Exploring and Evaluating Transitional Care for Young People with Chronic Conditions

Focus on type 1 diabetes mellitus

Mariëlle A.C. Peeters

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Exploring and Evaluating Transitional Care for Young People with Chronic Conditions

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Verkenning en evaluatie van transitiezorg voor jongeren met chronische aandoeningen

Focus op diabetes mellitus type 1

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Promotor:	Prof.dr. R.A. Bal
Overige leden:	Dr. H.M. van de Bovenkamp
	Prof.dr. P. Moons
	Em.prof.dr. F.J. Snoek
Copromotoren:	Dr. A.L. van Staa
	Dr. J.N.T. Sattoe

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Introduction

"THE UNWANTED GUEST"

Emma is an 18-year-old Dutch girl who looks and acts perfectly healthy. Yet, she was diagnosed with type 1 diabetes mellitus when she was only 6 years old. From that moment on, the never-ending demands of this chronic condition – such as eating carefully, exercising, monitoring blood glucose levels, and planning her day – have dominated her life completely. On a dinner date or a night out with friends, she must always keep diabetes in mind like some kind of unwanted guest. Emma can eat, drink, and dance the night away, as long as she stays within healthy blood sugar limits. Now that she has left her parental home and is fully participating in the irregular student life, she has to keep an eye on this even more. This is really complicated sometimes, as she prefers to talk as little as possible about her diabetes because of the prevailing misconceptions contributing to experiences of stigma. Diabetes is commonly perceived as the result of a failure in personal responsibility. But Emma says: "I do not want people to see me as an overweight, inactive, or lazy person."

From the onset of the diabetes, Emma was treated and supported by professionals of the multidisciplinary pediatric diabetes team of a regional hospital, which whom she and her parents had established strong long-term relationships. However, when she turned 18, Emma had to make the transfer to adult care. Although she transferred within the same hospital, she felt quite nervous about this. "In adult care, you will have to do it all by yourself," was all the preparation she received. Emma's first meeting with the internist in adult care made her feel a bit uncomfortable: "I was suddenly addressed by my surname and it felt like I had to start all over again," she explains. After the internist had introduced himself, he asked Emma how she was doing and what her expectations were regarding her blood glucose control. "I answered and the doctor seemed to be listening, but meanwhile he was typing non-stop," Emma tells. Her HbA1c measured at that visit was 58 mmol/mol, somewhat higher than before, when it was 53 mmol/mol. "Not that bad, but it could be better," the doctor concluded. He wrote down some more things in her electronic patient record, such as her family situation, school, sport activities, and when eye and foot checks were performed. He also asked whether Emma smoked, or used alcohol or drugs. After about ten minutes the next follow-up visit was planned, and the consultation was ended.

Later that day, Emma evaluated this first consultation in adult care with her parents. The way of working and communicating had overwhelmed her. She expressed her concerns: "I really felt like a number, there was no room for my own input. The doctor just focused on the management of my diabetes. He did not ask about my preferences or ideas about living with diabetes. Also, I would have asked him about the impact of drinking on my diabetes since I now live in a student city, but I did not have any chance." Emma would have liked to be better prepared for what awaited her in adult care, how things are going there, the new clinical guidelines, and the expected independency and responsibility. She did not expect the pediatric and adult care settings to be so different; she wished that the transfer process had been better prepared, managed and followed up.

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Emma's story is unique, but not exceptional – as confirmed by a very recent report of the Netherlands' Ombudsman for Children (2021) about children's and young people's position in Dutch health care. This report shows that, according to the children and young people, doctors are too much focused on their medical condition and pay only limited attention to their personal lives, views and priorities. Children and young people wish to be more involved in decision-making and asked about their individual needs and preferences. Especially for young people like Emma – who grow up into adulthood and have to deal with all kinds of challenges related to their chronic condition on the one hand, and the transition in care on the other – this situation is worrying.

This thesis elaborates on the current situation of transitional care for young people with chronic conditions in the Netherlands, with special attention to diabetes mellitus type 1 (T1DM) as one of the most common somatic chronic conditions among Dutch children and young people. After the importance of special attention to the care for young people with chronic conditions (particularly those with T1DM) has been clarified, essential elements in the provision and evaluation of good transitional care are explained. The exact outline and content of this thesis are presented at the end of this Introduction chapter.

Box 1
Type 1 diabetes mellitus

Type 1 diabetes mellitus (T1DM) is an autoimmune disease in which the immune system is activated to destroy the cells in the pancreas that produce insulin (Oram & Redondo, 2019). As a consequence, the body does not produce enough insulin and is unable to process glucose from food entering the body's cells, leading to high blood sugar levels unless glycemic control medication is used. T1DM has not yet been linked to modifiable lifestyle or environmental risk factors; it is still largely unknown what causes the autoimmune reaction (Fazeli Farsani et al., 2016). Up till now, there is no cure available for T1DM and implementing effective prevention programs is not possible too (Fazeli Farsani et al., 2016; Volksgezondheidszorg.info, 2021).

