Research: Care Delivery

A longitudinal, observational study examining the relationships of patient satisfaction with services and mental well-being to their clinical course in young people with Type 1 diabetes mellitus during transition from child to adult health services

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Abstract

Aim   We hypothesized that participant well-being and satisfaction with services would be positively associated with a satisfactory clinical course during transition from child to adult health care.

Methods   Some 150 young people with Type 1 diabetes mellitus from five diabetes units in England were recruited to a longitudinal study of transition. Each young person was visited at home four times by a research assistant; each visit was 1 year apart. Satisfaction with services (Mind the Gap; MTG) and mental well-being (Warwick–Edinburgh Mental Well-being Scale; WEMWBS) were captured. Change in HbA_{1c}, episodes of ketoacidosis, clinic and retinal screening attendance were used to assess clinical course. In total, 108 of 150 (72%) young people had sufficient data for analysis at visit 4.

Results   Mean age at entry was 16 years. By visit 4, 81.5% had left paediatric healthcare services. Median HbA_{1c} increased significantly ($P = 0.01$) from 69 mmol/mol (8.5%) at baseline to 75 mmol/mol (9.0%) at visit 4. WEMWBS scores were comparable with those in the general population at baseline and were stable over the study period. MTG scores were also stable. By visit 4, some 32 individuals had a 'satisfactory' and 76 a 'suboptimal' clinical course. There were no significant differences in average WEMWBS and MTG scores between the clinical course groups ($P = 0.96$, 0.52 respectively); nor was there a significant difference in transfer status between the clinical course groups.

Conclusions   The well-being of young people with diabetes and their satisfaction with transition services are not closely related to their clinical course. Investigating whether innovative psycho-educational interventions can improve the clinical course is a research priority.

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Introduction

'Transition' is the purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with long-term conditions as they move from child-centred to adult-oriented healthcare systems [1]. Transition usually occurs during adolescence, a time of important change in an individual's physiology, psychology and for societal expectations [2,3]. These changes and pressures are associated with potentially detrimental effects on health behaviours such as service engagement, and on biological markers of disease control.

Deteriorating glycaemic control is well-recognized in adolescents with Type 1 diabetes mellitus [4,5] with an associated increase in acute complications [6]. Although the deterioration is usually followed by an improvement in the third decade of life, a period of poor glycaemic control has a significant impact on a range of health indices, such as

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What's new?

• Well-being and satisfaction with services were stable during a 3-year longitudinal study of young people with Type 1 diabetes mellitus in transition to adult services.

• Well-being and satisfaction with services were not related to HbA_{1c} or the more general clinical course.

• Further work is needed to identify innovative and effective psycho-educational interventions to improve the clinical course.

the risk of microvascular complications many years later [7,8].

Improving transitional care for young people has the potential to improve health for many years to come, but the factors that influence this process from the perspective of the individual and healthcare professional are poorly understood.

The well-being of patients and their satisfaction with the transition services provided are two outcomes of importance to young people [9] and clinicians [10,11]. As well as being intrinsically worthwhile, it is also hoped that achievement of these outcomes makes a satisfactory clinical course more likely (defined later to include markers of HbA_{1c}, ketoacidosis, clinic and retinal screening attendance). However, it is unclear whether this is so. Reduced well-being in rheumatological problems is associated with more active disease [12] but in diabetes the picture is less clear with two studies showing no associations [13,14], and another showing a positive association between well-being and better disease control as measured by HbA_{1c} [15]. De Wit *et al.* [14] also found no association between HbA_{1c} and satisfaction with care. We hypothesized that young people with Type 1 diabetes and higher well-being would be more likely to experience a satisfactory clinical course during transition than those with lower well-being. Similarly, we hypothesized that young people who were more satisfied with their health service provision would be more likely to experience a satisfactory clinical course.

