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CLINICAL STUDY

Transition from paediatric to adult ophthalmology services: what matters most to young people with visual impairment

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Abstract

Purpose **To identify the views and experiences and thus the transition-related needs of young people with visual impairment (VI), so as to inform future practice and policies.**

Patients and methods **Qualitative study of 17 young people aged 16–19 years (ie the conventional transition age threshold) with VI (best-corrected acuity logMAR worse than 0.48) and without additional impairments, drawn from a sampling frame of paediatric ophthalmology patients attending Great Ormond Street Hospital and Moorfields Eye Hospital (London, UK). In-depth, semistructured interviews were conducted to elicit their experiences, preferences, and attitudes towards transitioning within health care. Qualitative thematic analysis identified themes related to participants' experience of transition.**

Results **Eight of 17 participants had transitioned out of paediatric ophthalmology services, 7 had not, and 2 were unsure. Their views and experiences varied. Only 2 of those who had transitioned preferred their prior paediatric service, and 1 still in a paediatric services did not want to transition. Age-appropriate communication and physical clinical environment were two key components of care, both associated with greater confidence to self-manage health care in the future as an adult. Emotional attachment to paediatric services/teams was associated with reluctance to transition.**

Conclusions **Generic guidance on transition is broadly applicable to children/young people with VI. Age-appropriate communication and appropriate physical clinical environments may be optimally delivered through adolescent ophthalmology services bridging paediatric and adult provision. Lack of research on transitions in paediatric ophthalmology has thus far restricted intervention studies; our findings serve to aid in developing an evidence base to achieve this.**

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Introduction

Most children with chronic conditions or disabilities, such as visual impairment, require long-term health care to maximise functional health status and health-related quality of life. The importance of ensuring a timely and successful transition from child to adult services is recognised internationally,[1–3] particularly for those who progress into adulthood with rare childhood onset conditions and complex health needs.[4] A growing literature has identified the impact of a timely and successful transition in terms of secure disease-related knowledge,[5] high self-efficacy and good confidence for self-management of health,[6] and assessed the effectiveness of technology-based systems and methods such as use of the internet and mobile phones to provide young people with access to transition-related information and increased control over their transition.[6–8] Formal transition processes are reported to achieve increased self-efficacy and transition preparedness,[6–8] fewer self-reported disease symptoms,[9] and better clinical outcomes.[10–13] Conversely, poor quality transitions have been associated with a 'drop-out' of patients who become disengaged with their health care[14] and poor mental health and psychosocial outcomes.[15]

Most children with visual impairment or blindness (VI for brevity throughout) transition

from paediatric to adult ophthalmology services during adolescence, usually at a fixed age, as determined by health service restraints. The majority will approach transition having been diagnosed in early childhood, grown up without experiencing normal sight, and having been managed within specialist paediatric services.[16] A minority will have experienced loss of vision (acutely or gradually), in some cases just before transition becomes necessary because of their age. Thus, the needs of this population with regards to health care transition can be expected to be complex, diverse, and, in some respects, different from other young people living with chronic health conditions or disabilities. There is currently very scant literature to inform transition planning and provision in ophthalmology. We report an investigation of the views about and experiences of transitioning of adolescents living with VI, so as to identify the transition-related needs of this population, and as the necessary first step in developing evidence-based models of transition.

Materials and methods

We conducted a classical qualitative study using in-depth, semistructured individual interviews to capture the perspectives and experiences of adolescents with VI—those who had and those who were on the verge of transition. This study was approved by the National Health Service Essex Research Committee (REC ref.: 12/EE/0455) and adhered to the tenets of the Declaration of Helsinki.

Participant eligibility, identification, and recruitment

Subjects were eligible if they met the following criteria:

(a) VI (visual acuity in the better eye Snellen worse than 6/18 or logMAR worse than 0.48).
(b) No other significant sensory, learning, or motor impairment.
(c) Aged between 16.0 and 18.6 years on date of recruitment (ie spanning the age group at which transition conventionally occurs in the UK National Health Service).

