Transition towards autonomy and psychological empowerment in self-management, among teenagers with type 1 diabetes

Agneta Karlsson

Department of Social and Welfare Studies
Faculty of Health and Sciences
Linköpings University

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Go in search of people.
Begin with what they know.
Build on what they have.

- Old Chinese proverb

To my son Carl-Henrik
This licentiate thesis is based on two original papers, referred to in the text by their Roman numerals, I and II.


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ABSTRACT

The general aim of this thesis was to study the transition process from dependency towards autonomy and psychological empowerment among teenagers with type 1 diabetes. Thirty-two teenagers (18 female/14 male) aged 13-17 took part in conversational interviews. The interviews followed a semi-structured question guide. Data comprised 31 tape recorded interviews (one informant did not want to be tape recorded). The research design was based on a phenomenological and life world perspective including two different analysis methods. The transition towards autonomy among teenagers with type 1 diabetes was elucidated in a phenomenological approach (paper I). Through the teenagers’ narratives about their daily life experiences with type 1 diabetes there emerged the over-riding theme “Hovering between individual actions and support of others”. This theme illustrates the main problem related to diabetes management - duality in dependence and independence. The themes “growth through individual self-reliance” and “growth through confirmation of others” seem to facilitate the transition process from dependency towards autonomy. Experiences of the Empowerment Education Programme (EEP) were studied by a qualitative content analysis (paper II). From the teenagers’ descriptions the over-riding theme was formulated as “Sense of community”, and this covered the categories of social fellow feeling, collaborative learning, and community of interests. A synthesis of the findings illustrates that individual self-reliance, confirmation of others, and sense of community are closely related to individual inner resources, trust in others, and the feeling of belonging, which are all suggested as specific goals of empowerment and fulfilment of psychological empowerment. A model was created to explain the relation between psychological empowerment and growth through individual self-reliance, confirmation of others, and sense of community. Professional nursing care might start from the unique situation and context the individual experiences and exists in. Social meetings with like-minded youth were highly appreciated among the teenagers. The teenagers showed their willingness to transform themselves towards becoming more independent in self-management, and the teenage years may be the right period to empower and coach the teenagers towards autonomy and prepare them for adulthood living with type 1 diabetes.

Key words: transition, life world, phenomenology, qualitative content analysis, psychological empowerment, teenage diabetes, adolescence.
INTRODUCTION

Being a teenager and at the same time struggling with diabetes management can mean additional demands such as constant metabolic control and other limitations caused by the illness. Type 1 diabetes is well known as a major global health problem and there has been a constant increase of the incidence in European countries. The frequency of type 1 diabetes in Finland has been reported to be the highest in the world, followed by Sardinia and then Sweden. Variation in incidence between countries and age-groups indicates reasons to look for environmental causes (Patterson, Dahlqvist, & Green, 2000) but there are both generic and environmental factors that play a role in the etiology of the disease (Laron, 2002). Little is known of the perspective of teenagers with type 1 diabetes about what facilitates the transition process to becoming autonomous in diabetes management. Being autonomous implies having the ability to reflect critically on preferences and desires and having the capacity for self-determination (Schroeder, 2007). An interdependent form of autonomy means that the individual makes decisions to act on free will, having been given an honest chance to do so (Arlebrink, 1996). Respect for autonomy means that individuals should be treated as having their own merits (Benner, 2003).

Information about teenagers’ experiences of living with type 1 diabetes or other chronic diseases might be helpful in developing methods to support and understand the teenagers’ transition from dependent to independence in self-management. Periods of personal development are important for the transition process. During these periods, new skills and behaviours are gained and reassessment occurs (Murphy, 1990). The adolescence period is characterized by the infancy situation of dependence changing into a situation of increased self-determination and autonomy (Eriksson, 1988). This period is complex and affected by many issues related to changes in life-style (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Teenagers usually experience a variety of physical, psychological and cognitive changes but teenagers with type 1 diabetes have also to cope with periods of health and illness and learn to handle new practical and emotional situations. The transition process includes a move from parental protection towards growing independence, from secondary school to post-school options, and, particularly for teenagers with diabetes, from paediatric health care to the adult diabetes clinic (McGill, 2002). Therefore, adolescence can be an especially difficult and vulnerable period for young people with type 1 diabetes. Individualised approaches might be able to meet teenagers’ needs and can provide a way to reach a good
transition (Cooke, 2007). A pilot study focusing on transitional management for young people with juvenile idiopathic arthritis showed that competence, autonomy and self-esteem need to be supported as soon as possible after disease onset. The authors conclude that acceptance of young people taking part in their own transition processes might strengthen their feeling of autonomy, which in turn could enable social participation and lead to a meaningful adult life (Östlie, Dale, & Möller, 2007). Soanes and Timmons (2004) concluded that young people with chronic illness need to be individualized and gradually prepared in the transition process to adult care. Schumacher and Meleis (1994) found that feelings of subjective wellbeing, role mastery, and comfortable relationships with others were indicators of a healthy transition.

**Phenomenological approach and the life world**

Theoretical structures in this thesis are, aside from transition, the life world and empowerment. The phenomenological life world is the living, concrete and experienced reality that individuals daily live in and talk about. Under the influence of historic, cultural, and social traditions a new meaning or value appears in interaction with earlier experiences. Thinking begins from lived experiences in all variations and abundance that appear, resulting in an experience conception or life world conception (Husserl, 1989). The present thesis focuses on a life world perspective of teenagers with type 1 diabetes, and lived experiences of the transition process from dependency towards autonomy and psychological empowerment.