DEFINING CHRONIC CONDITIONS IN CHILDREN AND YOUNG PEOPLE

Thanks to current possibilities for early detection, advances in medical treatment strategies, and improved health service systems, the number of children with chronic conditions that survive and grow up into adulthood has substantially increased in the past decades (Michaud et al., 2018; Patton et al., 2016). Although estimates vary with the operationalization of the definition of a chronic condition (Van der Lee et al., 2007; Van Staa, 2012), recent estimates state that more than 1,3 million (over 25%) of the children and young people in the Netherlands up to the age of 25 years suffer from a chronic condition (Van Hal et al., 2019). These encompass both physical (e.g., asthma, diabetes mellitus and cystic fibrosis) and emotional health problems (e.g., ADHD and depression).

T1DM is often diagnosed in childhood or early adulthood, although it can onset at every age. Health prospects of T1DM have significantly improved in recent years (Tauschmann & Hovorka, 2018), and incidence and prevalence rates among children and young people are still rising, both worldwide and in the Netherlands (Fazeli Farsani et al., 2016; Patterson et al., 2009). In the Netherlands, about 109,000 people (10% of all diabetes patients) have been diagnosed with T1DM, and this number is expected to increase by 20% over the coming 20 years (Dutch Diabetes Research Foundation, 2021). It is estimated that some 10,000 children aged 0 to 19 years have T1DM; this concerns about 5,900 people in the 20-24 years age group (Dutch Diabetes Research Foundation, 2021).

The chronicity of a condition is characterized by its repetitive nature, persistence in effects, and the lifelong treatment (Van der Lee et al., 2007; Van Hal et al., 2019). Although having a chronic condition does not necessarily mean that one is feeling sick, one must adjust to the demands of the condition and its treatment. This could change your lifestyle, seeing yourself, and relating to others. For example, Emma was first diagnosed with T1DM when she was only 6 years old, but after years of managing her diabetes together with her parents and health care professionals – learning more about her condition and how to monitor and manage blood glucose levels – diabetes is now fully incorporated into her self-identity. Still, Emma realizes that her health problem will not fix itself and can never be cured, and requires intensive management throughout her life course. She must find a balance between the demands of her condition and her "normal" developmental tasks – belonging to adolescent life. The challenge herein lies in adopting a lifestyle that does not involve major behavioral changes in daily routines and can be easily maintained in daily life. Today, young people with T1DM are still underrepresented in research on living with their condition (Monaghan et al., 2015; Weissberg-Benchell et al., 2007). Still, deeper insight into their challenges, needs and preferences is required to tailor support of health care professionals for this group.

ADOLESCENCE: A SPECIAL PHASE OF LIFE

Adolescence – i.e., the phase of life that stretches between childhood and adulthood – is a special period for every young person. The exact definition of adolescence has remained unclear for years (Sawyer et al., 2018). In the mid-20th century, adolescence was defined as the period between 10 and 19 years of age. Nowadays, it is defined as the period between 10-24 years, which includes the emerging adulthood phase (Sawyer et al., 2018). This corresponds more closely with contemporary patterns of adolescent growth and understandings of this special life phase (Michaud et al., 2018; Sawyer et al., 2018; World Health Organization, 1986). An appropriate term to denote people in this age range is therefore 'young people' – the term chosen to describe the participants of studies included in this thesis.

Adolescence has special significance in the life cycle because it is characterized by various turning points in personal life, called 'transitions' (Patton et al., 2016). A transition is defined as: *"a passage from one life phase, condition, or status to another that disrupts normal life and demands for adaptation"* (Chick & Meleis, 1986; Schumacher & Meleis, 1994). The adolescent transition from being a child, dependent upon one's parents, to an independent and self-reliant adult, represents one of the most dynamic, broad and influential periods of human development (Quas, 2014; Patton et al., 2016). Besides changes in social relationships, expectations, roles and responsibilities, adolescence is the time of rapid physiological and psychological (cognitive and emotional) growth and development. Also, young persons in this life stage develop new competencies, such as making independent decisions and taking responsibility for their own health.