Participants and methods

Data on young people with Type 1 diabetes were available from a longitudinal study of the transition of young people with long-term conditions from child to adult health services [16], which was itself part of a 5-year programme of research on transition (http://research.ncl.ac.uk/transition/). Data had been captured from young people with one of three long-term conditions, cerebral palsy, autism spectrum disorder or diabetes, over a 3-year period of healthcare transition.

Eligible young people, aged between 14 years and 18 years 11 months who were without significant learning difficulties were recruited from five hospital sites across England that are responsible for all young people with Type 1 diabetes in their area. All units used the diabetes tariff as a structure for implementing a high-quality programme of diabetes care [17]. The tariff includes guidance regarding care components such as frequency and nature of patient contact, HbA_{1c} measurement (four times per year) and highlights the importance of a clear policy regarding transition to adult services.

At recruitment, the young people had not transferred to adult services but were anticipated to do so during the study [16]. Young people were visited at home by research assistants on four occasions, 1 year apart. At each visit, questionnaires about satisfaction with services and mental well-being were completed by the young person. Also, the following variables concerning the previous year were collected by the research assistants from medical notes: mean HbA_{1c}, clinic attendance, hospital admissions for diabetic ketoacidosis and attendance for annual retinal screening.

The young people taking part in the study did not differ significantly from those who declined to take part by age or gender [18]. Those taking part had significantly ($P < 0.001$) lower scores on a socio-economic deprivation index (i.e. less deprived) than those who declined; however, the difference in overall Index of Multiple Deprivation score on a continuous scale ranging from 0.5 to 87.8, was only 6.1 [18]. Based on data from the National (England and Wales) Paediatric Diabetes Audit for year 2011/2012 [19], at recruitment, those participating were representative of the England and Wales population of young people with Type 1 diabetes in respect of age at diagnosis and mean HbA_{1c} in the previous year [19].

Mental well-being

Mental well-being was assessed using the Warwick–Edinburgh Mental Well-being Scale (WEMWBS) [20] completed independently by the young person at the annual visit by the research assistant. This scale includes 14 positively worded phrases with a five-category Likert scale response option from 'none of the time' to 'all of the time'; this yields a score from 14 to 70, with higher scores indicating higher mental well-being. The scale was developed and validated in the UK, including its use with young people aged 13–18 years [21].

Satisfaction with healthcare services during transition

The Mind the Gap (MTG) scale [22] was developed in the UK to evaluate satisfaction with services in adolescents with long-term health conditions. The 22-item questionnaire asks participants to rate their perception of current care and expectation of best care. All questionnaire items are scored on a seven-point Likert scale anchored by 'strongly disagree' at 1 and 'strongly agree' at 7. Satisfaction with each item is conceptualized as 'the gap' between best and current care for all questionnaire items. The overall score ranges from −6

most satisfied to +6 most unsatisfied with a score of 0 reflecting 'no gap' between current and best care. The instrument has demonstrated internal consistency with a Cronbach's alpha of 0.91 [22].

Clinical course during transition

There is no consensus on how best to assess a satisfactory clinical course during transition. Following discussion among the authors, the wider Transition Research Collaborative group and a review of the literature [11,23,24], a set of criteria based on collected clinical and attendance data was established to define a satisfactory clinical course. The four markers were: glycaemic control (HbA_{1c}), any episode of diabetic ketoacidosis, clinic attendance and retinal screening attendance.

Up to four HbA_{1c} values were recorded each year and these were extracted from the medical notes. The mean of these measurements each year was calculated. We chose an increase in HbA_{1c} (measured in mmol/mol) of > 7% from baseline to be a marker of suboptimal glycaemic control in order to account for analytic variance and intra-individual variation in measurement [25,26]. The second marker of clinical course was the presence or absence of hospital admissions with ketoacidosis. The third marker was a > 75% attendance each year for clinics scheduled as a standard of care and additional ones where clinically indicated. This figure was selected to allow for appointments being missed inadvertently. The fourth marker was attendance at retinal screening each year because this reflects both engagement with services and positive health behaviour.