In scientific research it is meaningful to take into consideration human beings’ knowledge in their daily lives. In phenomenological studies human beings are seen as subjects with individual lives and qualities (Bengtsson, 2001). Individuals can never be completely understood if they are not viewed with a holistic approach. By exploring how individuals manage their daily life, their ordinary life patterns, and the habits they develop, might contribute to a deeper understanding of human beings’ life experiences and reality. That means faith and willingness to listen, characterized by respect for each human being. The phenomenon being studied must speak of its self, which means doing full justice to the lived experiences and come close to the world as it is experienced (Dahlberg, Drew, & Nyström, 2001). Phenomenology involves the methodological discovery of what appears to the individual and in what way it appears. The nature of the phenomenon as an essentially human experience can be understood by researchers going back to the data and taking an unprejudiced look at the essential elements of the phenomenon (McNamara, 2005).
Theories of health are described by Brulde and Tengland (2003). They illustrate different perspectives of health that can be explained as absence of disease, ability, wellbeing and balance. In a phenomenological approach, health and wellbeing mean an integrated view of the mind and body starting from the individual’s realistic capacity. Health and illness must be understood as a lived experience and the authors prefer the concept of wellbeing that describes the subjective perspective. According to Benner and Wrubel (1989) goals of care means to assist the individual to live in a way that suits what is important to the individual. They declare that caring activities might start from the individual’s subjective needs and the context in which they live because illness can mean loss of abilities that hinder easy and carefree living. Further, the authors state that the nurse’s role is to support the individual in handling the life situation from a holistic attitude and in utilising the individual’s own experience of the situation. Eldh et al (2006) also agree that health professionals need to respect and be aware of each individual’s knowledge and descriptions of their own situation.

**Psychological and community empowerment dimensions**

Empowerment can be another view of health and wellbeing, recognized as a subjective belief in one’s own competence and responsibility for managing special situations and one’s ability to control one’s health and life. Empowering individuals should be one of the priorities of health promotion, (Canadian Public Health Association, Health and Welfare Canada, & World Health Organization, 1986; World Health Organization, 1997). Empowerment occurs chiefly in public health and represents a bottom up approach, and is a process in which individuals discover and develop the capacity to handle and be responsible for their own care (Anderson & Funnell, 2005; Bracht, 1999; Laverack, 2004). The roots of empowerment can be traced back to the education science of the 1960s and 1970s, particularly to the work by Freire (1970). The first concept of empowerment was coined in the field of social psychology and the aim was to improve the possibilities for people to control their own lives (Rappaport, 1981). As individuals become empowered they can build up a sense of self-esteem and self-confidence regarding changes in life behaviour. Empowerment processes are believed to lead to healthier management of different diseases and afflictions (Aujolet, d’Hoore, & Deccache, 2007). In health promotion there can be difficulties with less motivated individuals because management will never be successful if the individual is not responsive or willing to change their behaviour. The interaction between professionals and individuals in this case should be
seen as teamwork with the purpose of facilitating empowerment processes (Koelen & Lindström, 2005).

According to the literature on this subject, empowerment can be separated into community and individual dimensions (Rissel, 1994). Community empowerment means a state of communities or subgroups within communities where individuals mobilize and organize themselves towards social and political change (Bracht, 1999; Laverack, 2004; Wallerstein, 1992). The term reflects social actions and processes that aim to promote participation of individuals, organisations and communities in achieving individual and community control, political efficacy, improved quality of community life and social justice (Wallerstein, 2002). The dimension of psychological empowerment has been described in several studies as individual subjective feelings of competence, responsibility and greater control over one’s life (Bracht, 1999; Rissel, 1994; Wallerstein, 1992; Zimmerman & Rappaport, 1988).

**General and specific goals**
Empowerment has been described as a goal of engaging in activities but also as a process to reach goals. Tengland (2007) distinguishes between general and specific goals. General goals comprise control over health and life and have to do with managing life and health and how to influence the environment that affects wellbeing and avoids health hazards. Specific goals encompass individual competence including inner resources such as knowledge, self-esteem, self-confidence and autonomy. Aspects of knowledge mean consciousness about the context in which individuals live. Gaining knowledge has to do with skill development and problem-solving capacity but also awareness about individual strengths and shortcomings. Self-esteem is linked to the individual’s evaluation of him/herself as a person of some worth and self-confidence is related to beliefs about abilities to manage situations and special tasks. Becoming psychologically empowered means that the individual moves towards autonomy, and is explained as being able to decide one’s own plans (Tengland, 2007).

**Supporting empowerment – a process**
The idea of empowerment has been described as a process that focuses on the human being as a free, responsible and active individual (Freire, 1970). This means that problem solving comes from the individual and actions for change are decided by the individual. In such
projects, professionals might support and believe that the individual or group has the capacity to solve their own problems (Laverack, 2004). The empowerment education approach will engage people through a group dialogue process and help them in identifying their problems and developing action strategies to change their personal and social lives. The professional’s role is to empower individuals to take greater control for self-management and to support them in reaching their goals (Cooper, Both, & Gill, 2003). The study of Howorka et al (2000) showed that feelings of empowerment and independence, growth when individuals were self-responsible and relied on their own decisions to successfully take control of their chronic conditions.