ADDITIONAL CHALLENGES FOR YOUNG PEOPLE GROWING UP WITH CHRONIC CONDITIONS

The process of transition towards adulthood – characterized by risk, instability and vulnerability – may be even more challenging for young people with chronic conditions, such as Emma (White et al., 2018). In addition to the various life-course changes, for their health and well-being they are dependent on uninterrupted care (Blomquist et al., 1998; Kirk, 2008; Lotstein et al., 2005), which requires a smooth move from pediatric to adult health care services. The process around this '*transfer*' – including transition preparation, planning, tracking, and follow-up – is named '*transition in care*' (Cooley et al., 2011; Sawyer et al., 2007). In other words, the transfer or actual movement between care systems is merely an event within the total process of transition in care (Kennedy & Sawyer, 2008). Schumacher and Meleis (1994) identified four different types of transition in this turbulent period:

1. *Developmental transitions* – e.g., the process of growing up and becoming a young adult, changing roles between Emma and her parents (i.e., shifting responsibilities).
2. *Situational transitions* – e.g., Emma's discharge from pediatric services and her entry in adult care.
3. *Health–illness transitions* – e.g., self-management of the chronic condition, including fluctuating glucose levels.
4. *Organizational transitions* – e.g., changes in care structures or models, such as the difference in the duration of the consultation (shorter in adult care).

Multiple transitions may occur simultaneously during a given period of time (Schumacher & Meleis, 1994). Thus, young people with chronic conditions are expected to find a balance between different developmental milestones inherent to adolescence and emerging adulthood on the one hand, and the adaptive tasks related to the management of the condition in daily life – including the transition to adult care – on the other. This makes the period of adolescence even more complex for these young people. Moreover, with the changing epidemiology in the past few decades (Patton et al., 2016), transition has become more and more an essential part of the care for this age group (Michaud et al., 2018; Zhou et al., 2016). Attention for access and good quality of care – that is, transitional care – for this population is therefore required.

TRANSITION IN CARE FROM A HOLISTIC PERSPECTIVE

Yet, the question of what good transitional care actually entails still remains unanswered. In 1993, Blum and colleagues published the first position paper from the American Society of Adolescent Medicine on transition in care, in which they defined 'transition in care' as follows: *"the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems. (…) The optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive"* (Blum et al., 1993). Although this definition is still widely used among policy makers, health care professionals and researchers involved in transitional care, much is still uncertain about how to implement effective models of transitional care. In the Netherlands, attention for transition in care of young people with chronic conditions arose almost ten years later (2002), when two Dutch pediatricians – Donckerwolcke and Van Zeben – published about this theme for the first time (Donckerwolcke & Van Zeben-Van der Aa, 2002). They mainly focused on the organizational aspects and on medical management, and stated the purpose of transition in care to be twofold: 1) preparing the patient for the transfer to adult care by providing insight into the condition and the aim and possibilities of its treatment, and supporting self-management and take-up of responsibility for medications and dietary restrictions; and 2) creating alliance between pediatric and adult care services, whereby transitional care procedures should be written in protocols (Donckerwolcke & Van Zeben-Van der Aa, 2002).

However, transition in care involves more than just a physical transfer from pediatric to adult care services; it has many components because other life-course transitions occur simultaneously, as described before in this chapter. Emma's story clearly illustrates why a broader perspective on transition in care should be adopted. At the time she has to make the transfer to adult care, she is also going to leave her parental home to start her life as a student in a new city, which implies building new social relationships and becoming independent from her parents and caretakers. Achieving developmental milestones like these is highly relevant in the light of adjusting to adult life, but also has a major impact on the lives of young people with chronic conditions in general. These life changes often result in adherence problems, possibly leading to poor clinic attendance and loss to follow-up in specialist care services, non-compliance with treatment regimens, and lower physical well-being (Garvey et al., 2017; Hanghoj & Boisen, 2014; Heery et al., 2015; Sheehan et al., 2015). Moreover, psychosocial issues are common in this turbulent phase of life (Iyengar et al., 2019).

In turn, such difficulties might lead to increased emergency room visits or hospital admissions and adverse health outcomes, thereby affecting both public and private health expenditures. For example, glycemic variability in young people with T1DM increases the risk of acute or even chronic complications such as ketoacidosis or vascular problems (Altamirano-Bustamante et al., 2008; Bächle et al., 2012; López-Bastida et al., 2017; Ying et al., 2011).

THE 'ON YOUR OWN FEET' TRANSITIONAL CARE FRAMEWORK

Although different studies and numerous guidelines have proposed core elements and beneficial features of, or statements on good transitional care from the broad perspective described above (Betz et al., 2016; Colver et al., 2018; Fair et al., 2018; Foster et al., 2017; Hergenroeder & Wiemann, 2018; Mazur et al., 2017; National Institute for Health and Care Excellence [NICE], 2016; Schultz & Smaldone, 2017; Surís & Akré, 2015; White et al., 2018; White et al., 2020), an overview of core elements and related good practices has long remained absent. In this context – inspired by the *On Your Own Feet* research program, which this thesis is part of – the *On Your Own Feet* transitional care framework was established to fill the gap in the literature (Figure 1) (Van Staa et al., 2020). This framework is guided by the three basic recommendations on transitional care of Viner (2008), the first one of which has it that young people and their families should be prepared well in advance for moving from pediatric to adult services and that they must have the necessary skills to survive and thrive there. Secondly, adult services should be prepared and nurtured to receive these young people. Thirdly, health care professionals should listen to young people's views (Viner, 2008).

