, evidence would suggest that there are still unmet needs in this area of diabetes management and services providing effective transitional care are not yet universally available. The aim of this paper is to review the recent transitional care literature with particular reference to diabetes, and consider the translation of the aforementioned policy and guidance into clinical practice. The current evidence supporting the positive benefits of transitional care and the need for the adoption of a developmental framework in transitional care development based on the core principles of adolescent medicine will be specifically considered.

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Key words

transition; transitional care; adolescent health; adolescent diabetes; chronic conditions

Introduction

In the UK, numerous policy and guidance documents have been published in recent years addressing the developmentally specific health care needs of adolescents.[1–3] Many of these documents acknowledge that young people, whether they have a chronic condition or not, are young people first and foremost and that the principles of adolescent medicine are core to their health care including transition. The aim of this paper is to review the recent transitional care literature with particular reference to diabetes, and consider the translation of the aforementioned policy and guidance into clinical practice.

Transitional care and diabetes

The literature suggests that the transition process between paediatric and adult diabetes services is not always smooth from the young person's perspective, and has been described as being 'slippery'.[4]

The morbidity associated with transfer of care is well described. In a Canadian study of 1507 young people with diabetes for at least five years, a significant increase in inpatient episodes was observed in the two years following transfer.[5] The risk of hospitalisation was related to previous inpatient episodes, lower income, female gender and areas with fewer doctors.[5] Other authors have noted a decrease in hospital clinic attendance following transfer to adult care[6–8] with the proportions lost to follow-up similar in different models of care delivery.[7] The authors in the latter study suggested that this similarity was more to do with the developmental status of the young people concerned rather than the type of service provided.[7] Several studies have examined young people who are lost to follow-up, and the factors identifiable prior to transfer included poor metabolic control, fewer outpatient visits in the year prior to transfer, greater hospitalisation for diabetes-related illness and not being in post-secondary education.[6,9]

A potential identifier not considered in these studies is the lack of preparation for transfer. Such preparation is a core aspect of transitional care advocated in many guidance documents (e.g. those from the UK Department of Health [DoH])[1,2] and the Royal College of Physicians of Edinburgh [RCPE]).[3] However, in a national survey in the US, only 29% of parents of 1411 young people with diabetes reported prior discussions regarding transfer of care.[10]

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Evidence base for effective transitional care

Over the last two decades, evidence has been established to support how effective transitional care for young people with chronic conditions can influence outcomes[6,11–20] as detailed in Table 1.

There is further evidence to support components of transitional care, many of which reflect the core nature of adolescent medicine principles *to transition*. For example, the opportunity for young people to be seen independently of their parents was considered to be 'best practice and feasible in the majority of UK clinics' by young people with juvenile idiopathic arthritis (JIA), their parents and a range of health professionals involved in their care.[21] Furthermore, this practice was observed as a baseline predictor of improvement in health-related quality of life (HRQoL) in young people with JIA,[16] and a determinant of successful transfer as defined by the attendance at the first adult clinic appointment in cardiology.[22]

Further evidence to support effective transitional care is that young people prefer to meet adult team members prior to transfer.[9,17,23–25] Positive benefits are observed with such practices including higher rates of adherence to appointments post transfer.[9]

The quality of relationships made with health care personnel (HCP) is potentially very important to young people. Provider characteristics have been reported to be significantly more important determinants of adolescent satisfaction with transitional care than physical environment and process issues (e.g. waiting times).[19] Furthermore, the most essential aspects of best practice as perceived by young people were staff knowledge and staff honesty.[19]

Another important aspect of adolescent health and transitional care provision is continuity of HCP. This was highlighted as a key issue by young people with diabetes.[26] If continuity of HCP is actively promoted, 77% of young people with diabetes were less likely to be hospitalised following transfer to adult care.[5]

A study examining the benefits of a transitional care coordinator in 191 young people with diabetes also found a reduction in admissions and readmissions for diabetic ketoacidosis and reduced length of hospital stay, as well as an improvement in metabolic control.[12] Further support for a coordinating role has come from the Canadian Maestro project that advocates the role of a 'Health Navigator' for young people aged 18–30 years.[14]

In a critical review of diabetes-specific literature, the three components which were associated with one particular readily measurable outcome of transition, i.e. an improvement in attendance post transfer, were: (i) an educational programme, (ii) a transition care coordinator, and (iii) a young adult clinic involving both paediatric and adult physicians.[27]