The process of participating in group education means to inherently empower individuals to understand their own situations and gain increased control over factors affecting their lives. With regard to the transitional process, during the adolescence period it is especially important to gradually support and incorporate educational and skills training to help people assume responsibility for self-management (Barlow & Ellard, 2004). Young people participating in local efforts have been shown to gain a sense of psychological empowerment (Holden D, Messeri P, Evans D, Crankshaw E, & Ben-Davis M, 2004; Holden, Crankshaw, Nimsch, Himant, & Hund, 2004). Engaging youth in community participation activities that bond them to each other should be a good way to increase their self-awareness and healthy development (Lerner & Thompson, 2002). Youth empowerment programmes have been suggested to create possibilities to engage teenagers in identifying, designing and conducting social action projects (Wilson, Minkler, Dasho, Wallerstein, & Martin, 2006). Zimmerman and Rappaport (1988) found that membership in community activities is related to psychological empowerment and can help in creating personality, and developing individual cognitive and motivational positions of control and competence. Membership has boundaries that bring emotional safety, a sense of belonging and identification. McMillan (1996) defines a sense of community as the spirit of belonging together, sharing others’ views, a belief that there are trustworthy structures, and an understanding that mutual profits come from being together.

**Teenagers and self-management**

Self management is described as the process though which individuals discover their responsibility for disease management through their daily life experiences and the results of trial and error (Kralik, Koch, Price, & Howard, 2004). Previous studies exploring the
The everyday problems of teenagers with diabetes have focused on self-care management, how self-determination affects metabolic control, and the perception of social support. Diabetes-management includes daily and lifelong activities in which teenagers and their parents make decisions about diabetes care tasks in co-operation (Andersson et al., 2002; Schilling, Grey, & Knafl, 2002). Early adolescents aged 11-15 years handle a great deal of their own diabetes management but parents actively take part in their children’s self-management. However, among pre-adolescent children (8-11 years) parents perform diabetes care to a greater extent (Schilling, Knafl, & Grey, 2006). When parents deal with problems of diabetes management they are viewed as collaborating with as opposed to controlling their teenagers (Wiebe et al., 2005). The process of transferring to responsibility and autonomy in diabetes management is related to age, psychological and physical maturity (Palmer et al., 2004) and need to develop gradually and should involve parental teamwork (Andersson B & Wolpert H, 2004), (McConnell, Harper, Campbell, & Nelson, 2001). Excessive family involvement and nagging in diabetes tasks can be a reason for diabetes-related family conflicts (Dickinson & O’Reilly, 2004; Shroff Pendley et al., 2002). To promote dietary self-management and wellbeing, teenagers may benefit from a supportive peer group whose lifestyles agree with the health regimens (Skinner, John, & Hampson, 2000). Young peoples’ search for identity includes awareness of the ego and ideological confirmation of others in order to overcome feelings of alienation (Eriksson, 1982). Closeness is an integral aspect of friendship. Lindholm (1998) found that friendship with peers and gentle family members are vital in nurturing the teenagers’ inner life.

**The research project**

This thesis is a partial study of a larger intervention study in empowerment education among teenagers with type 1 diabetes. It was carried out as a qualitative follow up with semi-structured interviews with the participating teenagers. The objective of the main study was to describe and elucidate the effects of evidence-based education among teenagers with diabetes. The central questions were intended to elucidate whether the education model led to positive effects regarding knowledge, proficiency and attitudes related to diabetes, self-care and flexibility in self-care, self-consciousness, self-determination and self control of diabetes treatment, metabolic control and self-estimated health. The pedagogic approach in the program - Empowerment Education Programme (EEP) - was grounded upon the view that participants are dynamic and engaged as Freire (1970) suggests. Problem-based learning
(PBL) was used in the educational process (Silén, 2000). The procedure began by introducing a starting point illustrating a predetermined subject for each meeting. The group meetings continued for six weeks, including weekly two-hour group sessions (Viklund, Örtqvist, & Wikblad, 2007).

The present thesis is an attempt to qualitatively elucidate young peoples’ subjective lived experiences of being a teenager living with type 1 diabetes as well as the teenagers’ experiences of participating in a short group program.

**AIMS OF THE THESIS**

**General aim:**
The overall aim of this thesis was to study the transition process from dependency towards autonomy and psychological empowerment among teenagers with type 1 diabetes.

**Specific aims:**
- To elucidate lived experiences, focusing on the transition towards autonomy in diabetes self-management among teenagers with type 1 diabetes (I).
- To study teenagers’ lived experiences and the meaning of participating in an Empowerment Education Programme (II).

**METHODS**
The design is based on a phenomenological and life world perspective including two different analysis methods. The transition towards autonomy among teenagers with type 1 diabetes was elucidated in a phenomenological approach (paper I). Experiences of the EEP were studied by qualitative content analysis (paper II).

**Sample**
All teenagers between 12 and 17 years of age, with type 1 diabetes (n = 284) attending the diabetes clinic at a children’s hospital in Central Sweden were informed about the study by mail. Thirty-eight started the programme and 35 completed the programme. After finishing the EEP the teenagers were asked to take part in conversational interviews. Three declined participation. Two weeks after completing the education the 32 remaining teenagers aged 13-
17 years (Table I) were interviewed with the purpose of elucidating and exploring their thoughts addressing lived experiences of diabetes self-management and the meaning of the group meetings.

