

Thesis summary

Living with diabetes during transition to adult life – Relationships, support of self-management, diabetes control and diabetes care

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The transition to adult care for adolescents with diabetes is a complex issue, and several studies have shown that one of the important barriers to successful transitions is the health care system itself. Adolescence is also a vulnerable time in life as many of the patterns of self-care behaviour are set which coincides with a struggle for independence from adults. The overall aim of this thesis was to illuminate main concerns related to the transition of adolescents/ emerging adults with type 1 diabetes to adult life and adult diabetes care and to gain a deeper understanding of how care providers, patients and their parents handle this situation.

Participant observations of visits to physicians, nurses and group sessions (n=51) were conducted in two paediatric and two adult diabetes clinics in two different hospitals in Sweden, using the grounded theory method. Interviews with care providers (n=10) were also included in the analysis of exploring implications of differences in the diabetes care system in relation to adolescents'/ emerging adults' needs. Adolescents/ young adults (n=104) were followed between the age of 18 to 24 through record audit in order to explore glycaemic control and its relation to diabetes care utilization. Interviews with young adults (n=13) and parents (n=13) were conducted to explore factors enabling and hindering transition conditions, experiences and outcome. Chat communication between adolescents/ young adults on a national diabetes website was also included in this analysis.

The results showed that differing care culture in paediatric and adult diabetes care has implications for care providers, emerging adults and their parents' experiences of caring relationships and diabetes care. While youths are receiving multidimensional support in paediatric care, they become less visible after transition to adult care due to differences in structural and organisational conditions and strategies. The young made less visits per year in adult care than in paediatric care. Females visited adult care more often than males. The glycaemic control (as measured by HbA_{1c}) was poor during the whole study period, where both

males and females exceeded the recommended level. HbA_{1c} levels decreased significantly over time for females but not for males. Findings indicate that more visits in adult care are associated with worse glycaemic control.

Another important finding was that the preparation phase and transition process were facilitated in the clinic with special transition strategies where logistic problems such as lost referral letters could be prevented. This indicates that mutual understanding between care providers can be created in professional meetings that also enable integration of care.

The transition to adult life for emerging adults with diabetes was found to be characterized by a relational and reflective process involving reconstruction of supportive relationships with care providers and significant others and a re-consideration of the self. This interactional process implies that an ongoing redefinition of relationships and identity occurs during the transition. The study indicated that individual trust is hindered by an unsettled relationship to the new care provider and institutional trust by declining accessibility and less continuous care.

Conclusions relevant for integrated care are that some barriers are easier to overcome in smaller hospitals that have fewer clinics to refer their patients to and where joint visits and combined posts can influence the transition process on both the organisational and individual level. These strategies lead to increased contact between care providers and thereby contribute to the promotion of transition preparation and the improvement of understanding of the patient's individual needs during transition. With some contact between care providers it seems to be easier to find more and other forms of collaborative strategies. Building trust between different parts of the system through creating relations between care providers could mediate between institutional and individual levels of care

The results presented in this summary are based on the author's thesis presented at the Sahlgrenska Academy, University of Gothenburg on 16 May 2008.

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Further information on this research has been published by this author in the International Journal of Integrated Care:

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