Transitional care outcomes	**Disease**	**References**
Stable and/or improved disease	Diabetes	Busse *et al* (2007)[8]; Vidal *et al* (2004)[11]; Holmes-Walker *et al* (2007)[12]
	CF	Duguépéroux *et al* (2008)[13]
↑ Adherence to appointments	Diabetes	Frank M (1996)[6]; Kipps *et al* (2002)[9]; van Walleghem *et al* (2008)[14]
	JIA	Vanelli *et al* (2004)[15]
↑ Self-management	Diabetes	Vidal *et al* (2004)[11]
↑ Disease knowledge	Diabetes	Vidal *et al* (2004)[11]
	JIA	McDonagh *et al* (2007)[16]
↑ Patient satisfaction	CF	Steinkamp *et al* (2001)[17]; Zack *et al* (2003)[18]
	JIA	Shaw *et al* (2007)[19]
↑ Parent satisfaction	JIA	Shaw *et al* (2007)[19]
↑ Health related quality of life	JIA	McDonagh *et al* (2007)[16]
↑ Vocational readiness	JIA	McDonagh *et al* (2007)[16]
↑ Documentation of adolescent issues	JIA	Robertson *et al* (2006)[20]

CF: cystic fibrosis; JIA: juvenile idiopathic arthritis.

Table 1. Evidence to support effective transitional care

Integrating the evidence base into clinical practice

Despite the evolving evidence base, why are transitional care programmes not fully integrated into clinical services for diabetes and other chronic conditions as reported in several recent national and international surveys?[4,28–33] (Table 2.)

Terminology

One of the problems with the body of literature in transitional care is the confusion with respect to terminology, particularly with regard to the terms 'transition' and 'transfer'. Health transition is a *process* which meets the medical as well as psychosocial, educational and vocational issues as young people move from child to adult centred services. Transfer is one of many *events* within the process of transition and does not represent the end of transition. Health transition is only completed when young people are functioning competently within the adult service.

The multidimensional nature of transitional care can also be overlooked, with outcomes being limited to medical ones such as metabolic control, complication rates, hospitalisation and/or clinic attendance. In a study of young people with cystic fibrosis (CF), even when medical outcomes were good, i.e. when clinical status remained stable during transfer, educational outcomes were less favourable with a significant increase in young people not in school or employment.[13] Future transitional care research needs to consider all outcomes, i.e. psychological, social and vocational, and not just the traditional medical outcomes.

Transition planning

The key components of transitional care have been widely reported[1,3] and are summarised in Table 3. One of these is individualised transition planning but this has yet to be universally adopted.[20,32–35] (Table 4.)

Most of the guidance documents advocate a start to transition planning in early adolescence. In a rheumatology study, greater improvements were observed when planning started at age 11,[16] an age when young people are already anticipating and/or experiencing change in the UK as they move from primary to secondary school. An early start to planning is called for by young people themselves in several

	Total no. of responding services	**% of services with transition/adolescent provision**	**Reference**
UK			
Diabetes	n=129	76% (specific local protocol)	Gosden *et al* (2010)[29]
Endocrine	n=72	56% (specific clinic)	Kirk J, Clayton P (2006)[28]
Gastroenterology	n=28	39% (specific clinic)	Davies IH, Jenkins HR (2003)[30]
International			
International Society for Pediatric and Adolescent Diabetes	n=92	50% (structured programme)	De Beaufort *et al* (2010)[4]
Paediatric dialysis	n=58	A third (transition programme)	Bell L (2007)[31]
Cystic fibrosis	n=170	18% (written protocol); 28% (specific transition-focused visits)	McLaughlin *et al* (2008)[32]
Grown up congenital heart disease	n=51	29% (transition programme)	Hilderson *et al* (2009)[33]

Table 2. Current transitional care services for young people with special health care needs

- Written transition policy, agreed with all major stakeholders
- Agreed timing of transition and transfer
- Appropriate young person friendly environments in both paediatric and adult settings
- Age and developmentally appropriate education and skills training programme for the young person
- Individualised transition planning including assessment of readiness of the young person for transition and transfer
- Mechanisms to address parental needs during transition
- A transition coordinator
- Interested and capable adult services
- Staff training (paediatric and adult) in transitional care and adolescent health
- Primary care involvement
- Administrative support for information transfer
- Monitoring and 'fail-safe' mechanisms, e.g. tracking mechanisms post transfer
- Regular evaluation and audit
- Participation of young people and their parents in service evaluation and future development

Table 3. Key components of an effective transitional care programme

	Total no.	% with individual transition planning	Reference
Outpatient case notes (UK: rheumatology)	n=93	3%*	Robertson *et al* (2006)[20]
Inpatient case notes (Australia: Children's Hospital)	n=247	13%	Lam *et al* (2005)[34]
Young people with special health care needs	n=5533	29%	Lotstein *et al* (2005)[35]
Cystic fibrosis programmes (USA)	n=170	50%	McLaughlin *et al* (2008)[32]
Congenital heart disease centres	n=51	29%	Hilderson *et al* (2009)[33]