Participants were assigned to the 'satisfactory clinical course group' if, at the final visit 4, their HbA_{1c} was < 7% above the baseline value; and over the 3 years they had no admissions with ketoacidosis, they had > 75% clinic attendance each year and had attended for retinal screening each year; they were categorized as having a 'suboptimal clinical course' if they did not meet all the criteria.

The study received a favourable ethics opinion from the Newcastle and North Tyneside1 Research Ethics Committee 12/NE/0059.

Statistical analysis

Participant satisfaction, well-being and HbA_{1c} were analysed as continuous variables, whereas clinic attendance, retinal screening and episodes of ketoacidosis were analysed as categorical variables. Wilcoxon signed ranks test was used to compare HbA_{1c} between baseline (visit 1) and visit 4.

The correlations of both WEMWBS and MTG with HbA_{1c} and duration of diabetes were investigated using Pearson product moment correlation coefficient. WEMWBS and MTG scores were tested for association with the satisfactory and suboptimal clinical course groups using the Mann–Whitney U-test. The chi-squared test was used to compare the gender distribution in the two clinical course groups. MTG and WEMWBS scores of those recruited who did and did not complete the study were compared using independent samples t-tests.

This study was powered to detect a difference in the chosen variables; for example, to recognize a change of 1.5 in the WEMWBS at a 5% significance level using the general population mean of 48.8 (SD 6.8).

Results

Some 150 young people with Type 1 diabetes were recruited; 108 (72%) had complete data through to visit 4 and constituted the group for analysis. There were no significant differences in the baseline details of age, gender or duration of diabetes between the 150 young people recruited and the 108 with complete data through to visit 4 (Table 1). Of the 42 young people not remaining in the study, 14 were lost to follow-up and 28 withdrew. Of those withdrawing, 23 said they were no longer interested and five had changes in external physical or emotional circumstances, such as a road traffic accident or a parent dying or developing cancer, which made it difficult to continue.

There were no significant differences in the MTG or WEMWBS scores at the baseline visit between those recruited and those with complete data to visit 4 ($t(148) = 1.14$, $P = 0.26$ and $t(146) = 1.85$, $P = 0.66$) (data not shown).

Some 81.4% of those with complete data had left paediatric health care services by visit 4, of whom three had follow-up with their general practitioner and the remainder had transferred to secondary hospital healthcare services.

Median annual HbA_{1c} values increased over the study period and were significantly higher at visit 4 than at visit 1. Visit 1: 69.2 mmol/mol, i.q.r. 19 (8.5%); visit 2: 72.2 mmol/mol, i.q.r. 24 (8.8%); visit 3: 70.0 mmol/mol, i.q.r. 24 (8.6%) and visit 4: 74.8 mmol/mol, i.q.r. 19 (9%) (Wilcoxon signed rank test $Z = -2.44$, $P = 0.01$).

Mean annual WEMWBS scores did not change significantly over the study period ($P = 0.97$). There was no significant correlation between mean visit 4 WEMWBS and either HbA_{1c} ($r = 0.13$, $N = 92$, $P = 0.22$) or duration of diabetes ($r = 0.05$, $N = 97$, $P = 0.61$).

Mean annual MTG scores did not change significantly over the study period ($P = 0.28$). There was no significant correlation between visit 4 MTG score and HbA_{1c} ($r = 0.02$, $N = 87$, $P = 0.83$).

Table 2 shows the number of young people (from the 108 who completed the study) who did not meet the criterion for each marker in the year before each visit.