Table I. Sample in study I and II

<table>
<thead>
<tr>
<th>Participants (n)</th>
<th>Teenagers with type 1 diabetes n = 32</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of females/ males</td>
<td>Females = 18 / Males = 14</td>
</tr>
<tr>
<td>Age (years)</td>
<td>Range 13 – 17</td>
</tr>
<tr>
<td></td>
<td>Mean 14.5</td>
</tr>
<tr>
<td>Duration of diabetes (years)</td>
<td>Range 1 – 14</td>
</tr>
<tr>
<td></td>
<td>Mean 6.8</td>
</tr>
<tr>
<td>Age at onset of diabetes (years)</td>
<td>Range 1 – 14</td>
</tr>
<tr>
<td></td>
<td>Mean 7.8</td>
</tr>
</tbody>
</table>

**Data collection**

The data comprises 31 tape recorded interviews. One informant did not want to be tape recorded, and instead handwritten memo notes were used. All interviews were conducted by the first author (AK). Two of the 32 informants were interviewed through tape recorded phone calls. Interviews were carried out with the teenagers two weeks after they completed the EEP. The interviews followed a semi-structured question guide, designed from a guide used in focus groups among adults with type 2 diabetes (Wikblad, Leksell, & Smide, 2004) but revised and adjusted for the age of the informants (Table II). It was tested before the interviews. Topics of the conversations were established from themes in the EEP constructed as an aid to dialogue for the young informants to help them describe their experiences. The interviews took place at the outpatient clinic at the children’s hospital and lasted for 45-75 minutes. The interviews were tape recorded and transcribed word for word, either by the interviewer or by a secretary, and were then verified by the interviewer listening to the tape.
Table II. The question guide

<table>
<thead>
<tr>
<th>Can you please tell me something about?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How you experience living with diabetes?</td>
</tr>
<tr>
<td>• How you found out that you had diabetes?</td>
</tr>
<tr>
<td>• Your experiences during the very first period after onset of diabetes?</td>
</tr>
<tr>
<td>• A situation when you experienced stress?</td>
</tr>
<tr>
<td>• A situation when you felt well?</td>
</tr>
<tr>
<td>• How you handle your diabetes and self-care?</td>
</tr>
<tr>
<td>• In what way you make yourself master of your everyday life?</td>
</tr>
<tr>
<td>• The role of friends and parents in managing your diabetes self-care?</td>
</tr>
<tr>
<td>• What attitudes towards diabetes you encounter in society?</td>
</tr>
</tbody>
</table>

Those question were used in paper I

<table>
<thead>
<tr>
<th>Why did you end up taking the course?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What did you want to get out of it?</td>
</tr>
<tr>
<td>• How did it turn out?</td>
</tr>
<tr>
<td>• What experiences did you have on the course?</td>
</tr>
</tbody>
</table>

Those question were used in paper II

**Data analysis**

**Vancouver School of Doing Phenomenology**

The analytic process in paper I is inspired by The Vancouver School of Doing Phenomenology, described by Halldorsdottir (2000). This method is built on the phenomenological philosophy of Husserl (1989). The aim of phenomenology is the rigorous and unbiased study of things as they appear in order to arrive at an essential understanding of human consciousness and experiences. Exactness and cogency are reached through intuitions, insights and reflections on different levels (Bengtsson, 2001). The phenomenological approach was chosen as a way to move into teenagers’ inner worlds to understand their thoughts and experiences with respect to the transition towards autonomy in self-management. In this approach the researcher assesses the data together with research participants who are seen as dialogue partners. Through listening, the researcher can develop a deeper understanding of the phenomenon and can share understanding with the dialogue partner. In this paper the first nine question areas from the question guide were used (Table II). The analytic process involved stepwise procedures of consideration of the phenomenon, identifying themes and sub-themes, and finally formulating the over-riding theme. This comprises the understanding of the meaning of the phenomenon. Lastly the researcher
discussed the essential structure of the phenomenon with two teenagers in the study, asking: “How do my descriptive findings compare with your experiences?” (Halldorsdottir, 2000). The purpose was to see whether they recognized their own experiences in the analytic description.

**Qualitative content analysis**

Qualitative content analysis is a wide concept concerned with the analysis of qualitative data. In paper II the steps from Graneheim and Lundman (2003) were used to analyse the teenagers’ lived experiences and the meaning of the EEP. This approach is useful to develop inferences focusing on human communication because questions are more direct and straight (Denscombe, 2000). In this analysis the last four questions were used to study the meaning of the EEP and the experiences it provided to the teenagers (Table II). The analytic process consists of organizing meaning units, categories and codes in a structural scheme aimed at illustrating the over-riding theme being studied. One methodological question when performing qualitative content analysis is to decide whether the study will focus on manifest or latent content of the text (Graneheim & Lundman, 2003; Kondracki, Wellman, & Amundson, 2002). Manifest content refers to what the text says, describing the obvious and visible. Latent content is the analysis of the underlying meaning of the text and requires developing constructs to add broader meaning to the text. This study use both manifest and latent qualitative dimensions in the analytic process. From the analysis, three main categories emerged as expressions for *What* the teenagers described that means the manifest dimension. Finally, the underlying meaning of the main categories was formulated into the over-riding theme that explained the latent content of the text, answering the question *How*.

**Ethical considerations**

Ethical considerations took into particular consideration personal integrity and promotion of self-esteem. The Research Ethics Committee at Karolinska Institute, Stockholm (KI Dnr 03-319), reviewed and approved the study protocol. All ethical standards in regard to informed consent and right to withdraw were upheld. Before the study, the teenagers were informed by letter about the interview aim and the areas the questions would cover, and later they were verbally updated in connection with the interviews. It was especially pointed out that participation was voluntary and that they had the right to terminate the interview at any time. Both the teenagers and their parents signed an informed consent before the main study started.
Validity of trustworthiness

The approach to the question of rigour differs in qualitative and quantitative approaches. While quantitative research aims at refutation or confirmation of a hypothesis, qualitative research aims at a deeper understanding of a phenomenon. Scientific strictness in qualitative studies is built on descriptions of how trustworthy the findings are. Those aspects speak to validity and reliability, dependent on the methodological skill, understanding and honesty of the researcher. In qualitative studies the researcher is the instrument, and preconceptions and professional theoretical foundation should be disregarded in order to avoid influencing the research process (Patton, 1990). Findings have to be evaluated in relation to the developmental process of emerging findings.