Following these principles, the *On Your Own Feet* framework addresses eight core elements regarding the preparation and follow-up of young people with chronic conditions in their journey to adulthood and their transition from pediatric to adult care (Table 1; Figure 1) (Van Staa et al., 2020). These elements are divided into three categories:

Categories of core elements

🟦 Interventions to improve the organization of transitional care
🟪 Collaboration with young people (and their families) and within the multidisciplinary team of healthcare professionals representing both pediatric and adult care
🟩 Interventions to stimulate independence and self-management of young people

Figure 1. Transitional care framework *'On Your Own Feet'* (Van Staa et al., 2020)

1) interventions to improve the organization of transitional care; 2) collaboration with young people (and their families) and within the multidisciplinary team of health care professionals representing both pediatric and adult care; and 3) interventions to stimulate independence and self-management of young people.

In 2018, the framework was validated as part of the research described in this thesis by comparing the eight core elements with recent systematic literature reviews (Schultz & Smaldone, 2017), international guidelines (NICE, 2016; White et al., 2020), consensus statements (Betz, 2017; Cooley et al., 2011; Mazur et al., 2017; American Academy of Pediatrics et al., 2002; Surís & Akré, 2015; White et al., 2018), and proposed beneficial features of transitional care (Colver et al., 2018). The results of this validation process

Table 1
The eight core elements of the *On Your Own Feet* transitional care framework explained (Van Staa et al., 2020)

ORGANIZATION OF TRANSITIONAL CARE	
Future-oriented	Written protocols and policies are useful to organize planned, developmentally appropriate and holistic transitional care. Early preparation and gradual movement towards more responsibilities and independence for the young person are important elements in this, as well as meeting the new health care professionals prior to the transfer.
Coordination	It is recommended to appoint a transition coordinator to monitor the transition process; e.g., the collaboration and communication between pediatric and adult health care professionals and the logistics around the transition and transfer. This coordinator should be easy to contact for young persons (and their families) in case of problems or misunderstandings.
Continuity of care	A shared vision on transition, adequate transfer of information (both orally and written) knowing to whom the young person is being transferred, and monitoring and evaluation of follow-up are factors that contribute to continuity of care.
COLLABORATION AND YOUTH INVOLVEMENT	
Young person	Transition should be tailored and developmentally appropriate. In addition, young people should be actively involved in their own care. Their wants, needs and preferences must be identified and taken seriously.
Team	Interdisciplinary coordination and alignment between pediatric and adult care professionals, alignment of working methods and procedures (where possible and relevant), and meeting new care professionals prior to the transfer are essential elements for adequate transitional care.
INDEPENDENCE AND SELF-MANAGEMENT	
Parent involvement	Parents should be involved in their child's transition process and must be supported in gradually giving their child more control and responsibilities.
Self-management	A person-oriented and holistic approach is important to support young people in their transition. Attention should not only be paid to medical aspects, but also to psychosocial developments and challenges faced by the young people in this phase of life. Young people should be prepared for independence and self-management in adulthood and adult care. Developmentally appropriate care to work on self-efficacy and to achieve transfer readiness is of great importance here.
Psychosocial care	Attention for psychosocial issues is a critical part of transitional care. Timely referral of young people to psychosocial care (e.g., a psychologist, social worker, or dietician) is important to prevent psychosocial problems from escalating. Routine measurement of psychosocial patient-reported outcome measures is helpful in monitoring.

revealed that the framework covered all core elements proposed in these documents (Van Staa et al., 2020). What the *On Your Own Feet* framework adds, however, is the combination of these elements that recognizes the importance of maintaining a broad perspective on transition in care. By focusing on organizational aspects such as co-ordination and continuity of care, combined with attention to self-management and active youth involvement, the *On Your Own Feet* framework seems to be even more "complete" than other conceptual frameworks (Van Staa et al., 2020). For example, despite enough evidence on its importance (Sattoe, 2015; Sawyer et al., 2007; Surís et al., 2004), self-management is not included as a core element of transition in the NICE guideline (2016), and the need for a holistic, integrative approach and attention to psychosocial issues is not specifically mentioned in the Six Core Elements of the United States' Got Transition program (White et al., 2018; White et al., 2020). Young people with chronic conditions experience many challenges in self-management, which places them at a higher risk for delays in psychosocial development (Maurice-Stam et al., 2019). Also, they should be supported in having their voices heard in matters that directly affect their lives (Cohen, 2017; Coyne & Gallagher, 2011). The active participation of the young people and the teams of both pediatric and adult care is considered vital for good transitional care (NICE, 2016; White et al., 2020) and is, therefore, placed at the heart of the framework (Van Staa et al., 2020). Nevertheless, it is not always explicitly stated in former studies (Colver et al., 2018; Schultz & Smaldone, 2017).