Potential participants were identified using patient attendance lists and correspondence from the Department of Ophthalmology at Great Ormond Street Hospital and the Paediatric Glaucoma Service at Moorfields Eye Hospital (London, UK). Clinical records of each patient were checked for up-to-date clinical information and contact details. A sampling framework of eligible patients ($N = 383$) was compiled from which subjects were selected using a stratified random sampling approach to achieve a representative sample with respect to clinical and sociodemographic characteristics. Patients were invited to take part in the study that formed a component of our broader programme of research on the impact of living with VI.[17–19]

Forty-four eligible patients were invited to participate based on the following considerations:

(a) The principles of data saturation,[20,21] that is, the number of interviews needed to achieve comprehensive coverage of issues, as determined using findings from similar studies.[17,22]
(b) Anticipated participation rate of 30% based on prior studies recruiting children and young people with VI.[17]

Table 1 Questions and probes included in the topic guide used to prompt discussions centred upon young peoples' experiences of ophthalmic health care

Questions	*Probes*
Do you regularly attend hospital appointments?	Where/which hospital do you go to? How often do you go? Can you tell me what it is like? Is there anything that bothers you about going to hospital? Which doctor do you see? Do you like your doctor? Why (not)? Have you ever had to change doctor? How did that make you feel?
Do you know if you're seen in clinics for children or have you transferred to adult care?	Can you tell me what happened? How do you feel about being seen in child/adult-centred clinics? Is there anything you would have done differently if you had the chance? Do you have any recommendations for doctors or nurses/other patients who are transitioning?

Each subject was sent an invitation pack by post comprising an invitation letter, study information sheet, and consent forms. The pack was addressed to the parent/guardian, including an introductory letter and information sheet for the parent, but included a separate sealed letter addressed to the young person. Prepaid envelopes were included for return of completed documents.

All families were contacted by phone 2 weeks later to answer any queries and a postal reminder was sent a fortnight later.

Data collection

Interviews were conducted by a single interviewer (AR) between March and June 2015. The interview topic guide was developed *de novo* to explore many areas of everyday life (eg home, school, social life) as well as participants' experience of ophthalmic health care and the transition from paediatric ophthalmology services (Table 1). The topic guide was used flexibly during in-depth, semistructured interviews in which participants were encouraged to elaborate upon issues that they felt were important to the experience of living with VI and transitioning in health care. After confirmation of consent, an 'ice-breaker' activity preceded each interview in accordance with best practice.

Qualitative data analysis

Each interview was digitally recorded, transcribed, and exported into NVivo 10. Qualitative analysis based on the tenets of grounded theory[23] was conducted to identify key themes related to participants' everyday lives, including their experiences of ophthalmic health care. This approach was selected based on source data stemming from spontaneous speech in addition to answers to questions that were further probed. Thus, both inductive and deductive methods were incorporated. Interview transcripts were read by two researchers (AR and VT) to collaboratively develop a codebook, which was then used on the entire data set. Codes were grouped according to emerging themes. Themes were described and labelled.

Results

As shown in Table 2, 17 young people took part (39% participation rate). Their mean age was 16.8 years (SD: 0.9 years), 10 (58.8%) were male and 11 (64.7%) were White British. Fourteen (82.4%) had early onset VI (earlier than 5 years of age), 12 (70.6%) were visually impaired and 5 were classified as severely visually impaired or blind (WHO taxonomy based on logMAR acuity in the better seeing eye[24]). Eleven (64.7%) had non-progressive VI. Thus, the sample was representative of the population of visually impaired children and young people without additional impairments in the United Kingdom.[16]

Table 2 Demographic and clinical characteristics of participants categorised according to transition status

	Transitioned	*Not transitioned*	*Unsure/ unable to tell a researcher*
N (% of total sample)	8 (47)	7 (41)	2 (11)
Age (N, *% of category)*			
16	3 (37)	3 (42)	1 (50)
17	3 (37)	4 (57)	1 (50)
18	1 (12)	0	0
19	1 (12)	0	0
Gender (N, *% of category)*			
Male	5 (62)	3, (42)	2 (100)
Female	3 (37)	4, (57)	0
VI severity (N, *% of category)*			
VI	5 (62)	5 (71)	2 (100)
SVI/BL	3 (37)	2 (28)	0
VI onset (N, *% of category)*			
Early	5 (62)	7 (100)	2 (100)
Late	3 (37)	0	0
Nature of VI (N, *% of category)*			
Stable	5 (62)	4 (57)	2 (100)
Progressive	3 (37)	3 (42)	0
Current clinical placement/ arrangement (*N*)	6 adult ophthalmology services 2 specialist adolescent/ young-person ophthalmology services	7 paediatric ophthalmology services	Not under regular review

Abbreviations: BL, blind; SVI, severely visually impaired; VI, visual impairment.