*This increased significantly to 35% following participation in a transitional care research programme.[20]

Table 4. Prevalence of transition planning for young people with special health care needs

studies,[23,25,36] and yet studies of professionals reveal a difference in opinion with 96% of paediatricians (n=99/103) reporting that transition should start later than recommended (i.e. within one year of the proposed transfer).[37] In a recent international survey, 90% of diabetologists (n=92) recommended that transition planning begin at least one year prior to transfer.[4] Sawicki *et al* have recently published preliminary validation data of the Transition Readiness Assessment Questionnaire (TRAQ), which appears useful both to assess transition readiness and to guide educational interventions by providers to support transition.[38] Such tools will potentially be very useful in transitional planning from both a clinical and research perspective.

Transition administration

The administrative challenges with which transitional care presents services are a further consideration as to why policy is not always put into practice. The transfer of information between paediatric and adult services has been reported to be a concern of young people and their parents,[23,25,36] and suboptimal information exchange has been reported.[20] One solution to ensuring effective transfer of information is to provide a written summary for the young person themselves.[1,3] However, such practices are not universal. In a US study, only 50% of paediatricians provided written transfer summaries for young people with a range of special health care needs.[37]

Another administrative issue is the provision of a mechanism to track patients into adult care to ensure successful transfer. This has been highlighted in the UK Department of Health guidance,[1] which proposed the attendance at the second adult appointment as a potentially useful outcome measure. Sixty per cent of the 92 respondents to the International Society for Pediatric and Adolescent Diabetes survey 2010 reported that such mechanisms were either non-existent or rare.[4] In US cystic fibrosis programmes, 40% of 170 programmes had no such mechanism.[32]

Core nature of adolescent health

One possible reason for the lack of progress in translating transitional care into clinical practice is the fact that the interdependence between transition and the rest of adolescent medicine has yet to be fully recognised and/or acknowledged.[39]

The two major frameworks underpinning adolescent medicine, namely, development and resilience, are equally pertinent to transitional care. If transitional care is to be developmentally appropriate, transition policies, individualised transition planning, self-management, health and disease education programmes, as well as the services that provide these, should all reflect this philosophy.

Health care transition takes place during the mid and late stages of adolescent development when young people are experimenting and testing boundaries, and this includes experimenting with health risk behaviours and adherence. Young people with a chronic condition are reported to be more likely than their 'healthy peers' to report three or more risk behaviours,[40] and diabetes is no exception. In a study of 16–30 year olds with diabetes (n=85), 29% reported street drug use, 15% of whom were poly drug users and 68% using drugs at least once per month.[41] In two studies, health-risk behaviours such as substance misuse have been found to be associated with non-adherence.[42] Conversely, the lack of substance use has been reported to be a predictor of successful transfer in a cardiology clinic as defined by attendance at the first adult appointment.[22]

The recent advances in the understanding of adolescent brain development are particularly relevant, especially with respect to adherence and health-risk behaviours.[43] The two main aspects of adolescent brain development are (i) regulation of behaviour and emotion, and (ii) perception and evaluation of risk and reward. Frey *et al* reported findings that reveal the discrepancy between such perception and evaluation of risk.[44] In a study of 155 young people aged 10–20 years, 10–39% were reporting at least one health-risk behaviour, and were aware of the risks of such behaviours but perceived themselves as being less at risk compared to their healthy peers.[44] Clinical skills which are useful to address health risk behaviours and non-adherence, such as motivational interviewing,[45] are important components of future training programmes in adolescent diabetes care.

Brain development is now recognised to continue into the early 20s[43] and the concept of 'emerging adulthood' is helpful in this regard. Whereas identity *development* is a key milestone in adolescent development, identity *exploration* is a milestone of emerging adult development.[46] In a study of 194 emerging adults with diabetes, young people were found to have lower scores on identity exploration in breadth and depth compared to controls, raising the possibility that this age group perceive fewer opportunities to explore identity issues due to illness. In this study, identity development was found to be linked to illness-specific coping and outcomes.[46] Further research is needed as to how HCP integrate developmental frameworks into intervention efforts. Furthermore, it will be important to consider whether health transitions act as an additional stressor affecting identity exploration.

