

Living with diabetes during transition to adult life

- Relationships, support of self-management, diabetes control and diabetes care

AKADEMISK AVHANDLING

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av

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Avhandlingen baseras på följande delarbeten:

- I. Sparud Lundin, C. Öhrn, I & Danielson, E (2008). From multi-dimensional support to decreasing visibility: a field study on care culture in paediatric and adult diabetes outpatient clinics. *International Journal of Nursing Studies* 45 (2), 180-190.
- II. Sparud Lundin, C. Danielson, E & Öhrn, I (2007). Handling the transition of adolescents with diabetes: participant observations and interviews with care providers in paediatric and adult diabetes outpatient clinics. *Journal of Integrated Care* 7 (15), 1-10.
- III. Sparud Lundin, C. Öhrn, I. Danielson, E & Forsander, G. Glycemic control and diabetes care utilization in young adults with Type 1 diabetes. (*Resubmitted for publication*).
- IV. Sparud Lundin, C. Öhrn, I & Danielson, E. Redefining relationships and identity in emerging adults with type 1 diabetes (*Submitted for publication*).

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ABSTRACT

The overall aim of the thesis was to illuminate main concerns related to the transition of adolescents/emerging adults with Type 1 diabetes to adult life and diabetes care and to gain a deeper understanding of how care providers, patients and their parents handle this situation.

In paper I and II, participant observations of visits to physicians, nurses and group sessions (n=51) were conducted in two paediatric (PDC) and two adult (ADC) diabetes clinics as well as interviews with care providers (n=10). Focus was to explore the care culture in the settings and its implications for care of and how care providers handle the transition in relation to adolescent needs. In paper III, 104 emerging adults were followed (18-24 years) through record audit in order to explore glycemic control and its relation to diabetes care utilization. In paper IV, interviews with young adults (n=13) and parents (n=13) were conducted to explore the meaning of interactions with and support of self-management from parents and other significant others. Internet communication between youths with diabetes was also included in the analysis. Qualitative studies (I, II, IV) were analyzed with using a constant comparative method. In paper III, parametric and non-parametric statistical methods were used and a generalized linear mixed model was used for the longitudinal data analyses.

This thesis shows 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 frequency of visits declined from time in PDC to ADC and females visited ADC more than males. The glycemic control 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 ADC are associated with worse glycemic control. The preparation phase and the transition process were facilitated in the clinic with special transition strategies where logistic problems such as lost referral letters could be prevented. Mutual understanding between care providers can be created in professional meetings which also enables 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. In conclusion, the findings reveal that individual trust is hindered by an unsettled relationship to the new care provider and institutional trust by declining accessibility and less continuous care. Interventions at an organizational as well as individual level are required in order to meet the needs of emerging adults with diabetes in a life phase characterized by changing conditions. Patterns of diabetes care utilization are important to take into account and more forums for professional meetings might enable integration of paediatric and adult diabetes care.

Keywords; adolescents, young adults, type 1 diabetes, paediatric diabetes care, adult diabetes care, diabetes care utilization, transition, glycemic control, grounded theory.

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