SPECIFIC CHALLENGES OF YOUNG PEOPLE WITH T1DM

As indicated at the beginning of this chapter, this thesis pays special attention to the case of young people with T1DM (such as Emma) and the transitional care for this group. Since T1DM cannot be cured, controlling one's blood sugar levels is the only way to manage the condition – for life (Fazeli Farsani et al., 2016). This asks for adequate self-management skills, including a series of daily tasks, such as glucose monitoring, administering insulin injections or boluses through an insulin pump, carbohydrate counting and regulation, and physical activity (Ding et al., 2021). As Emma told: "*Diabetes must always be kept in mind like some kind of unwanted guest*." Moreover, diabetes is an invisible condition, hardly noticeable to others and difficult for healthy people to understand. Young people with T1DM on average have the least optimal blood glucose values of all age groups, and diabetes management is often not their main priority (Iyengar et al., 2019; Vallis et al., 2018). This manifests itself, among other things, in loss to follow-up and deterioration of glycosylated hemoglobin (HbA1c) levels, which situations could even contribute to further adverse health outcomes (Burns et al., 2018; Clements et al., 2016; Farrell et al., 2018; Fegran et al., 2014; Gray et al., 2018). The transition from pediatric to adult care may result in a gap in services that not only negatively affects young people's health situation, but also their health-related quality of life (Iyengar et al., 2019; Sequeira et al., 2015). They might be worried about facing the unknown, communicating with and trusting new staff, and taking up self-management tasks and responsibilities for their chronic condition (Coyne et al., 2019). These different aspects often overwhelm them. Studies repeatedly report about a profound emotional burden that comes with living with T1DM (Wentzell et al., 2020) and young people are at a significant risk for psychological diagnoses (e.g., depressive symptoms, anxiety and eating disorders)

(Buchberger et al., 2016; De Wit & Snoek, 2011; Young et al., 2013). Also, diabetes distress – *"the negative emotional or affective experience resulting from the challenge of living with the demands of diabetes"* – is a serious problem in people with diabetes (Skinner et al., 2020), associated with unfavorable clinical and psychosocial outcomes (Delamater et al., 2018).

In summary, having T1DM can take its toll on young patients while transitioning to adulthood and adult care because of its impact on various life areas. Adopting a broad perspective on transition by providing integrated care to these young people is therefore highly recommended. Young people with T1DM should also be empowered to take an active role in their own care and express their unique views, needs, and concerns, so that they can adequately be supported in their diabetes management.

TRANSITIONAL CARE IN THE NETHERLANDS

Studies suggest that well-organized, effective transitional care can prevent deterioration in young people's health and disengagement with health care, and lead to stable or improved control of the condition, more knowledge about the condition, better self-management skills and patient satisfaction, and improved relationships with health care professionals and more parent satisfaction (Gabriel et al., 2017; Ladouceur et al., 2017; Mackie et al., 2018; Pyatak et al., 2017; Van Staa et al., 2015). However, the sense of urgency and the uptake in Dutch transitional care practices still lags behind. For instance, while multidisciplinary pediatric care is often extensive and child-centered, adult care services expect their patients to be much more independent and responsible for their own treatment. A background paper of Van Staa (2018) provides an overview of Dutch studies around transition in care between 2000 and 2018, revealing that the number of studies conducted in the Netherlands was still very limited at the time compared to the large amounts of international publications on this theme. Dutch national guidelines, standards and statements are also scarce; the generic Quality Standard on Transition in Care (currently being developed by the Knowledge Institute of the Federation of Medical Specialists, together with partners from professional groups, patient representatives and health insurers) being an exception. Moreover, while transition in care is generally considered a shared responsibility of both pediatric and adult health care professionals (Blum et al., 1993; Coyne et al., 2019; Meleis, 2010), Dutch studies mainly focus on pediatric care; the role of adult care professionals remains largely underexposed. This thesis therefore elaborates on several existing transitional care arrangements in the Netherlands involving both sides of the transfer and the challenges of evaluation.

