

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

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2 Transition from paediatric to adult ophthalmology services: what matters most to young people with
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5 Transition to adult ophthalmology services.

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36 ABSTRACT.

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

39 Methods: Qualitative study of 17 young people aged 16-19 years (i.e. the conventional transition age
40 threshold) with VI (best corrected acuity logMAR worse than 0.48) and without additional
41 impairments, drawn from a sampling frame of paediatric ophthalmology patients attending Great
42 Ormond Street Hospital and Moorfields Eye Hospital, UK. In-depth, semi-structured interviews were
43 conducted to elicit their experiences, preferences, and attitudes towards transitioning within
44 healthcare. Qualitative thematic analysis identified themes related to participants' experience of
45 transition.

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

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

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58

59 INTRODUCTION.

60 Most children with chronic conditions or disabilities, such as visual impairment, require long-term
61 healthcare to maximise functional health status and health-related quality of life. The importance of
62 ensuring a timely and successful transition from child to adult services is recognised internationally<sup>1-
63 3</sup>, particularly for those who progress into adulthood with rare childhood onset conditions and
64 complex health needs.⁴ A growing literature has identified the impact of a timely and successful
65 transition in terms of secure disease-related knowledge,⁵ high self-efficacy and good confidence for
66 self-management of health⁶ and assessed the effectiveness of technology-based systems and
67 methods such as use of the internet and mobile phones to provide young people with access to
68 transition-related information and increased control over their transition.⁶⁻⁸ Formal transition
69 processes are reported to achieve increased self-efficacy and transition preparedness,⁶⁻⁸ fewer self-
70 reported disease symptoms⁹ and better clinical outcomes.¹⁰⁻¹³ Conversely poor quality transitions
71 have been associated with a 'drop-out' of patients who become disengaged with their healthcare¹⁴
72 and poor mental health and psychosocial outcomes.¹⁵

73 Most children with visual impairment or blindness (VI for brevity throughout) transition from
74 paediatric to adult ophthalmology services during adolescence, usually at a fixed age, as determined
75 by health service restraints. The majority will approach transition having been diagnosed in early
76 childhood, grown up without experiencing normal sight, and having been managed within specialist
77 paediatric services.¹⁶ A minority will have experienced loss of vision (acutely or gradually), in some
78 cases just before transition becomes necessary due to their age. Thus the needs of this population
79 with regards to healthcare transition can be expected to be complex, diverse and in some respects
80 different to other young people living with chronic health conditions or disabilities. There is currently
81 very scant literature to inform transition planning and provision in ophthalmology. We report an
82 investigation of the views about and experiences of transitioning of adolescents living with VI, so as

83 to identify the transition-related needs of this population, and as the necessary first step in
84 developing evidence-based models of transition.

85 METHODS.

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

90 Participant eligibility, identification and recruitment

91 Subjects were eligible if they met the following criteria:

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

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

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

- 105 a) the principles of data saturation^{20,21} i.e. the number of interviews needed to achieve
106 comprehensive coverage of issues, as determined using findings from similar studies,^{17,22}
107 b) anticipated participation rate of 30% based on prior studies recruiting children and young
108 people with VI.¹⁷

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

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

115 Data collection

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

124 [TABLE 1: Questions and probes used to prompt discussions centred upon young people's
125 experiences of ophthalmic healthcare.]

126 Qualitative Data Analysis

127 Each interview was digitally recorded, transcribed and exported into NVivo 10. Qualitative analysis
128 based on the tenets of Grounded Theory²³ was conducted to identify key themes related to
129 participants' everyday lives, including their experiences of ophthalmic healthcare. This approach
130 was selected based on source data stemming from spontaneous speech in addition to answers to
131 questions which were further probed. Thus, both inductive and deductive methods were
132 incorporated. Interview transcripts were read by two researchers (AR and VT) to collaboratively
133 develop a codebook which was then used on the entire dataset. Codes were grouped according to
134 emerging themes. Themes were described and labelled.

