



Transition from Paediatric to Adult Diabetes Services: A Narrative Review of the Years When Control Is Lost

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Abstract

Moving from paediatric to adult diabetes services coincides with worsening glycaemic control and increased hospitalisation, and services have responded by building structured transition programmes. The evidence for them is more mixed than the enthusiasm suggests. In a comparison of 62 young people transferred either by letter or through a planned handover, the structured group had better attendance and lower HbA1c at one year, but some cohorts report no change after transfer and others report deterioration. A retrospective cohort of 118 found 62.5 per cent maintaining regular adult follow-up and 27.5 per cent with discontinuity. Several features recorded before transfer predicted non-attendance, including higher HbA1c, fewer preceding visits and asking no questions at the transition appointment. A complication runs through the literature: adolescent control predicts young-adult control, so much of the deterioration attributed to transition may precede it. Systematic review of 22 interventions concluded that effective models are yet to be identified.

Keywords: Transition of care; Type 1 diabetes; Young adults; Loss to follow-up; Glycaemic control

Introduction

Young people with type 1 diabetes leave paediatric services in their late teens and enter adult care at a point of considerable change in almost everything else [1,2]. The period is associated with worsening glycaemia, increased diabetes-related hospitalisation and greater risk-taking, and it coincides with leaving home and with changes in employment and finances [3,4,30]. The problem has been described in similar terms for two decades [20,33,34].

Services have responded by building structured transition programmes, with planning, coordination, pre-transfer education and dedicated young adult clinics [5,6,29,31]. Structured programmes have been evaluated prospectively [18,22], and navigator models tested separately [23]. These are widely recommended and increasingly standard [7,8]. Systematic reviews have catalogued the components that appear to help [26,27], and a national research programme examined transition across long-term conditions generally [28].

This review examines what those programmes achieve, which young people are lost from follow-up, and how much of the deterioration is caused by transition rather than merely occurring alongside it.

Material and Methods

Search strategy: PubMed and the archives of the major diabetes, paediatric and adolescent health journals were searched for studies of transition from paediatric to adult diabetes services. Search terms combined transition and transfer of care with type 1 diabetes, young adults, loss to follow-up, glycaemic control and structured programme. Reference lists of the principal systematic review [9] and narrative overviews [5,10] were screened by hand for primary sources.

Eligibility: Studies were included if they reported clinical or attendance outcomes across the transfer from paediatric to adult services, evaluated a transition intervention, or examined predictors of disengagement. Qualitative studies are included

where they identify mechanisms and are identified as such.

Data extraction and handling: Design, setting, cohort size, the comparison made and the reported estimate were extracted as published. Whether an estimate compares before with after transfer, or one transfer method with another, is stated alongside every figure, because those answer different questions and are frequently conflated. No pooling or re-analysis was performed. Figures 1 to 6 and Tables 1 to 3 reproduce published values only. This is a narrative synthesis and was not registered as a systematic review.

Results

What happens to follow-up: A retrospective analysis of 118 individuals with type 1 diabetes who transferred to adult care found that 67 per cent (80 people) went through a formal transition council, of whom 62.5 per cent (50) maintained regular follow-up in adult care while 27.5 per cent (30) experienced discontinuity of follow-up (Figure 1) [11].

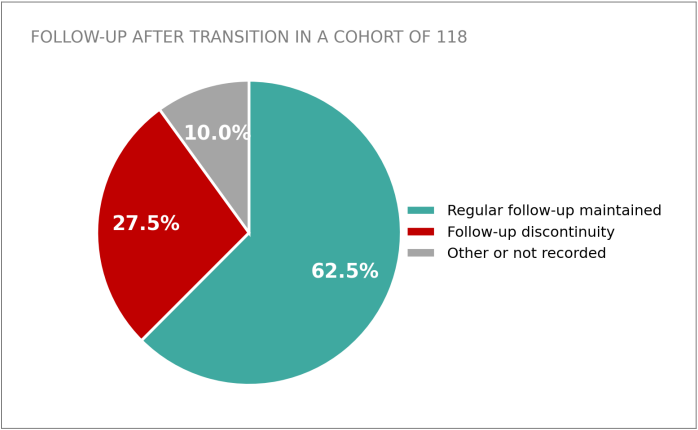


Figure 1: Follow-up continuity after transfer in a cohort of 118 [11]

Structured against unstructured transfer: A retrospective comparison examined 62 adolescents and young adults discharged from paediatric services between 1994 and 2004. Thirty-two were transferred by letter alone and 30 through a handover planned with the receiving adult physicians (Figure 2). The interval to first adult appointment was longer in the unstructured group, with a gap in medical assistance ($p < 0.001$). At the first adult visit, before any intervention, HbA1c had improved in the structured group relative to their last paediatric measurement ($p < 0.01$) while the unstructured group showed a trend to worsening. After one year in adult services, attendance was better and HbA1c lower in the structured group ($p < 0.05$), and all participants in that group reported a favourable view of the process ($p < 0.0001$) [12].