Aspects of credibility, transferability, dependability and conformability are considered in this thesis as intertwined and inter-related as Graneheim and Lundman (2003) suggest. Describing the researcher’s pre-understanding, data collection, participants and analysis steps is helpful to secure internal validity. In this thesis the researchers pre-understanding comes from the theoretical perspective of caring and health promotion as well as from professional clinical meetings with adults living with lifelong disease, and from private and personal meetings with teenagers in daily life. To structure the interviews a guide was constructed for the young informants. In order to obtain credible and truthful findings, the question guide was tested on two teenagers with type 1 diabetes, who were not included in the study. Semi-structured questions created new conversation insights that influenced different follow up questions viewing the individual perspective. To increase the credibility of the interview data the interviewer returned to the interview question several times in order to invite the teenagers to develop their thoughts, for example by asking questions like “what do you mean” or “can you give an example” in order to encourage the teenagers to focus on their own life experiences when describing situations.

The steps of the analysis process in papers I and II are designed to show how themes emerge from the text. Through a procedure of systematically questioning the findings, rethinking and critically reviewing the phenomenon, it was verified that the findings were in fact founded in the data questions. Discussion and valuation with the other researchers highlighted the importance of being aware of the theoretical outlook and personal experiences in order to avoid conceptual blindness. The context in demographic data concerning age, gender,
duration and age at onset of diabetes in which the study took place is described in order to
decide whether the findings are transferable to other situations.

All teenagers who had completed the EEP were asked to take part in the interviews and there
was no discrepancy during data collection. The first author (AK) conducted all the interviews.
The 31 interviews were tape recorded and transcribed word for word either by the interviewer or
by a secretary, and then were verified by the interviewer listening to the tape. The handwritten
memo notes from one interview were kept through the whole analysis process. All quotations
in the findings are marked with a code number, and the sex and age of the interviewees to
demonstrate the multi-voiced nature of the text. The interviewer had some knowledge of
qualitative interviewing from earlier studies and from the two test interviews conducted
before the study begin. The first author read the interviews and carried out the
categorization and development of themes. The co-authors coordinated their work on the
different stages via periodic checks and debriefing opportunities, scrutinizing the transcript
coding, categorization and themes to verify conformability with the entire text.

The essential structure of the phenomenon in study I was discussed with two of the
participating teenagers in order to confirm whether they recognized their own experiences in
the analytic description. They confirmed the analysis and had nothing to add.

**FINDINGS**

*Teenagers with type I diabetes – a phenomenological study of the transition towards autonomy in self-management. Paper I.*

In this paper the aim was to elucidate lived experiences, focusing on the transition towards
autonomy in diabetes self-management among teenagers with type 1 diabetes. Through
teenagers’ narratives about daily lived experiences with type 1 diabetes there emerged the
over-riding theme “Hovering between individual actions and support of others” that illustrates
the problem with duality in dependence and independence related to diabetes management.
Some times the teenagers were willing to take full responsibility for their own diabetes
management while they in other cases felt insecure and were too immature to take this step.
The teenagers alternated between readiness to completely handle diabetes management and
insecurity, and also, though immature, took full responsibility. Such a situation causes unclear
responsibility with respect to diabetes self-management activities that might lead to
difficulties between parental involvement and teenagers’ efforts to realize autonomy. Being
given adequate reminders about self-management was described as positive support but
conflicts often arose due to endless niggling questions about self-management activities. The
teenagers’ lived experiences of the transition towards autonomy reflected the dialectic
opposites of being or not being self-determined, psychologically mature and motivated, as
well as having or not having the encouragement, acceptance and support of others. The
transition is presented by the over-riding theme, as well as themes and sub-themes described
below.

Growth through individual self-reliance
The theme “growth through individual self-reliance” comprised the sub-themes of self-
determination, psychological maturity and motivation. The developmental process of self-
determination required factual and experiential knowledge as well as skill development. The
teenagers’ ability to take complete responsibility for diabetes management decreased because
of insecurity about adequate diet and lack of knowledge about the physical processes
connected to diabetes disease. The transition towards increased responsibility was perceived
as unsafe and risky because teenagers had previously trusted parental competence completely.
The teenagers expressed the view that choices and guidelines for diabetes management and
insulin doses were established on their experiential knowledge of unstable blood glucose, and
therefore they were their own experts in managing diabetes activities. They declared that
others can assist with good advice but can never make the decisions because others have no
experience of living with diabetes.

Psychological maturity enabled increased responsibility and freedom to make changes but
also involved acquiring the skills and knowledge required for successful problem-solving.
The teenagers had discovered that they gained increased freedom when parents believed in
their ability to handle self-care, and the more responsibility teenagers showed, the more
freedom they were given. The increased maturity and freedom developed their odds of
practicing problem-solving while away from the family. This increased maturity and entailed
spending more time away from the family, which they felt expanded, their chances of
practicing problem-solving.

Motivation increased with successful self-management and was related to the level of
successful management and regulation of blood glucose. Complicated diabetes due to
fluctuating blood glucose despite efforts to gain control, caused illness and feelings of helpless that reduced their motivation to handle own care. The teenagers’ own experiences taught them how they felt when blood glucose was out of control, which strengthened their motivation to improve diabetes-management.