135 RESULTS.

136 As shown in Table 2, seventeen young people took part (39% participation rate). Their mean age was
137 16.8 years (SD: 0.9 years), 10 (58.8%) were male and 11 (64.7%) were White British. Fourteen
138 (82.4%) had early onset VI (earlier than 5 years of age), 12 (70.6%) were visually impaired and 5 were
139 classified as severely visually impaired or blind (SVI/BL) (WHO taxonomy based on logMAR acuity in
140 the better seeing eye²⁴). Eleven (64.7%) had non-progressive VI. Thus the sample was representative
141 of the population of visually impaired children and young people without additional impairments in
142 the UK.¹⁶

143 Mean interview duration was 76 minutes (SD: 22 minutes; range: 40-113 minutes) and 16 interviews
144 were conducted at participants' family home. Participants were encouraged to speak to the
145 interviewer independently, however, a parent/guardian was present for some or part of 4
146 interviews.

147 Eight of the participants had already transitioned: 6 into adult services and 2 into dedicated
148 adolescent services. Only 2 (25%) of these participants preferred their prior paediatric service, due
149 to its more child-centred approach to communication, although pros and cons were identified by all.
150 The two participants now in an adolescent service identified significant positive benefits of this

151 specialist service bridging child and adult care. Only 1 subject (14%) still in paediatric services did not
152 want to transition, attributable to a strong relationship with their managing clinician. Two
153 participants were unsure whether they had transitioned: both had stable VI and had not been
154 reviewed for some years.

155 [TABLE 2: Demographic and clinical characteristics of participants categorised according to transition
156 status.]

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

162 Confidence to self-manage healthcare in the future as an adult

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

170 *Communication with professionals within clinical contexts*

171 Participants who had transitioned described the major differences between paediatric and adult
172 services in relation to communication with their managing clinicians (Table 3). This reflected, in part,
173 the shorter duration of outpatient appointments and the larger clinical teams in adult services,

174 which meant that participants were not certain of seeing the same clinician(s) at each visit. Some
175 participants who had not yet experienced a transition and remained in paediatric services described
176 parents 'taking over' the consultation and communicating on their behalf. Attitudes towards parents
177 'taking the lead' varied: some felt excluded or embarrassed when parents intervened, whereas
178 others valued their parents' input and disease-specific knowledge (Table 3).

179 *Physical clinical environment*

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

186 Notably the two participants who had transitioned into specific adolescent/young person services,
187 valued the new clinical environment, appreciating, in particular, the opportunity for contact with a
188 peer group similar in age, which enhanced their sense of belonging, and age-appropriate provision of
189 televisions and computers (Table 3).

190 *Emotional attachments to Paediatric Ophthalmology Services*

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

197 [TABLE 3: Qualitative analysis of interviews: Codes, sub-themes, issues relevant to transition and
198 corresponding quotes.]

199 DISCUSSION.

200 Our findings indicate that young people with VI understand the need for, and value the benefits of,
201 transition from paediatric ophthalmology services but their experiences reflect variability in the
202 content and timing of current transition practices in the UK. This is likely to reflect provision in other
203 similar healthcare settings. Nevertheless, we found that certain aspects are valued by young people
204 with VI and are likely to be associated with effective transition: age-appropriate communication,
205 suitable physical clinical environments and an appropriate peer group also being served by the
206 service. Given the current lack of primary research that could inform transition policies in paediatric
207 ophthalmology, intervention studies are some way off, in particular randomised controlled trials
208 comparing different processes or policies and using patient-reported outcome measures capturing
209 vision-related quality of life and functional vision¹⁷⁻¹⁹ and patient-reported experience measures as
210 end-points to assess the role of effective transition. Thus we suggest our findings serve as the
211 foundation for developing an evidence base to inform the design and content of models of
212 transition.