Comparison of the clinical course subgroups

There were 32 young people in the satisfactory clinical course group and 76 in the suboptimal group. The two groups were comparable for disease duration (Table 3). There was a greater proportion of men than women in the

Table 1 Baseline demographic details of all participants recruited and the 108 participants with complete data to visit 4

	Total participants recruited $N = 150$	Participants with complete data to visit 4 $N = 108$	Participants with incomplete data to visit 4 $N = 42$
Gender, *n* (%)			
Men	77 (51.3)	53 (49.1)	24 (57)
Women	73 (48.7)	55 (50.9)	18 (43)
Mean (SD) age at study entry in years	16.2 (1.3)	16.0 (1.3)	16.5 (1.2)
Median (IQR) disease duration in years	6.7 (5.3)	7.5 (5.8)	5.1 (5.4)
Mean (SD) age at diagnosis in years (range 1–16 years)	9.5 (3.8)	8.5 (3.8)	10.8 (3.0)
Outcome at visit 4, *n* (%)			
Transferred to adult services	100 (66.7)	88 (81.5)	12 (28)
Paediatric services	26 (17.3)	19 (17.6)	7 (17)
Outcome unknown	24 (16.0)	1 (0.9)	23 (55)

satisfactory group (difference not significant, $P = 0.17$). By visit 4, 87.5% in the satisfactory group and 78.9% in the suboptimal group had transferred to adult services (difference not significant, chi square 1.09; $P = 0.3$). There was no significant difference in the average WEMWBS score ($U = 955$, $P = 0.52$) or average MTG score ($U = 908$, $P = 0.96$) between the groups. The most common criteria for allocation to the suboptimal group were 'less than 75% clinic attendance' and 'increase in HbA$_{1c}$'. Fifteen young people had hospital admission for ketoacidosis during the study. In the suboptimal group 43 of 76 met only one criterion; (17 clinic attendance, 13 HbA$_{1c}$, 6 ketoacidosis, 7 retinal screening). Some 24 of 76 young people met only two criteria, most frequently HbA$_{1c}$ and clinic attendance; 9 of 76 met three criteria.

Discussion

We found no evidence that the mental well-being and satisfaction with services of young people with Type 1 diabetes were associated with a satisfactory clinical course as defined by the four clinical markers HbA$_{1c}$, ketoacidosis, clinic and retinal screening attendance. The median HbA$_{1c}$ increased significantly during the 4-year study period but this also was not associated with mental well-being or satisfaction with services. The mental well-being of those with Type 1 diabetes was similar to that of the general population of 13–16-year-olds in England and Scotland [21] and did not change significantly over time. Scores of satisfaction with services were comparable with published data of adolescents with long-term conditions during transition [22]. Participant satisfaction did not change significantly over time. In summary, mental well-being and satisfaction with healthcare services were good and were not associated with the clinical course, which was suboptimal in 70% of young people in this study.

There is no consensus about what constitutes a 'satisfactory clinical course' in Type 1 diabetes during transition, from an adolescent or clinician perspective. Our assessment was based on biological markers of disease control as well as

Table 2 Number of participants (from the 108 who completed the study) that did not meet the criterion for each marker in the year before each visit.

Marker	Visit 2	Visit 3	Visit 4
Not met target of HbA$_{1c}$ difference from baseline visit, *n* (%)	23 (21.3)	20 (18.5)	34 (31.5)
One or more episodes of diabetic ketoacidosis, *n* (%)	7 (6.5)	8 (7.4)	3 (2.8)
< 75% paediatric clinic attendance, *n* (%)	23 (21.3)	14 (13.0)	20 (18.5)
Not received annual retinal screening, *n* (%)	10 (9.3)	4 (3.7)	16 (14.8)

Table 3 Baseline demographic data, Mind the Gap score and mental well-being score by clinical course group