Growth through confirmation of others
The theme “growth through confirmation of others” comprised the sub-themes of parental encouragement, peer acceptance and support from the diabetes team. Parental encouragement increased the certainty of teenagers’ standpoints and supported individual competence in handling diabetes-management in the form of practical advice such as changing one’s diet and insulin doses. When diabetes management was too troublesome and hard to handle single-handedly the teenagers felt it was a relief that responsibility could be transferred to parents. Parents who gave reminders about diabetes-related tasks were sometimes identified as supportive but in other cases the teenagers perceived such reminders as nagging, and viewed them as a source of conflict.

Peer acceptance and emotional support made it easier to integrate diabetes management in everyday activities. The transition towards autonomy entailed spending a great deal of time outside the family, and socialization with other teenagers. One condition was that the teenagers felt safe and secure knowing their friends were aware of their diabetes. Becoming autonomous should be seen as a broadening of relationships to include others but did not mean that a teenager had to separate from his/her family.

Support from the diabetes team appeared to strengthen the teenagers’ self-esteem. The diabetes team positively encouraged the teenagers to make individual choices to arrive at their own viewpoints, from their own free will. Teenagers reported that the physician had medical knowledge, gave advice and suggested treatment, but also listened and answered questions. Sometimes the professional advice did not match a teenager’s life situation and therefore it was felt to be hard to adhere to the health regimen. The teenagers felt they were their own experts in making decisions about self-management since the professionals were not familiar with their everyday activities. Anyhow, the diabetes team did support the teenagers in their trial and error process.
Teenagers’ experiences of participation in an Empowerment Education Programme for people with type 1 diabetes. Paper II.

The aim of this paper was to study teenagers lived experiences and the meaning of participating in the EEP. These findings illustrate the over-riding theme “Sense of community” that covered the categories of social fellow feeling, collaborative learning and community of interests. Social relationships were highly appreciated and the teenagers emphasized the benefits of having dialogues with young people in the same situation and with similar problems.

**Sense of community**

*Social fellow feeling* was characterized by shared diabetes-related problems linked to diabetes self-management, parental conflicts and relationships with friends. Discovering a great deal in common in respect to diabetes-related problems contributed to identifying and understanding the problems of other youths. The fact that the teenagers were meeting others who were struggling with the same difficulties and working equally hard to overcome them gave rise to the feeling of being similar to others. These factors resulted in being part of a peer group, which decreased feelings of loneliness and isolation.

*Collaborative learning* was recognized as obtaining knowledge or skill over time and giving and receiving something from others, and was described as a give-and-take relation of life experiences. The PBL process encouraged discussions and reflection about diabetes-related problems and members obtained knowledge about how others handled upcoming difficulties. The teenagers stated that it was valuable that group members were about the same age because experiences are different depending on maturity and age. Belonging to a group of people who understood created feelings of cohesiveness and provided opportunities to learn new skills in relation to self-managing their diabetes and to issues arising from their own experiences. Struggle and strife in diabetes management was something the teenagers jointly shared and was a reason for the sense of friendship that decreased feelings of loneliness and alienation. Obviously, the teenagers felt it an advantage to experience fellowship with other young people in the same situation and of the same age since this allowed them to discuss everyday events and exchange thoughts and views in order to recognize and compare their methods of diabetes management. They exchanged knowledge with each other and realized that members had similar experiences about diabetes-related conflicts, and received tips on how to facilitate diabetes management. Through such sharing, the teenagers heard more about
the experiences of the life situations of others and about how other people’s lives worked. According to the teenagers they did not learn anything new about the diabetes disease. In fact, their main motivation for taking part in the EEP was to exchange everyday life experiences through discussion and listening to how others handle problems.

The group members discussed subjects they found interesting and which were relevant to their everyday events and circumstances. This *community of interests* resulted in discussing problem-solving and everyday events closely related to the teenagers’ puberty and adolescent period, as well as the diabetes disease. They considered problem-solving, the hard work involved in self-care management, and their visions for their future. The teenagers called attention to the importance of discussing various topics, not just the diabetes disease.

**SYNTHESIS OF FINDINGS**
The life world of these 32 teenagers appears to abound with meanings of individual self-reliance, confirmation of others and sense of community. These are aspects that also appear similar to the indicators of healthy transition standing for “subjective wellbeing and wellbeing of relationship” described by Schumacher and Meleis (1994). In regard to empowerment, specific goals are connected to inner resources and general goals are related to the process of achieving control over health and life (Tengland, 2007). In this thesis, specific goals and psychological empowerment are central because the findings emerging from papers I and II seem to be closely related to inner resources and trust in others as well as to feelings of belonging. These aspects have been shown to promote the developmental process in becoming psychologically empowered (Bracht, 1999; McMillan, 1996; Rissel, 1994; Zimmerman & Rappaport, 1988).

The transition towards autonomy among teenagers with type 1 diabetes presented in paper I was characterized as ‘hovering between parental dependency and a willingness to make one’s own decisions’. Empowerment advocates the competence and freedom to handle life and health, and a deficit in this regard seems to be a reason for duality in dependence and independence. Therefore the teenagers’ additional burden of diabetes needs to be understood in all the various transitions they go through during the period of adolescence, as Meleis et al (2000) propose. Individual self-reliance can be a sign of what can be understood as specific goals emerging as self-determination, psychological maturity and increased motivation. From
the teenagers’ descriptions, acquiring experiential knowledge is an essential process in building self-determination. In the present context, practicing autonomy implies parental involvement, but with respect to each teenager’s individual needs. This agrees with the interdependent model of autonomy that stands for supporting the individual’s viewpoint and decision making (Arlebrink, 1996). During the period of adolescent development, childish dependencies change towards a more individualistic sense of self. This implies that young people have to make choices and choose standpoints that will be important for their whole life (Eriksson, 1982). This, in turn, indicates that this period in life can be an opportunity to change to a lifestyle in which diabetes self-management is a natural and healthy part of one’s own life. Increased freedom resulting from psychological maturity is beneficial in gaining control and power over health and individual circumstances. Motivation towards diabetes management grows when teenagers successfully discover they can handle self-care management.