213 We have captured what matters most to young people with VI at the either side of the threshold of
214 transition within the context of a broader research programme on the impact of living with VI. Using
215 an appropriate qualitative design, interviews were conducted with the aim of exploring broader
216 'quality of life' among young people with VI. Questions targeting the experiences of healthcare,
217 including the healthcare transition in most cases were included at the end of the interview and the
218 probes used may have been less extensive than in an interview scenario that was *solely* about the
219 transition experience. Neverthelss, within each interview, participants were encouraged to discuss
220 the issues and experiences that they felt were most important in the transition process. Thus,

221 although unlikely, it is possible there may be some omissions. Nevertheless, our findings identify key
222 components of transition that could be assessed in future research on models of provision. Equally
223 the nature and size of our participant sample reflected our primary research objective and thus the
224 principle of qualitative data saturation i.e. a comprehensive account of patients' experiences rather
225 than an intention to allow statistical analysis of associations between experience of transition and
226 clinical or socio-demographic characteristics such as sex or VI severity or progression. We have thus
227 been cautious in formally comparing those who had transitioned and those who had not, mindful of
228 our sample size. The restriction of the study sample to young people without other significant
229 impairments was essential to achieve a focus on VI *per se*. The extant generic child health literature
230 indicates that transition processes are particularly successful when young people's health needs are
231 predominantly due to one condition²⁵ and that successful transition for those with a number of co-
232 morbid health conditions relies on excellent communication and organisation between caregivers,
233 specialities/departments and institutions²⁶ and may occur at varying time points.²⁷ Thus whilst our
234 findings are drawn from a subgroup, they are nevertheless, likely to represent key components
235 which are important to the broader population of young people served by paediatric ophthalmology
236 services.

237 The generic paediatric literature identifies the key elements of a successful transition in healthcare
238 to be: a) professional support and an environment which is sensitive to the developmental needs of
239 the patient, b) involvement of the young person in decision-making and consent, c) support from
240 family members and peers and d) sensitivity of the healthcare professional to psychosocial issues
241 related to disability.²⁸ Barriers to effective transition are considered to be young people's lack of
242 confidence to independently manage their hospital visits,^{29,30} reduced opportunity to see a clinician
243 independently of their parents,³¹ and lack of involvement in transition in ways which are meaningful
244 to them.³² This thinking has been incorporated in national guidelines which emphasise a patient-
245 centred, individually-tailored approach to transition recognising the developmental needs of the

246 young person and the biological and socio-emotional changes experienced during adolescence,³³
247 and by incorporating aspects such as collaborative planning between patients, their parents/family
248 and their healthcare providers and institutions.^{1,25}

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

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

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

269 In 2015 74.7% (5.2 of 7.07 million) of outpatient appointments in adult ophthalmology services in
270 the UK, were attended by patients over the age of 50 years. This is in contrast to 10.5% (764.4
271 thousand) which were attended by infants and children aged 0-15 years and a mere 0.9% (65.2
272 thousand) which were attended by young people aged 16-19 years.³⁵ Given this skewed age
273 distribution and the specific needs of adolescents and young people, it is arguable that transition
274 from paediatric ophthalmology should ideally be into specialist adolescent/young adult service.
275 Models of this provision exist in other areas of child health, for example endocrinology services for
276 the late sequelae of childhood cancer³⁶ which have promising patient reported outcomes.³⁷ This
277 would address the challenges of the “no-man’s land” that lies between child and adult
278 ophthalmology services.

279 Although further research is required to establish what constitutes a ‘good’ transition for young
280 people with VI and the pros and cons of generic versus condition-specific guidelines are being
281 debated,³⁸ some improvements in both the evidence base and current practices can be achieved by
282 applying best practice and evidence from child health services more broadly. For example within the
283 UK, national guidance¹ already recommends that before they transition, young people should visit
284 their new clinical environments and receive accessible (and age-appropriate) information about
285 disease progression and the full range of care and support going forward. Both these
286 recommendations address some of the specific functional limitations of VI and speak to the
287 importance of appropriate physical clinical environments flagged by our study.

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

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