The other framework in adolescent medicine, pertinent to transitional care, is that of resilience or the capacity of the individual to resist or 'bounce back' in spite of significant stress or adversity. Adoption of a resilience framework ensures that, as well as the traditional consideration of risk factors, we also consider the protective factors at play such as the resources available to an individual young person (both intrinsic and extrinsic), their competencies, talents and skills. Skills which can be nurtured within the clinical setting include those of communication, negotiation, goal setting, problem solving, decision making, self-management, information seeking, and disclosure. In the evaluation of a transitional care programme in rheumatology, self-advocacy skills such as self-medication and seeing professionals independently of parents were reported to predict health-related quality of life.[16] Murphey *et al* reported that the number of assets with respect to school and voluntary work – e.g. talking with parents about school, representation in school decision making, participation in youth programmes, volunteering in the community – were directly related to health-promoting behaviours and inversely related to engagement in risk behaviours.[47] Assessment of resilience should therefore be an integral component of transitional care programmes.

One means of assessing resilience (as well as risk) is by using a psychosocial screening tool such as HEADSS.[48] It is important that such tools are used primarily to engage young people and not used in an interrogative manner. As at any age, the young person has the right not to tell. Such tools are also useful in providing information to formulate interventions. Evidence suggests that the asking of sensitive questions may have potential benefits. Brown *et al* reported that discussion of sensitive issues in a primary care setting was associated with significant benefits in that young people had a more positive perception of the provider, were more likely to have their worries eased, were more likely to be allowed to make decisions about treatment and were more likely to report taking responsibility for treatment.[49]

Transition and parents

One cannot discuss transitional care or adolescent health without considering the parents of young people. Many studies have reported the difficulties parents experience at this time.[23,24,50] Parents are also going through a transitional process both as their child moves from child to adult centred services as well as when their child becomes an independent adult. A major aspect of this is the gradual move from primary responsibility for health management to enabling the young person to self-care. Ivey *et al* reported the major themes in such parent–child interactions regarding diabetes management at this age to be frustration, fear, normalising, trusting and discounting.[50] A shared leadership to management is the ideal with the parent moving from providing all of the care, to managing the care as the young person begins to participate in care provision. As they become more skilled, the young person takes the role of manager with the parent as the supervisor and eventually, when competent, the young person becomes their own supervisor with their parent as the consultant when problems arise. Transition planning similar to that for the young person has been employed by some researchers and has been found to be useful.[16]

Workforce competency

Key to delivering adolescent health care, and therefore transitional care, is having appropriately trained HCP. In a Delphi study involving young people with JIA, their parents and professionals from paediatric and adult sectors, professionals knowledgeable in transitional care was best practice but only feasible in a few UK hospitals.[21] The UK lags behind other countries that have a dedicated training stream focusing on adolescent health care.[51] In a large UK paediatric hospital, 60% of HCP (including doctors, nurses and allied health professionals, n=95/159) had received no prior specific training in adolescent health.[52]

A component of training is around communication. Hambly *et al* described a preliminary study examining the effect of communication skills in paediatric diabetes services, and found that although HCP (doctors, nurses and dietitians) perceived that communication skills to address psychosocial issues were more important than medical issues, confidence in their ability to do so was significantly lower.[53] Suris *et al* highlighted the need for adolescent training in a study of adult physicians (n=102) looking after young people with chronic conditions: at least a third of physicians did not discuss sensitive issues, including 73.5% who did not discuss sexual health and 57.8% did not discuss emotional well-being. Furthermore, only 46% of adult physicians saw such young people independently of their parents – a core component of young person friendly health services.[54]

The EuTEACH (European Teaching Effective Adolescent Care and Health, www.euteach.com) initiative provides an excellent foundation for development of adolescent health training in Europe. In the UK, the e-learning package, Adolescent Health Project (www.e-lfh.org.uk), is a major first step in taking training developments forward in the UK, hopefully assisted by current discussions regarding formal training opportunities in several of the Royal Colleges, both paediatric and adult.

Conclusions

The evidence for effective transitional care and improvements in outcome is now available to support the development and implementation of transitional care services as advocated by the many current guidance documents (e.g. DoH[1,2] and RCPE[3]). The key components of an effective transition service are now well known (Table 3) and, if incorporated into services, are likely to ensure that transition becomes 'smooth and less slippery' for young people with diabetes.[4] The interdependence with adolescent medicine needs to be acknowledged[39] and a developmental framework to transitional care in diabetes adopted by both clinicians and researchers as proposed by a recent commentary.[55] Quality standards for young person friendly health services are a useful standard against which to benchmark services for young people with diabetes.[2] Working with other co-located disciplines will enable 'efficiencies of scale' in service development within institutions[56] and will ensure that we don't waste time and energy in re-inventing 'transition wheels'. Young people with diabetes are, after all, young people first and foremost and it is their youth in which we need to invest for their future.

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Conflict of interest statement

There are no conflicts of interest.

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