Mean interview duration was 76 min (SD: 22 min; range: 40–113 min) and 16 interviews were conducted at participants' family home. Participants were encouraged to speak to the interviewer independently; however, a parent/guardian was present for some or part of four interviews.

Eight of the participants had already transitioned: six into adult services and two into dedicated adolescent services. Only two (25%) of these participants preferred their prior paediatric service, because of its more child-centred approach to communication, although pros and cons were identified by all. The two

Table 3 Qualitative analysis of interviews: codes, subthemes, issues relevant to transition and corresponding quotes

Code	*Subtheme*	*Pertinent issues identified from interviews*	*Sample quotes*
• The way I'm spoken to • The way they explain things to me • Talking to me vs. talking to my mum/dad • Explaining medical history to a new consultant • Reduced communication about support that is available to me and the progress of research • Increased responsibility for me to tell consultants if something is wrong	Communication with professionals within clinical contexts	• Reduced time to communicate within adult-centred environments • Difficulties vocalising views and ensuring voices are heard by new consultants • Consultants' knowledge of patients' medical history • Describing medical history to new consultants • Dependence on parents during consultations • Dominance of parents during consultations	…[in child-centred care] you'll be treated like a child but in adult clinics you'll be treated like you would be if you were in an interview. (Male, 16 years, transitioned). …My mum will get me involved in the conversation […] and says she'd rather me speak to them cos obviously it's my eyes and not hers but sometimes it feels like my mum and doctor are having the conversation and I'm like "hello I'm here"! (Female, 18 years, transitioned). …I think my mum knows more about my condition than I do! So [I'd rather have her there] than kick her out and go "oh I wanna do this by myself". (Male, 16 years, not transitioned). …[Now I've transitioned] they take a bit more time. They used to treat me like a child. They talk to you that way. (Female, 17 years, transitioned).
• Age-appropriate surroundings • Availability of activities/ entertainment in the waiting room • Proximity to home • Waiting times • Others in the waiting room • Size of the hospital • Clinics which are tailored to my age-group • Knowing my way around/ learning the new layout	Environment	• Differences in lighting, colours, and activities/ entertainment in waiting rooms • Growing dislike of child-centred environments • Appreciation of age-appropriate adolescent/ young-people's clinics and age-appropriate support available • Comparisons between patients and others in the waiting room • Learning the layout of new adult-centred environments • Getting lost when navigating without a parent/guardian • Familiarity with a new clinical environment	…When I had my first appointment I remember it being *so* different! I thought "what is this?!" [laughs]. Cos it's duller. You just sit there and wait and then get called and go. (Female, 18 years, transitioned). …I won't play with the toys or watch cartoons. […] I'd rather watch some news or sports on the TV and sit quietly. (Male, 16 years, not transitioned). …There's load of little kids. You're the big one and you don't feel like you're in the right place anymore. (Female, 18 years, transitioned). …I hate little kids! […] because I'm looking there [gestures at eye level] and they're quite short. Sometimes they're running. And I want to smack them! (Male, 16 years, not transitioned). …In the kid's one there were baby things to do there, whereas when you go to the teenage ward there's more grown up things. […] there's a pool table, TV's and computers (Male, 16 years, transitioned to adolescent services).

Table 3. (Continued)

Code	*Subtheme*	*Pertinent issues identified from interviews*	*Sample quotes*
• Building a family/close relationship(s) • Emotions related to leaving/transitioning	Emotional attachments to paediatric ophthalmology services	• Beliefs that a consultant/ health care professional will always be involved in a patients' health care • Losing contact with a consultant • Reduced access to vision-specific support	…When I was with J and they told me that I'd eventually go blind, she came over and gave me a hug […] I've stayed in children's' clinics simply because of J. I have a funny feeling that when I move to adult's clinics I will still see J. (Female, 17 years, not transitioned). …There was more support. P was there and she would understand some stuff. (Male, 16 years, transitioned). …I'm a bit sad that I'm leaving my doctor. Most of the doctors I have known for quite a few years, I've got used to them. (Female, 17 years, not transitioned).

participants now in an adolescent service identified significant positive benefits of this specialist service bridging child and adult care. Only one subject (14%) still in paediatric services did not want to transition, attributable to a strong relationship with their managing clinician. Two participants were unsure whether they had transitioned: both had stable VI and had not been reviewed for some years.