INSIGHTS FROM DUTCH DIABETES TRANSITIONAL CARE

The two-year '*Better Transition in Type 1 Diabetes*' project – a nationwide mixed-methods research and quality improvement program aimed to advance diabetes transitional care – formed the basis of this thesis and started with a quick scan of the situation of diabetes transitional care in 2016. Participants included 384 young people with T1DM (aged 12-25 years) (Peeters et al., 2017) and 156 health care professionals from 58 different organizations (43% working in adult care; 63% nurses) (Bronner et al., 2017). Young people scored their transfer experiences with a mean of '7.0' on a scale from 1 to 10 (± 1.53; median = 7.0; *n* = 167), even though 14% reported an unsatisfactory grade (≤ 5) (Peeters et al., 2017). Most of them had prior to the transfer not met their new professionals from adult care, and for them it was often unclear what to expect. Only about half of the young people felt they had been involved in the transition process (e.g., information provision, shared decision-making). Little attention was paid to psychosocial aspects during consultations, with no significant differences between pediatric and adult care. In general, the young people would like to have more attention for psychosocial topics: *"The importance of personal attention and the necessity to address psychosocial issues, prospects and the future should not be underestimated. It seems so obvious, yet it is still a fundamental concern in transitional care"* (D. de Ronde, personal communication, March 1, 2018). Despite these flaws, most of the young people felt ready to make the transfer to adult care and thought the moment of transfer was well chosen. Professionals from both pediatric and adult care were generally trusted, even though those from adult care had less consultation time (Peeters et al., 2017).

Professionals recognized the flaws pointed out by the young persons (Bronner et al., 2017). A small majority (57%) mentioned they shared a joint vision on transition between pediatric and adult care. They also indicated that preparation started quite late (around age 16 or 17 years), while Zhou et al. (2016) highly recommended to start active preparation in the early teens. Furthermore, transition interventions were generally not part of current transitional care arrangements. Implementation of essential interventions recommended in the NICE guideline (2016) (e.g., transition clinic, transition protocol, multidisciplinary team meetings) varied much between organizations. For example, while direct access to the health care team was often available both in pediatric and adult care (80%), structural attention for non-medical topics was lacking (35%). All this together made professionals feel insufficiently capable of providing optimal care to the young people with T1DM in this crucial life phase when support is highly needed. Hence, they recognized the importance of improving the organization and working methods in transitional care (Bronner et al., 2017).

The results of the quick scan confirmed that attention for diabetes transitional care in the Netherlands had increased during the past years, but the uptake of recommendations in practice seemed to be slow. Professionals need more support to implement transition interventions and to provide developmentally appropriate health care services. This concerns not only diabetes care; it is a common issue in the care for young people with any chronic condition (Mubanga et al., 2017; Rapley et al., 2019).

THIS THESIS

Back to the case of Emma… Her story illustrates that a smooth, well-organized and well-prepared transition to adult care requires a holistic approach, with attention for more than only her diabetes, its management, and the actual transfer to adult care. Evidence shows that this lack of a holistic approach is a well-known problem with regard to young people with chronic conditions, in particular those living with T1DM. Many patients and health care professionals still experience large gaps between pediatric and adult care settings (Agarwal et al., 2017; Goralski et al., 2017; Van Staa et al., 2011; Zhou et al., 2016), despite that the importance of and the need to improve T1DM transitional care are acknowledged both nationally and internationally (DiMeglio et al., 2018; Dutch Diabetes Federation, 2021). Much has been learned in recent years about the principles of good transitional care and the risks of a poorly organized transfer in T1DM, but consensus on the definition of transition success remains absent (Campbell et al., 2016; Garvey et al., 2014; Wafa & Nakhla, 2015). Also, to further embed and improve transitional care in practice, more evidence is needed on how to compare and evaluate various transitional care arrangements (Campbell et al., 2016; Surís & Akré, 2015; Wafa & Nakhla, 2015; White et al., 2018).

Therefore, the main research question in this thesis is: ***"What is good transitional care and how can it be evaluated?"*** This question is dealt with in two parts.

PART I – A holistic perspective on transition in care for T1DM

According to the principles of the *On Your Own Feet* framework, young people's health situation and the transition in care encompass more than just physical or medical aspects. This is no less true for those living with T1DM, for whom transition can be considered challenging, emotional and often even stressful. Therefore, part I of the thesis aims to provide insight into how T1DM impacts on the lives of young people, and how they are currently supported in their transition towards adulthood and adult care. Deeper understandings could contribute to sharpening the vision on what good transitional care entails and what is needed to evaluate it. The following research questions are addressed in part I:

- What is the impact of T1DM on young people's health-related quality of life and how do their perceptions of their health-related quality of life compare with those of healthy young people and those with other chronic health conditions? *(Chapter 2)*
- What are the differences in transfer experiences, self-management and health-related quality of life between young adults with T1DM with and without diabetes distress? *(Chapter 3)*
- How do communication processes between young people with T1DM and health care providers work during outpatient hospital consultations in the transitional phase? *(Chapter 4)*