	Satisfactory clinical course $N = 32$	Suboptimal clinical course $N = 76$
Mean (SD) age at baseline in years	15.8 (1.1)	16.1 (1.2)
Median (IQR) age at diagnosis in years	9.0 (6.0)	9.0 (6.0)
Median (IQR) duration of diabetes in years	6.5 (6.0)	7.0 (6.0)
Men	59.4%	44.7%
Women	40.6%	55.3%
Average Mind the Gap score (IQR)		
Baseline (visit 1)	0.57 (1.6)	0.50 (1.1)
Visit 4	0.64 (1.2)	0.61 (1.1)
Average Mental wellbeing score (SD)		
Baseline (visit 1)	53.5 (8.5)	52.9 (8.0)
Visit 4	52.6 (8.3)	53.2 (7.3)
Transferred to adult services	87.5%	78.9 %

None of the differences between the two groups was statistically significant, $P > 0.05$.

markers of engagement. Change in HbA$_{1c}$ was included because it is a key biological marker of disease control in Type 1 diabetes. A systematic review of interventions that

improve transition to adult care in adolescents with Type 1 diabetes noted that 16/18 studies included HbA$_{1c}$ as an outcome [24]. Our justification for using ketoacidosis was that episodes are associated with poor disease control and poor adherence to treatment [6]. We considered clinic attendance to be an important part of satisfactory transitional care because it correlates with a better disease outcome [23]. Clinic and annual retinal screening attendance are markers of positive health behaviour and are both recommended by the National Institute of Health and Care Excellence (NICE) guidelines for transition services and management of young people with diabetes [27].

The median HbA$_{1c}$ increased significantly during the study period. This has been reported in previous studies – a trend of deteriorating glycaemic control during adolescence with subsequent improvement, plateauing by about age 30 years [4,5]. During the study, 81% of the young people transferred to adult healthcare services. Similar proportions of those who had and had not transferred were in each clinical course group, raising the possibility that healthcare transfer may not be relevant to this deterioration in metabolic control. Deterioration of glycaemic control during adolescence may be related to hormonal changes and insulin resistance. However, a study by Morris *et al.* [6] involving adolescents found increases in HbA$_{1c}$ were associated with deteriorations in adherence to treatment, as demonstrated by reductions in volumes of insulin administered.

Participant satisfaction with services did not change significantly over time and was not related to the clinical course. Satisfaction with services was comparable with that of young people with another long-term condition (rheumatological disorders during transition) [22] and in an evaluation of an intervention in transitional care for young people with juvenile idiopathic arthritis [28]. This suggests that some adolescents with Type 1 diabetes are not aware of the optimal clinical course they should expect and are therefore happy with the service they receive.

The mental well-being of those with Type 1 diabetes was similar to that of the general population of 13–16-year-olds in England and Scotland [21]. Mental well-being did not vary during the period of transition, suggesting that healthcare transition per se is not detrimental to well-being. Finally, there was no association between well-being and clinical course. This is not the case for juvenile idiopathic arthritis where there is an association between disease activity and health-related quality of life [12]. In Type 1 diabetes there is in general no development of adverse symptoms in response to suboptimal glycaemic control and this may explain why well-being is not affected.

We chose to measure general well-being for three reasons: (1) it enables comparisons to be made across conditions; (2) international Delphi studies indicated that this was regarded as an important outcome of transition, not hitherto addressed [10]; and (3) diabetes-specific quality of life instruments tend to capture negative consequences of disease, which may bear

little relation to the overall well-being of an individual. Vallis *et al.* [29] found that young people with Type 1 diabetes aged 18–25 years had better overall well-being than those aged over 30 years but more diabetes-specific distress. Diabetes-specific quality of life, although often reduced, may also bear little relation to markers of disease control, such as HbA$_{1c}$ [13]. Further, an intervention which improved health-related quality of life failed to demonstrate a subsequent improvement in glycaemic control [14].