Fourteen codes emerged from the analysis of interview data, identifying two key components relevant to transition: 'Communication with professionals within clinical contexts' and 'Environment'. Both were associated with the overarching theme: 'Confidence to self-manage health care in the future as an adult' (Table 3). 'Emotional attachments to child-centred care' was a further subtheme, which influenced participants' self-reported willingness to transition.

Confidence to self-manage health care in the future as an adult

Participants discussed having increased responsibility for their own health care, with most recognising the diminishing role their parents would play once they entered adult services, in some cases describing parents as 'handing over' or encouraging them to take control and build confidence to manage their health care independently. They recognised that growing up involved greater maturity and transition into adult care enhanced feelings of autonomy, confidence, and control. Nevertheless, attitudes varied, ranging from strong preferences to take control of the transition and subsequent clinical care to disengagement.

Communication with professionals within clinical contexts

Participants who had transitioned described the major differences between paediatric and adult services in relation to communication with their managing clinicians (Table 3). This reflected, in part, the shorter duration of out-patient appointments and the larger clinical teams in adult services, which meant that participants were not certain of seeing the same clinician(s) at each visit. Some participants who had not yet experienced a transition and remained in paediatric services described parents 'taking over' the consultation and communicating on their behalf. Attitudes towards parents 'taking the lead' varied: some felt excluded or embarrassed when parents intervened, whereas others valued their parents' input and disease-specific knowledge (Table 3).

Environment

Participants who transitioned noted the different environment in adult services: some welcomed this, in particular the reduced sensory 'overload' of paediatric out-patient play areas, but for others this was initially unwelcome and surprising, adversely impacting their feelings of belonging, confidence, and involvement in health care (Table 3). However, those who had not yet transitioned expressed strong dislike of child-centred environments, which was often the primary cause of desire to move into adult-centred care.

Notably, the two participants who had transitioned into specific adolescent/young person services valued the new clinical environment, appreciating, in particular, the

opportunity for contact with a peer group similar in age, which enhanced their sense of belonging, and age-appropriate provision of televisions and computers (Table 3).

Emotional attachments to paediatric ophthalmology services

Emotional attachment to the managing clinician was cited as a reason to be unwilling to transition by two participants with late-onset and/or progressive VI: one participant explained the role of their managing clinician in the process of diagnosis and acceptance of progressive visual deterioration and the desire that this practitioner would be involved in her future health care. The other described losing contact with his paediatric ophthalmologist as causing loss of accessible vision-specific support, which subsequently impacted his acceptance of and adaptation to late-onset VI.

Discussion

Our findings indicate that young people with VI understand the need for, and value the benefits of, transition: from paediatric ophthalmology services, but their experiences reflect variability in the content and timing of current transition practices in the United Kingdom. This is likely to reflect provision in other similar health care settings. Nevertheless, we found that certain aspects are valued by young people with VI and are likely to be associated with effective transition: age-appropriate communication, suitable physical clinical environments, and an appropriate peer group also being served by the service. Given the current lack of primary research that could inform transition policies in paediatric ophthalmology, intervention studies are some way off, in particular randomised controlled trials comparing different processes or policies and using patient-reported outcome measures capturing vision-related quality of life and functional vision[17–19] and patient-reported experience measures as end points to assess the role of effective transition. Thus, we suggest that our findings serve as the foundation for developing an evidence base to inform the design and content of models of transition.

We have captured what matters most to young people with VI at either side of the threshold of transition within the context of a broader research programme on the impact of living with VI. Using an appropriate qualitative design, interviews were conducted with the aim of exploring broader 'quality of life' among young people with VI. Questions targeting the experiences of health care, including the health care transition in most cases were included at the end of the interview and the probes used may have been less extensive than in an interview scenario that was *solely* about the transition experience. Nevertheless, within each interview, participants were encouraged to discuss the issues and experiences that they felt were most important in the transition process. Thus, although unlikely, it is possible there may be some omissions. Nevertheless, our findings identify key components of transition that could be assessed in future research on models of provision. Equally the nature and size of our participant sample reflected our primary research objective and thus the principle of qualitative data saturation, that is, a comprehensive account of patients' experiences rather than an intention to allow statistical analysis of associations between experience of transition and clinical or sociodemographic characteristics such as sex or VI severity or progression. We have thus been cautious in formally comparing those who had transitioned and those who had not, mindful of our sample size. The restriction of the study sample to young people without other significant impairments was essential to achieve a focus on VI *per se*. The extant generic child health literature indicates that transition processes are particularly successful when young people's health needs are predominantly due to one condition[25] and that successful transition for those with a number of comorbid health conditions relies on excellent communication and organisation between caregivers, specialities/departments, and institutions,[26] and may occur at varying time points.[27] Thus, while our findings are drawn from a subgroup, they are nevertheless likely to represent key components, which are important to the broader population of young people served by paediatric ophthalmology services.

