The transition from paediatric to adult diabetes services: what works, for whom and in what circumstances?

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Executive Summary

Background

The importance of getting the transition from paediatric to adult diabetes services right for young people is increasingly acknowledged but research evidence to inform the design of services is weak.

Aims

This study aimed to:

- identify, map, categorise and enumerate the range of diabetes transition models in use in England,
- develop a conceptual framework of models, building on National Institute for Health Research Service Delivery and Organisation programme research on continuity of care,
- undertake in-depth evaluation of a purposive sample of models to develop an understanding of users’/carers’/providers’ experiences of, and preferences for, transition services, the processes and organisational challenges involved and assess costs,
- make recommendations about what works best to promote ‘a smooth transition’, for whom and in what circumstances,
- contribute to understanding of pathways through transition and develop further theories of continuity of care.

Methods

The study was informed by the seven dimensions of continuity identified by Forbes et al. in their review of transition service arrangements: experienced continuity (smooth progression of care from the service users’ point of view); continuity of information (excellent information transfer); cross-boundary continuity (effective communication between professionals and services); flexible continuity (adjustment to the needs of an individual over time); longitudinal continuity (care from as few professionals as possible); relational or personal continuity (a therapeutic relationship with a named health professional) and developmental continuity (care which grows with the changing demands of the client group and works to facilitate that change). These concepts were refined through an iterative data generation and analysis process.
Stage 1: Service Mapping

A survey instrument was developed in order to map transition services in England. It was predicated on the assumption that smooth transition depends on achieving different kinds of continuity and that there were different ways of achieving these effects reflecting local service constraints. It included questions about context, structure, mechanisms for transfer and organisational practices associated with the continuities of care identified as contributing to smooth transition. The survey was administered to a 20% random sample of services drawn from the Directory of Diabetes Care. Sampling continued until no new service arrangements were identified. A typology of transition models was developed reflecting the range of transition services.

Stage 2: Realistic Evaluation of Transition Models

The typology was used to select a sample of five transition models for in-depth exploration informed by the principles of realistic evaluation. Each model represented an identifiable configuration of service components designed to manage the transition pathway between paediatric and adult services. Observations, the analysis of organisational documents and interviews with health professionals were used to build up model descriptions. Case studies were undertaken with young people and their carers (n=46). Each participated in separate qualitative interviews on three occasions over 12-18 months. The interviews generated data on their experiences of, and preferences for, transition. Medical record review was combined with clinical interviews with health professionals to build up an understanding of each case. Individual case studies were treated as ‘outcomes’ and informed the model evaluations. They were also taken into account during the analysis of users’/carers’ experiences to ensure that their views were interpreted in the context in which they were expressed. The quality of life domains nominated by young people were described and their stability or change over time assessed.

For each model, parallel surveys of young people with type 1 diabetes, approaching, undergoing or less than 12 months post transition and their carer were administered. The questionnaires included instruments that measured satisfaction (including perceived continuity), healthcare climate and quality of life, selected following a systematic review and appraisal of instruments. Analysis takes the form of summary statistics and regression models.

The study also included a costs and consequences analysis.
Results

Stage 1: Service Mapping

All services included elements of practice designed to promote cross-boundary and informational continuity, and most included elements to promote relational and longitudinal continuity. The features that discriminated between services were the extent to which they included interventions designed to ensure developmental and flexible continuity and the number of stages in the transition process. The survey revealed a strong trend towards sequential transition. By combining the structural characteristics (one, two or three stages) with the process characteristics (the proportion of continuity interventions) we created a typology of transition models.

Stage 2: Realistic Evaluation of Transition Models

What works?

Data synthesis across the sample of models revealed that seven types of continuity contribute to users’/carers’ experiences of smooth transition: relational, longitudinal, informational, management, cultural, developmental and flexible. These continuity concepts are a modification of Forbes et al.’s original framework.

Relational and longitudinal continuity are central to transition because they facilitate other kinds of continuity: flexible and management continuity (continuity of diabetes management through a common purpose and plan). They also provide a sense of safety at times of change, obviating the need for formal informational continuity interventions. Flexible and cultural continuity also emerge as important.

Cultural continuity is a new concept developed for the purposes of this study. The literature on transition focuses on the differences between child and adult service cultures and the need to support young people in adjusting to this. While some models fitted this portrayal, in others paediatric and adult services were culturally continuous. Young people and their families in models exhibiting high levels of cultural continuity experience better outcomes on a range of measures.

There are challenges involved in achieving a balance between developmental and flexible continuity interventions. Young people and their families experience better outcomes in those models where support is responsive to individual need (flexible continuity) than in those with more proactive approaches (developmental continuity).

Across models a range of service components are deployed to achieve the continuities that contribute to smooth transition. The relative effectiveness of individual service components was assessed as well as the combined costs and consequences of the interventions comprising each model.
For whom?

Overall there were high levels of agreement between young people and carers about the mechanisms central to smooth transition.

There was, however, one area where what works for young people does not work for carers. Mothers are an important source of continuity for young people, but this is not formally recognised in policies in this field. Whilst the progression to lone consulting and/or transfer to adult services is a key developmental milestone for young people, many mothers become cut off from the process and can no longer access the advice needed to support their child. They also have their own needs for support which is lost when they are no longer routinely interacting with service providers.

Young people who were poor clinic attenders and/or who had strained relationships with carers were not represented in the user/carer case studies. We do not know to what extent the study findings can be extended to this group.

In what circumstances?

Models with high levels of relational, flexible and cultural continuity achieve smooth transition with relatively informal, low cost informational and management continuity mechanisms.

Models with more complex divisions of labour and low levels of relational and longitudinal continuity need to invest in more formal interventions to facilitate management, flexible and informational continuity to ensure smooth transition is not compromised.

Conclusions

Whilst the language of ‘models’ has been used to describe the phenomena of interest for the purposes of this report, the real world of practice is infinitely more complex. In a given locale, the configuration of service components necessary to ensure smooth transition will depend on local organisational context and related model components, and services may experience on-going modifications in response to wider organisational exigencies. Accordingly, the aim of this study was not to compare models for the purpose of identifying the best model in an absolute sense; but rather to consider in-depth a sample of models reflecting the range of existing service provision in order to identify and understand the generative mechanisms central to smooth transition, their inter-relations and the service components through which these can be achieved in a given organisational context.

There are questions we believe warrant further research. These are:
• Research to address young people’s singular support needs at this stage of the life-course and their implications for service delivery and organisation.

• Research to address young people’s needs for, and access to, information and their preferences for information format.

• Longitudinal research to examine how far self-care practices in adolescence and young adulthood are predictive of adult health behaviours.

• Research which examines the costs and benefits of strict and relaxed approaches to diabetes management at this stage of the life-course.

• Research to develop and evaluate different interventions to support the management continuity needs of carers.

• Research to develop and evaluate different interventions to address carers’ support needs.

• Research to address mechanisms for promoting cultural continuity across services.

• Research to address young people’s needs and preferences in relation to dietary advice.

• Research to address the relationship between continuity mechanisms and clinical outcomes.

• Research to address the relationship between continuity mechanisms and clinical outcomes on large populations using quasi-experimental methods.

• Development and evaluation of a ‘Rolls-Royce’ model of transition through a randomised controlled trial.
Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

Addendum

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