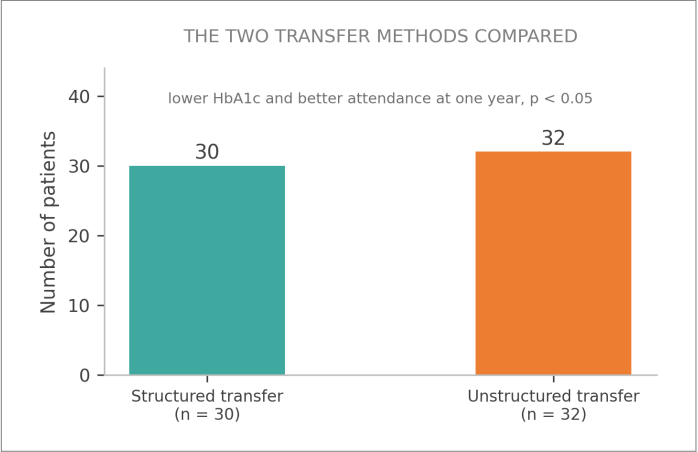


Figure 2: The two transfer methods compared in a cohort of 62 [12]

Who is lost: A Canadian study following young people through a structured transition clinic identified features ascertainable before transfer that predicted non-attendance in adult care: diagnosis before the age of 12, insulin given twice or three times daily rather than by pump or multiple daily injections, higher HbA1c, fewer diabetes appointments in the preceding year, and asking no questions at the transition clinic visit (Figure 5) [13].

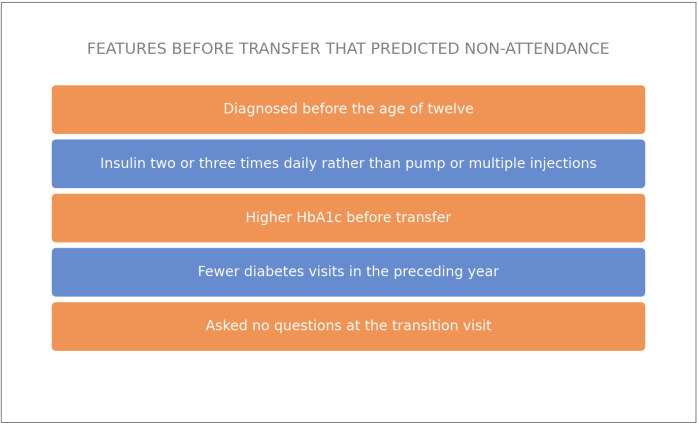


Figure 5: Features before transfer that predicted non-attendance in adult care [13]

Why they are lost: A mixed-methods study of 20 young adults newly enrolled in a transition clinic after a period of lost follow-up identified three categories of challenge: psychosocial, health provider and system, and developmental (Figure 6). The number of stressful life circumstances correlated with higher HbA1c ($r = 0.60$, $p = 0.005$) and with longer time since the last routine diabetes visit ($r = 0.51$, $p = 0.02$), as well as with greater emergency service use (Figure 3) [14].

Table 1: Principal studies reviewed, with the finding as reported by the original investigators

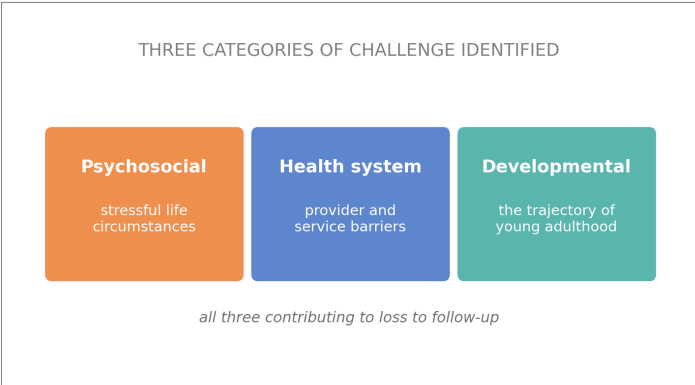


Figure 6: Three categories of challenge contributing to loss to follow-up [14]