The generic paediatric literature identifies the key elements of a successful transition in health care to be: (a) professional support and an environment which is sensitive to the developmental needs of the patient, (b) involvement of the young person in decision-making and consent, (c) support from family members and peers, and (d) sensitivity of the health care professional to psychosocial issues related to disability.[28] Barriers to effective transition are considered to be young people's lack of confidence to independently manage their hospital visits,[29,30] reduced opportunity to see a clinician independently of their parents,[31] and lack of involvement in transition in ways that are meaningful to them.[32] This thinking has been incorporated in national guidelines, which emphasise a patient-centred, individually tailored approach to transition recognising the developmental needs of the young person and the biological and socioemotional changes experienced during adolescence,[33] and by incorporating aspects such as collaborative planning between patients, their parents/family, and their health care providers and institutions.[1,25]

Good communication between patients, their families and their managing clinicians lies at the heart of effective paediatric ophthalmology services. The importance of age- and stage- appropriate communication is evidenced by the experiences reported in our study—both the risk of reduced and also less effective communication after transitioning, attributed to clinicians being less familiar with the young person's specific needs. To some extent, this is predictable as a patient moves into a new service and can be mitigated by planned and consistent communication between all parties including clarity for the patient about what to expect after transition.[25] However, the challenges inherent in a change to a larger clinical team without a single key managing ophthalmologist are harder to address in conventional adult ophthalmology services.

There is a limited literature on what constitutes an appropriate physical clinical environment for young people.[33,34] However, as articulated by our study participants, it is usually clear when a child-centred environment has been outgrown and an adult environment is not yet appropriate, and equally that where appropriate provision is in place, it is valued. This is particularly challenging in ophthalmology where paediatric ophthalmology services, especially secondary/tertiary care, are skewed to provision for infants and preschool-aged children and adult services predominantly serve older adults—that is, the design of the physical environment is driven by the extremes of age.

The value placed by young people in our study on an appropriate peer group confirms the key importance of considering 'stage' as opposed to 'age' in timing of transition to ensure it occurs after the developmental tasks of adolescence have been completed.[34] Transition that is too early in this trajectory risks feelings of insecurity in the new environment.

In 2015, 74.7% (5.2 of 7.07 million) of out-patient appointments in adult ophthalmology services in the United Kingdom were attended by patients over the age of 50 years. This is in contrast to 10.5% (764.4 thousand), which were attended by infants and children aged 0–15 years and a mere 0.9% (65.2 thousand), which were attended by young people aged 16–19 years.[35] Given this skewed age distribution and the specific needs of adolescents and young people, it is arguable that transition from paediatric ophthalmology should ideally be into specialist adolescent/young adult services. Models of this provision exist in other areas of child health, for example, endocrinology services for the late sequelae of childhood cancer,[36] which have promising patient-reported outcomes.[37] This would address the challenges of the 'no-man's land' that lies between child and adult ophthalmology services.

Although further research is required to establish what constitutes a 'good' transition for young people with VI and the pros and cons of generic- versus condition-specific guidelines are being debated,[38] some improvements in both the evidence base and current practices can be achieved by applying best practice and evidence from child health services more broadly. For example, within the United Kingdom, national guidance[1] already recommends that before they transition, young people should visit their new clinical environments and receive accessible (and age-appropriate) information about disease progression and the full range of care and support going forward. Both these recommendations address some of the specific functional limitations of VI and speak to the importance of appropriate physical clinical environments flagged by our study.

Effective transition into adult services is recognised to be important to long-term outcomes in all areas of child health. Children and young people with VI constitute a small population who have a range of complex health conditions and health care needs. We suggest our study exploring the transition process through their eyes provides valuable insight as to both their perceptions and preferences and current transition processes, laying the foundation for future larger scale empirical research.

Summary

What was known before

- A growing literature has identified the positive impact of a successful transition from paediatric to adult health services. The transition-related needs of young people with VI are likely to be complex. There is currently scant literature to inform transition planning.

What this study adds

- This study identified for the first time the transition-specific needs of young people with VI. Extant generic guidance on transition in paediatrics is applicable; however, research is needed to develop an ophthalmology-specific evidence base and our findings contribute to its development.

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