Confirmation of others appears to provide emotional safety and seems to be a salient element in the developmental process of trust in others. The transition towards becoming autonomous is promoted through support, acceptance, and the encouragement of others. Transferring responsibility to parents was described by the teenagers as an essential need whenever diabetes self-management was too burdensome and hard to manage alone. This is also confirmed by the findings of Shilling et al (2006) where teenagers and parents share responsibility, but parents oversee. Feelings of certainty of personal standpoints arise when the teenagers can show their competence and ability to deal with diabetes self-management. Friends were viewed as sources of encouragement, and peer awareness of diabetes as a disease as well as willingness to adapt to self-management activities resulted in the teenagers’ feelings of being part of the peer group. This support of Skinner et al (2000) suggests that teenagers benefit from a supportive peer group that understands the burden of diabetes. The diabetes team strengthens self-esteem through supporting standpoints that facilitate the process of decision making. This agrees with Benner and Wrubel’s (1989) goal of ensuring that care and health professionals understand the individual’s perspective.

The analysis in paper II highlighted benefits such as social fellow feeling, collaborative learning, and community of interest that have been assumed as representing a “sense of community”. This is in harmony with McMillan’s (1996) definition of sense of community including positive feelings of membership, shared experiences and awareness that mutual
benefit comes from being together. When the teenagers were provided with an opportunity to participate through group meetings they seem to have developed a positive identity that may be helpful in building self-esteem, understanding of others and feelings of belonging to the group, identified as fellow feeling. Meeting others who understood each other created feelings of cohesiveness and provided opportunities for collaborative learning. A community of interests linked the teenagers together and helped them have conversations relevant to their existing circumstances and affairs regarding teenagers living with type 1 diabetes.

**Description of the model**

The model was created to explain the relation between psychological empowerment and growth through individual self-reliance, confirmation of others and also the sense of community related to participating in the EEP among teenagers with type 1 diabetes. The major components of the model are the teenagers’ experiences of the transition process to becoming autonomous in diabetes management (paper I) and participating in the EEP (paper II). This might contribute to an additional approach to understanding the specific situation of teenagers with type 1 diabetes during the adolescent transition period. Some basic steps were followed in the development of the model. First, the features to be considered in the synthesis model were established, based on those that had emerged from the analysis in papers I and II. These were then used to structure stages for the model. Second, the literature was obtained to identify and confirm aspects related to these features.
There are three boxes in the model symbolizing what has been found to be helpful in the transition to becoming psychologically empowered. The model illustrates that growth through self-reliance and the support of others can be helpful in the transition process to becoming autonomous, and that community participation creates a sense of community. Individual self-reliance developed from self-determination, psychological maturity and motivation seems to be closely related to inner resources. Confirmation of others demonstrates, support and acceptance that seem to build up trust in those with whom one has close contact, as adults, friends and health professionals. The EEP generated social fellow feelings, collaborative learning and community of interests which were subjectively viewed as representing a sense of community. The concepts of individual self-reliance, confirmation of others and sense of community seem to share in common the idea of helping individuals to gain more power in life and health issues that fulfil the process of psychological empowerment.

**Implications for practice**
Social meetings with like-minded teenagers were highly appreciated as providing a good chance to organize a youth empowerment programme to coach the teenagers during the transition processes towards psychological empowerment. The teenagers showed their
willingness to transform towards becoming more independent in self-management, and this may be the right period to empower and prepare the teenagers for adult life living with type 1 diabetes. It is important that such meetings should focus on teenagers’ special needs related to the transitional adolescence period as well as the additional burden of the diabetes disease. This might also contribute to successful transfer from family focused paediatric diabetes care to adult diabetes services.

Professional nursing care might start from the situation an individual experiences and exists in. In empowerment as a process the teenagers themselves give expression to problems and categorize them according to how they influence life and health. The group meetings need to be marked by listening and understanding and then, though collaboration, problems can be identified and solutions found. The role of the health professionals as a motivational and power-transforming presence can make teenagers with type 1 diabetes aware of their own responsibilities, helping them to find ways to strengthen individual power and take the necessary actions to create youth empowerment. In general, health professionals believe they know, through their expert knowledge and experience, what is best for the individual, but this may not be related to the unique individual’s situation and context. From the teenagers’ perspective, as they pointed out, they are their own experts because others have no idea of what it is like to live with diabetes and are not familiar with teenagers’ daily activities. Supplementary studies are suggested to continuously explore methods and benefits of the youth empowerment programmes described above. Furthermore it might be valuable to explore how the transition from family focused paediatric diabetes care to the more individual perspective in adult services can be carried out gradually and successfully.

DISCUSSION OF METHOD
The aim of this thesis was to study the transition process from dependency towards autonomy and psychological empowerment of teenagers living with type 1 diabetes. The intention was not to answer questions about medical effects or learning processes from the EEP. The interviews were conducted at the outpatient clinic of a children’s hospital, a place the teenagers felt was familiar and safe. It was difficult to find suitable times for interview meetings since the teenagers were busy with different hobbies and activities in their leisure time. That was a reason for simplifying the interview meetings through planning them with a physician or diabetes nurse appointment. An alternative discussed was to conduct the
interviews in the teenagers’ homes but this was rejected because it was important to encourage the teenagers to speak without the influence of others. Having the interviews two weeks after completing the EEP was felt to allow enough time for the teenagers to reflect about the group meetings events and to be able to remember them well.