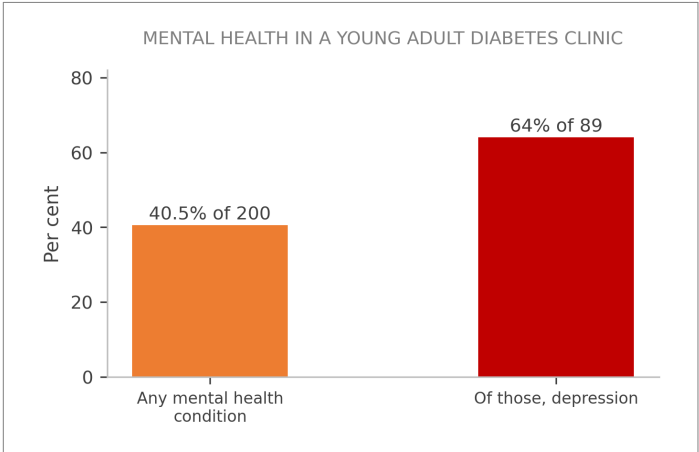


Figure 4: Mental health conditions in a young adult diabetes clinic [15]

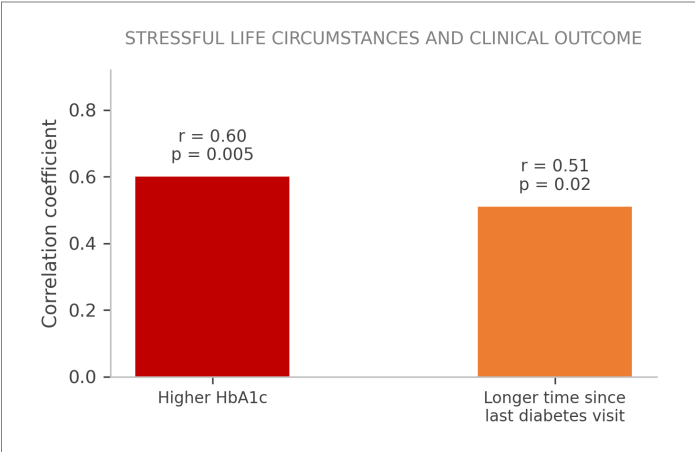


Figure 3: Stressful life circumstances against clinical outcome [14]

What the intervention literature concludes: A systematic review identified 22 studies of transition interventions in people aged 10 to 25. Most were service-oriented with little use of underlying theory, and included transition planning, service coordination, pre-transfer education, transition clinics and prompting strategies. Most reported metabolic outcomes with limited psychological data, and the review noted that outcomes were inconsistently defined, measured and reported, concluding that effective theory-based transition models are yet to be identified [9].

Study	Design and cohort	Principal reported finding
Transition cohort [11]	Retrospective, n = 118	62.5% maintained follow-up; 27.5% discontinuity
Structured comparison [12]	Retrospective, n = 62	Better attendance and lower HbA1c at one year
Predictors study [13]	Structured clinic, Canada	Five pre-transfer features predicted non-attendance
Mixed-methods study [14]	n = 20 with prior loss to follow-up	Stressors correlated with HbA1c, r = 0.60
Young adult clinic audit [15]	Eight-year audit, n = 200	40.5% had a mental health condition
Systematic review [9]	22 transition interventions	Effective models yet to be identified

Component	How often used	Evidence status
Transition planning	Common	Service-oriented, little theory [9]
Service coordination	Common	Associated with lower loss to follow-up [10]
Pre-transfer education	Common	Beneficial in review, definitions vary [9,10]
Dedicated transition clinic	Common	Better attendance in comparison studies [12]
Navigator or coordinator contact	Less common	Lower loss to follow-up reported [10]

Table 2: Components of transition programmes and the evidence behind each

Mental health in this population: An eight-year retrospective audit of 200 people attending a young adult diabetes clinic, of whom 184 (83.2 per cent) had type 1 diabetes, found that 40.5 per cent (89 people) had a mental health condition, most commonly depression in 57 of those 89, or 64 per cent (Figure 4). The investigators concluded that additional provision, including an in-house psychologist, was required to reduce complication risk in this group [15].

The confounding observation: Studies examining pre-transfer and post-transfer HbA1c report close association between the two, and adolescent glycaemic control generally predicts young adult control [5,16]. One of the earliest studies of transfer to a young adult clinic found HbA1c unchanged a year afterwards (p = 0.15), and other reports show no post-transfer change or an increase [5,10,17].

That reframing matters because it bears on what an intervention can achieve. If the problem is generated by the handover, then a better handover should fix it. If the handover coincides with the problem, a smoother transfer will improve continuity of care, which is worth having, without necessarily changing the glycaemic trajectory. The systematic review of 22 interventions is consistent with the second reading: most were service-oriented, outcome definitions were inconsistent, and effective models were judged not yet identified [9].

