

Promoting Evidence-Based Nursing Practice: Adolescents with type 1 diabetes: Transition between Diabetes Services

Introduction

This project responded to concerns by Royal District Nursing Service (RDNS) Clinical Nurse Consultants (Diabetes) that young people making the transition from paediatric to adult diabetes services may be falling through the gaps between services. In 2003 the RDNS Research Unit gained a grant from the Channel 7 Children's Research Foundation of South Australia. This project aimed to investigate ways to facilitate a coordinated approach to transition and as such collaborating partners were Royal Adelaide Hospital (RAH), Women's and Children's Hospital (WCH), Flinders Medical Centre (FMC), The Queen Elizabeth Hospital (TQEH), Lyell McEwen Health Service (LMHS), Modbury Hospital (Modbury), Diabetes Outreach (Department of Health) and RDNS.

Background

Transition was defined by Blum *et al.* as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems'. When transition to adult services is ineffective, young people may choose to 'drop out of the system'. A general practitioner (GP) may be accessed for the prescription of insulin however, it is thought that a multidisciplinary approach to diabetes care provides optimal management (Strategic Plan for Diabetes in South Australia 1999; Parsons *et al.*, 2000). When diabetes is poorly managed then young people are at risk of life-threatening acute complications requiring hospitalisation and/or developing long-term complications (DCCT 1993). A smooth transition into adult health services may prevent these situations occurring, thus having financial benefits for the community as well as improving the quality of life for those with diabetes.

Aim and Objectives

The primary aim of this project was to develop a sustainable and coordinated approach to facilitating the transition between diabetes services for adolescents. The objectives were to involve key diabetes health delivery stakeholders in expressing their concerns, claims and issues (CCIs) about current service delivery and ways to improve same and to reveal from the perspective of adolescents living with type 1 diabetes their experiences surrounding the process of transition from children's to adult diabetes services.

Methodology

The methodology was guided by fourth generation research principles (Guba and Lincoln 1989) which required the interviewer (Visentin) to focus on the CCIs around service delivery. Interview data were generated with health professionals ($n=21$) and adolescents ($n=10$). The analysis of data were clustered into common CCIs constructs.

Findings

Health professionals (HPs) felt that changing from paediatric to adult services was one of many life transitions experienced by adolescents. It was therefore not surprising that these young people commonly ranked dealing with their diabetes low on their list of priorities. Findings suggest that young people are more likely to be involved in health-compromising and mismanagement behaviours. One of the adolescents participating in the research project was Bernard aged 18 years. He was interviewed during June 2004, in the Paediatric Outpatient Department of an Acute Hospital. This was his second appointment with the paediatrician in the last 18 months, the first had been one week earlier.

Bernard was aged 14 when he was diagnosed with diabetes. At that time the only thing he 'was worried about was the needles part, don't really like needles'. His mother and grandfather live with diabetes and he explained that his diagnosis was discovered when he was playing around with his mother's blood glucose machine. Making dietary and other changes was not too difficult initially as he said: 'living with mum she changed my diet type of thing but then when I turned 16 I started to get my own money and find my own food and yeah that's when I started to decline type of thing'. Bernard moved out of home and he recognised the 'decline'. He said:

you get thirsty like its like a circle, your sugar goes up so you get more thirsty so you drink more stuff with sugar in it so it just keeps getting worse and worse ... I shouldn't be eating chocolate ... I eat one meal at the end of the day cos that's when I used to get hungry... I felt unwell, tired and angry and the smallest thing would get me. When my local doctor said that I'm starting to have problems that sort of like woke me up type thing so I made an appointment to see the dietician and made an appointment up here. Now I'm trying to get everything back under control... I didn't really like going to that doctor anyway like if you know what I mean, I don't like going to any doctors, if it were my choice now I wouldn't even be here today but I'm sort of getting it through my head that I have to do it, if I don't do it I'll get sicker and sicker. Having a chronic illness costs money. He said 'the money to get up here and stuff like that cos I only get, after I finish paying rent, \$160 a fortnight ... and that has to cover my diabetes stuff, like finger test strips and stuff like that...

Whilst living at home he made 3-4 monthly visits to see his endocrinologist until he was sixteen. In those years he had attended the diabetes camps and other activity days which he found most enjoyable. He valued the opportunity to be with others who had diabetes as he felt there was an understanding between them.

Unfortunately when he moved out of home he said 'I started making my own decisions and getting my own money and stuff like that then I made my mind up that I didn't want to go to a hospital at all, it didn't matter to see what doctor or anything'. Since leaving home it seems he has fallen through the gap. What are the consequences? Although Bernard appeared to be quite knowledgeable about his decline and what he should do, damage may already be irreparable.

Common Claims

A claim is an assertion that a service aspect is working well. HPs made a numbers of positive claims about their services. Noted were that (1) the RAH in collaboration with the WCH has set up a formalised transition process which has significantly improved attendance rates to the first and second appointment; (2) highly specialised and quality services are provided to this client group; (3) there is collaboration and communication between services and health professionals; (4) Clients are prepared for transition by the paediatrician/endocrinologist; (5) continuity and consistency are maintained in services that have paediatric and adult diabetes clinics co-located. It was noted that initiatives have not been evaluated. Meanwhile adolescents claimed that they were satisfied with their paediatric service and that they felt supported by the staff. In particular they had developed a close rapport with their doctor and/or diabetes nurse educator.

Common Concerns

A concern is distinguished from an issue as it was seen as an aspect of service delivery that could be addressed at a local health unit level. Three concerns were raised: (1) education and dietetic advice is often reactive not proactive; (2) there is a lack of communication and collaboration between some services; and that (3) current service delivery is under-resourced.

Common Issues

An issue is an aspect of service delivery requires a state-wide resolution approach. There were four main issues (1) some clients were 'lost' in the system and consequently have an increased risk of complications; (2) the paediatric model is different to the adult model of care; (3) not all phases of the transition process are being adequately addressed; and (4) there are access and equity issues around service provision for consumers from both rural and metropolitan areas.

Implications for RDNS

The research has provided RDNS as the community based service provider with the evidence about service delivery gaps as well as consumer issues and concerns. This will greatly assist the CNC Diabetes to collaboratively develop and facilitate a successful and sustainable transition process and experience for adolescents with diabetes from paediatric to adult diabetes services. Furthermore, the research has enabled the CNCs Diabetes to critically reflect on current

practices and relationships with allied health providers in this field including:

- Review of paediatric diabetes community pathways for newly diagnosed children with diabetes and their families
- Review and implementation of a paediatric diabetes assessment tool
- Development of paediatric specific competencies for children with diabetes
- Explore and create opportunities for RDNS staff to work in partnership with CNC Diabetes supporting children with diabetes in a range of community settings
- Development of specific competencies relating to succession training and mentoring of nurses in the field of paediatric diabetes

Summary

Overall findings suggest that it is imperative that paediatric services work proactively through utilising recall systems to make sure adolescents are reviewed regularly. Furthermore adult services need to ensure that data tracking processes are in place to flag all transition clients so that the multidisciplinary team can be involved in the clients care from the beginning. It is recommended that each health service continues to assess their own resource requirements and investigate ways in which human resources can be better utilised.

The need to build on existing databases and/or establish a central database with tracking mechanisms is an integral component of any transition program and as such needs to be a priority. In addition, if adolescents are more informed about what to expect from the adult service and how it may differ to their current service, this may make transition easier. Adequate preparation for transition is needed so that adolescents and their families are informed both written and verbally about the differences between paediatric and adult care as well as the transition process.

References

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