Why might it be that, although well-being was good and services were appreciated, the clinical course and in particular glycaemic control deteriorated in two-thirds of the population? A systematic review of the impact of transition processes and experiences on outcomes in Type 1 diabetes [30] identified three superordinate themes from qualitative studies with young people: 'Discontinuity of care', 'Practical issues with transitional care' and 'Renegotiating responsibility for self-management'. Compared with some of the studies from North America cited in the review, discontinuity of care in Type 1 diabetes in the UK is not a significant problem and this was borne out in our study. Also, practical issues with transition seem not to have been problematic in our study as the MTG scale indicated general satisfaction with services. Renegotiating responsibility for self-management may be worthy of further study. But even this may not work if adolescents view their disease burden to be less than that perceived by parents or health professionals. An intense psycho-educational programme was found to have no effect on HbA$_{1c}$ [31] and a systematic review in 2017 found there was insufficient evidence to recommend any psycho-educational programme [32].

Other important changes during this phase of life are the shift in importance from parent to peer relationships and the development of autonomy and independent coping skills. However, there is increasing evidence that parents remain important in health management [33,34] and that renegotiation of responsibility should be gradual and is unlikely to be complete by the time of transfer to the adult service. Further, although there is interest in peer support interventions, young people with diabetes who believe they would experience a negative reaction from their peers in social situations have reduced adherence, with a subsequent deterioration in glycaemic control [35].

Strengths and weaknesses

Our study captured data during the healthcare transition process, rather than at a time when transition is complete at around age 24 years. Although assessment of longer term outcome is important, changes to transition programmes must take place during transition and therefore the perceptions of young people and the control of their diabetes during this time are important to understand.

The original sample had lower recruitment from areas with more socio-economic deprivation, although, as mentioned

above, the difference was small. We followed the group of young people for 3 years. Although 42 adolescents with incomplete data could not be included in the analysis, they did not differ significantly in demographic characteristics or baseline variables from those with complete data.

The proportion of adolescents in the clinical course groups reflects the data collected as part of the study and does not necessarily cover every important parameter, such as episodes of severe hypoglycaemia, recording of annual blood pressure or renal status.

To conclude, mental well-being and satisfaction with healthcare services were good in this sample of young people with Type 1 diabetes, and were not associated with the clinical course, which was suboptimal in 70% of those taking part. Developmental changes may have more influence on the clinical course than transition per se. There remains a need to improve the support for young people to develop confidence in managing their condition, to help them benefit from peer support and to address any difficulties they may have with peers and family. The best ways to do this remain unclear and there is a need for evaluation of innovative interventions to address these issues.

Collaborators

The Transition Collaborative Group consists of the authors of this paper and other co-applicants: Angela Bate, Newcastle University, Caroline Bennett, Council for Disabled Children, London, Gail Dovey-Pearce, Northumbria Healthcare NHS Foundation Trust, Janet McDonagh, University of Manchester, Tim Rapley, Northumbria University, Newcastle, Debbie Reape, Northumbria Healthcare NHS Foundation Trust, Luke Vale, Newcastle University; Advisors: Nichola Chater, Northumberland Tyne and Wear Mental health NHS Trust, Helena Gleeson, Queen Elizabeth Hospital, Birmingham; Local investigators: Anastasia Bem, Norfolk and Norwich University Hospital, Stuart Bennett, Rake Lane Hospital, North Shields, Amanda Billson, Royal United Hospital Bath NHS Foundation Trust, Stephen Bruce, Rake Lane Hospital, North Shields, Tim Cheetham, Great North Children's Hospital, Newcastle, Diana Howlett, Sirona Care and Health, Bristol, Zilla Huma, Formerly Frimley Health NHS Foundation Trust, Mark Linden, Queens University Belfast, Maria Lohan, Queens University Belfast, Melanie Meek, Avon and Wiltshire Mental Health Partnership NHS Trust, Jenny Milne, Tyne, Esk and Wear Valley Mental Health NHS Trust, Julie Owens, Northumbria Healthcare NHS Foundation Trust, Fiona Regan, Frimley Health NHS Foundation Trust, Nandu Thalange, Norfolk and Norwich University Hospital.

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Competing interests

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