Reported pattern	Implication
Control deteriorates through adolescence	Decline begins before transfer [5,16]
Pre- and post-transfer HbA1c closely associated	Transfer may not be the cause [5]
Some cohorts show no change after transfer	Effect of transfer is inconsistent [10,17]
Structured transfer associated with better outcome	Observational, not randomised [12]

Table 3: Findings that complicate the attribution of deterioration to transition

Discussion

The association between this period and worsening control is not in doubt, and neither is the scale of disengagement: more than a quarter of one cohort had discontinuity of follow-up despite a formal transition process [11]. What is less settled is the causal claim embedded in most discussion of the topic, that the transfer itself produces the deterioration.

Three observations complicate it. Adolescent glycaemic control predicts young adult control, so the trajectory is established before the handover occurs [5,16]. One of the earliest studies of transfer found HbA1c unchanged a year later, and subsequent reports are inconsistent, some showing no change and some an increase [10,17]. And the period coincides with leaving home, entering employment or education and losing the parental involvement that sustained the regimen, none of which is caused by a change of clinic [3,4,14]. Transition may be better understood as the point at which a pre-existing decline becomes visible to services.

The predictor study offers the most immediately usable finding, and one item in it deserves particular notice. Alongside higher HbA1c and fewer preceding appointments, the young people who asked no questions at their transition visit were more likely not to attend adult care [13]. That is observable in a single consultation, costs nothing to record, and plausibly marks disengagement that other measures miss.

The mental health finding sets a limit on service-level solutions. Two in five attenders at a young adult clinic had a mental health condition, most often depression [15]. Stressful life circumstances correlated with both HbA1c and time since the last visit at $r = 0.60$ and 0.51 [14]. Transition programmes as described in the literature are largely administrative, concerned with appointments, letters and coordination. They are unlikely to address the psychosocial burden that these data identify as the proximate driver of disengagement. Qualitative work before and after transfer describes the same tension between administrative continuity and personal circumstance [24,25], and accounts given by young adults themselves are consistent across settings [19,24].

A related point concerns what is actually being measured when a young person is recorded as lost. Analyses drawing on universal health coverage data can follow individuals across

providers and report lower rates of true disengagement than single-service audits, which classify anyone not attending that clinic as lost [11,21]. Some proportion of the apparent attrition is therefore movement rather than disappearance, and the studies reviewed here cannot separate the two.

What would advance the field is more specific than another programme description. The systematic review identified inconsistent outcome definition as the barrier to synthesis, so an agreed core outcome set covering attendance, glycaemic control and psychological measures would allow the 22 existing studies to be compared [9,26,27]. A randomised comparison of transfer models with pre-specified endpoints would settle more than a further cohort, and the national programme examining transition across long-term conditions offers a template for how that might be structured [28].

Study limitations

The limitations belong to the underlying literature. The comparative studies are retrospective and non-randomised, and the structured comparison covers transfers spanning a decade during which care changed substantially, so period effects are difficult to separate from the intervention [12]. Cohort sizes are small, at 62, 118 and 20 for the principal studies, and the qualitative work involves 20 participants selected for prior loss to follow-up, who are not representative [11,12,14]. Outcome definitions differ across studies to a degree the systematic review identified as preventing synthesis [9]. Reported associations between structured transfer and better outcome are vulnerable to selection, since young people who engage with a structured programme differ from those who do not in ways that predict attendance [12,13]. Loss to follow-up is itself measured inconsistently, and a person attending elsewhere may be recorded as lost [11,21]. Population-level analyses using universal health coverage data avoid some of that misclassification [21], and transfer experience has been related to subsequent glycaemic control [32]. Most studies come from well-resourced services with a dedicated young adult clinic, which is not the general case [10,15]. And no randomised trial of a transition model with glycaemic control as the primary endpoint has reported [9,18].

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Conclusion

More than a quarter of young people transferring to adult diabetes care lose continuity of follow-up, and the features that predict it are recordable before they leave paediatric services, including higher HbA1c, fewer recent appointments and asking no questions at the transition visit. Structured transfer is associated with better attendance and lower HbA1c at one year in the comparative studies available, all of them observational. What the evidence does not support is the assumption that transfer causes the deterioration: adolescent control predicts young adult control, several cohorts show no change across the handover, and the period coincides with changes in living arrangements and support that no clinic process controls. A better transfer is worth building for continuity of care. Expecting it to reverse a decline that began earlier is asking more than the literature supports.

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Conflict of Interest

The authors declare no competing interests.

Ethics Statement

This article reviews previously published studies only. No new patient data were collected and no participants were recruited, so ethical approval was not required.

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