No judgement was made about who would be selected for participation and the number of participating teenagers was not decided in advance. All the teenagers who had completed the EEP were asked to participate in conversational interviews, thus the sample was governed by the teenagers’ willingness to attend the interviews. Thirty-five teenagers completed the EEP. Three teenagers declined to participate in the conversational interviews. The 32 (18 female and 14 male) remaining teenagers were interviewed with the aim of exploring their individual experiences of self-management. Two of them were interviewed through tape recorded phone calls because it was impossible to find a suitable time for a meeting. This may have caused the conversations to be less innovative and meant that information from body language was lost. In one case, handwritten notes were used during the interview because the informant did not want to be tape recorded. This did not influence the conversation but meant that fine distinctions in the conversation may have been missed while notes were written. The interview questions covered the same areas for all participants but were introduced in a different manner, depending on how the conversations proceeded. That gave new insights and opportunities for innovative questions and topics. This thesis included both girls and boys but there was nothing that indicated gender differences in statements. The mixed group settings seemed to offer a good chance for the teenagers to understand each other in different ways and there were no signs that anyone was inhibited from speaking in the group meetings. Neither was there any reason for a dependence relationship between the interviewer and informants because the researcher was not involved in the intervention procedure or diabetes care of the teenagers.

During reading and re-reading the transcripts it became clear that the statements focused on two dimensions in the conversations. These were duality of dependence and independence, and experiences related to self-determination and support in diabetes management, as well as benefits of taking part into the EEP. Because of this, it was decided to differentiate the two perspectives of experience. The interview questions in paper I and II were brought in at the same time, but were analyzed individually.
First was “The transition towards autonomy in self-management” analyzed through a phenomenological approach (paper I). Second was “The lived experiences of participation in an EEP” analysed by qualitative content analysis (paper II). The nature of the last four questions in the interview guide focusing on experiences and meanings of participating in the EEP was formulated to ask more directly about what and how things are, and this was a reason for using qualitative content analysis in this analytic process. Qualitative content analysis claims no particular disciplinary or methodological roots. Descriptions of the research design focus on the content of narratives to determine theme or patterns (Polit D & Hungler B, 1999). Such an approach is useful when the purpose is to explore aspects of communication that have direct or straight question areas (Denscombe, 2000). In this thesis there has been no quantification of words or sentences from the interviews. Questions reflecting daily lived experiences with type 1 diabetes were more open.

The phenomenological analytic process involved stepwise procedures of consideration of identifying sub-themes, themes, and finally formulating the over-riding theme. The objective was to search for the things as they appear. The participants were pivotal and the researcher’s subjective, intuitive reflection was crucial. The analytic process in qualitative content analysis consists of coding raw data and classification of this data in a category scheme to provide knowledge and understanding of the phenomenon under study. Organizing meaning units, codes and categories in a structural scheme is intended to illustrate the emerging theme being studied. The categories showed the content visible at the surface level of the text, answering the question ‘What?’ The latent context of the analysis illustrated the underlying meaning of the text answering the question ‘How?’ Discussion of different aspects during the analysis process with co-authors (MA, LH) helped the first author to reflect about her own prejudices. The interviewer (AK) had an understanding of living with life-long disease from professional nursing work and experiences from interview situations in earlier studies, and that was helpful in creating familiarity in communication. The health theory of Benner and Wrubel (1989) is used to convey a theoretical nursing care perspective that aims to elucidate the teenagers’ life world perspective.

As mentioned earlier, this thesis cannot evaluate medical effects of the diabetes disease. The significance of such views relates to objective statistical and laboratory results that provide important information about health care but are of limited value when the purpose is to illuminate the human being and the life world. Medical tests of the same group showed that
the empowerment programme had no positive effect on the participants’ glycaemia control, and the teenagers did not become empowered in respect of disease control (Viklund et al., 2007). That seems contradictory and complex in connection to the young people’s experiences described. An assumption may be that the education empowered the teenagers to become more autonomous in relation to their parents, resulting in a relaxed attitude to diabetes management, leading to more experiments and testing as well as mistakes in connection to diabetes control. It is difficult to define empowerment in terms of its effects because it includes psychological components that look different to different people. Empowerment can be easy to recognize when it occurs but the deficit is also easy to recognize; it is usually reflected as feelings of powerlessness, helplessness and alienation.

Limitations in the data collection were that two teenagers were interviewed through phone calls and that handwritten memo notes were used in one case. In this study the age-range of the teenagers’ was 13-17 years old and there are good reasons to consider teenagers’ age in making group discussions. Age can have a significant effect on discussion topics among young people because early adolescents (11-15 years) differ in maturity, interests, and experiences in comparison to mid-adolescents (15-17 years). Even if there is limitations of measurable effects regarding medical effects and the learning process this is a unique and extensive material that might initiate further research. All the teenagers completed the interviews and showed they were very interested in the study. The teenagers have clearly told about their struggles with the transition process towards autonomy and the meaning of the EEP. They appreciated the opportunity to be listened to and tell their story. Some of them said they had never discussed this kind of question with anybody before. The strength of this thesis is that it offers an inside-out perspective that contributes to a nuanced and deepened understanding of teenagers’ transition towards autonomy in self-management, and the benefits of participating in an EEP. The teenagers in this thesis were probably unusually reflective and willing to discuss problems close to self-management since they had taken part in the EEP and were therefore familiar with such thinking.
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