PART II – Evaluating transitional care: a complex matter

All studies included in part I of this thesis argue for adopting a holistic approach on transition in care. In this light, the 'transition clinic' – where professionals from pediatric and adult care are both involved in the delivery of outpatient transitional care – can be considered a key intervention that responds to all three categories of core elements of the *On Your Own Feet* framework (Van Staa et al., 2020). A transition clinic has been advocated as the best practice to provide continuity in transitional care (Crowley et al., 2011; Viner, 1999). Apart from realizing a smooth transfer to adult care, this concept includes the transition to adulthood, assessment of the young person's psychosocial wellbeing, and collaboration with the young person and between professionals (Betz et al., 2016). Evaluating the working of transition clinics has proven to be complex, however, due to multiplicity of outcomes, difficulty of using blinding strategies (i.e., of analysts and outcome assessors, or patients or personnel), and relatively small groups of patients (Le Roux et al., 2017). Although the shared core element of transition clinics is the collaboration between pediatric and adult health care services, models differ much regarding daily routines and used protocols, and little is known about effects (Betz et al., 2016). To achieve a better level of evidence, the evaluation of such multifactorial transition programs requires an appropriate and common methodology (Le Roux et al., 2017). Therefore, the studies presented in part II set out to develop and test an evaluation framework that could provide additional insights into the functioning and outcomes of outpatient transition clinics in different health care settings, alongside the following research questions:

- What study design and outcome measures are appropriate for the evaluation of transition clinics? *(Chapter 5)*
- What are – according to young people and their health care providers – differences in the functioning, experiences with, and outcomes of a transition clinic compared with direct hand-over care for young people with cystic fibrosis? *(Chapter 6)*
- What are – according to young people and their health care providers – differences in the functioning, experiences with, and outcomes of a transition clinic compared

with direct hand-over care for young people with inflammatory bowel disease? *(Chapter 7)*

- What are the benefits of transitional care investments for young people with T1DM in terms of transfer experiences and satisfaction, self-management-related outcomes, health care use, and clinical outcomes? *(Chapter 8)*

REFERENCES

Agarwal, S., Raymond, J. K., Schutta, M. H., Cardillo, S., Miller, V. A., & Long, J. A. (2017). An adult health care-based pediatric to adult transition program for emerging adults with type 1 diabetes. *Diabetes Educator*, *43*(1), 87-96. https://doi.org/10.1177/0145721716677098

Altamirano-Bustamante, N., Islas-Ortega, L., Robles-Valdes, C., Garduno-Espinosa, J., Morales-Cisneros, G., Valderrama, A., Calzada-Leon, R., Cuevas, M. L., Xancopinca, J. L., & Altamirano-Bustamante, M. M. (2008). Economic family burden of metabolic control in children and adolescents with type 1 diabetes mellitus. *Journal of Pediatric Endocrinology & Metabolism, 21*(12), 1163-1168. https://doi.org/10.1515/jpem.2008.21.12.1163

American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics, 110*(6 Pt 2), 1304-1306.

Bächle, C. C., Holl, R. W., Strassburger, K., Molz, E., Chernyak, N., Beyer, P., Schimmel, U., Rutschle, H., Seidel, J., Lepler, R., Holder, M., Rosenbauer, J., Icks, A., DPV Initiative; German BMBF Competence Network Diabetes Mellitus. (2012). Costs of paediatric diabetes care in Germany: current situation and comparison with the year 2000. *Diabetic Medicine, 29*(10), 1327-1334. https://doi.org/10.1111/j.1464-5491.2012.03645.x

Betz, C. L. (2017). SPN position statement: Transition of pediatric patients into adult care. *Journal of Pediatric Nursing, 35*, 160-164. https://doi.org/10.1016/j.pedn.2017.05.003

Betz, C. L., O'Kane, L. S., Nehring, W. M., & Lobo, M. L. (2016). Systematic review: Health care transition practice service models. *Nursing Outlook, 64*(3), 229-243. https://doi.org/10.1016/j.outlook.2015.12.011

Blomquist, K. B., Brown, G., Peersen, A., & Presler, E. P. (1998). Transitioning to independence: challenges for young people with disabilities and their caregivers. *Orthopedic Nursing, 17*(3), 27-35.

Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 14*(7), 570-576. https://doi.org/10.1016/1054-139x(93)90143-d

Bronner, M. B., Peeters, M. A. C., Sattoe, J. N. T., & Van Staa, A. L. (2017). *Ervaringen met de huidige transitiezorg voor jongeren met diabetes mellitus type 1: Resultaten van een quick scan onder zorgverleners [Experiences with current transitional care for young people with type 1 diabetes mellitus: Results of a quick scan among healthcare professionals]*. Rotterdam University of Applied Sciences, Research Center Innovations in Care.

Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: A systematic review and meta-analysis. *Psychoneuroendocrinology, 70*, 70-84. https://doi.org/10.1016/j.psyneuen.2016.04.019

Burns, K., Farrell, K., Myszka, R., Park, K., & Holmes-Walker, D. J. (2018). Access to a youth-specific service for young adults with type 1 diabetes mellitus is associated with decreased hospital length of stay for diabetic ketoacidosis. *Internal Medicine Journal, 48*(4), 396-402. https://doi.org/10.1111/imj.13649

Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., While, A., & Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews, 4*, CD009794. https://doi.org/10.1002/14651858.CD009794.pub2

Chick, N., & Meleis, A. I. (1986). Transitions: A nursing concern. In P. L. Chinn (Ed.), *Nursing research methodology: Issues and implementation* (pp. 237-257). Aspen.

Clements, M. A., Foster, N. C., Maahs, D. M., Schatz, D. A., Olson, B. A., Tsalikian, E., Lee, J. M., Burt-Solorzano, C. M., Tamborlane, W. V., Chen, V., Miller, K. M., Beck, R. W., & T1D Exchange Clinic Network. (2016). Hemoglobin A1c (HbA1c) changes over time among adolescent and young adult participants in the T1D exchange clinic registry. *Pediatric Diabetes, 17*(5), 327-336. https://doi.org/10.1111/pedi.12295

Cohen, M. D. (2017). Engaging patients in understanding and using evidence to inform shared decision making. *Patient Education and Counseling, 100*(1), 2-3. https://doi.org/10.1016/j.pec.2016.11.013

Colver, A., Pearse, R., Watson, R. M., Fay, M., Rapley, T., Mann, K. D., Le Couteur, A., Parr, J. R., McConachie, H., & Transition Collaborative Group. (2018). How well do services for young people with long term conditions deliver features proposed to improve transition? *BMC Health Services Research, 18*(1), 337. https://doi.org/10.1186/s12913-018-3168-9

Cooley, W. C., Sagerman, P. J., American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 128*(1), 182-200. https://doi.org/10.1542/peds.2011-0969

Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: children and young people's experiences in a hospital setting. *Journal of Clinical Nursing, 20*(15-16), 2334-2343. https://doi.org/10.1111/j.1365-2702.2010.03582.x

Coyne, I., Sheehan, A., Heery, E., & While, A. E. (2019). Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences. *Journal of Clinical Nursing, 28*(21-22), 4062-4076. https://doi.org/10.1111/jocn.15006

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood, 96*(6), 548-553. https://doi.org/10.1136/adc.2010.202473

De Wit, M., & Snoek, F. J. (2011). Depressive symptoms and unmet psychological needs of Dutch youth with type 1 diabetes: results of a web-survey. *Pediatric Diabetes, 12*(3 Pt 1), 172-176. https://doi.org/10.1111/j.1399-5448.2010.00673.x

Delamater, A. M., de Wit, M., McDarby, V., Malik, J. A., Hilliard, M. E., Northam, E., & Acerini, C. L. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes, 19*(Suppl. 27), 237-249. https://doi.org/10.1111/pedi.12736

DiMeglio, L. A., Acerini, C. L., Codner, E., Craig, M. E., Hofer, S. E., Pillay, K., & Maahs, D. M. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Glycemic control targets and glucose monitoring for children, adolescents, and young adults with diabetes. *Pediatric Diabetes, 19*(Suppl. 27), 105-114. https://doi.org/10.1111/pedi.12737

Ding, K., Reynolds, C. M., Driscoll, K. A., & Janicke, D. M. (2021). The relationship between executive functioning, type 1 diabetes self-management behaviors, and glycemic control in adolescents and young adults. *Current Diabetes Reports, 21*(3), 10. https://doi.org/10.1007/s11892-021-01379-3

Donckerwolcke, R. A. M. G., & Van Zeben-Van der Aa, D. M. C. B. (2002). Overdracht van de zorg voor adolescenten met chronische ziekten: van kindergeneeskunde naar specialismen voor volwassenen [Transfer of the care for adolescents with chronic illnesses: from paediatrics to specialisms for adults]. *Nederlands Tijdschrift voor Geneeskunde, 146*(14), 675-678.

Dutch Diabetes Federation. (2021, June 18). *Zorgstandaard Diabetes [Healthcare Standard Diabetes]*. https://www.zorgstandaarddiabetes.nl/type-1/kind/inhoud/behandeling/transitiefase/

Dutch Diabetes Research Foundation. (2021, June 18). *Diabetes in cijfers [Diabetes in numbers]*. https://www.diabetesfonds.nl/over-diabetes/diabetes-in-het-algemeen/diabetes-in-cijfers

Fair, C., Rupp, S., Hart, L. C., Alvarez-Elias, A. C., Perry, M., & Ferris, M. (2018). Defining successful transition: pediatric provider perspective. In A. C. Hergenroeder & C. M. Wiemann (Eds.), *Healthcare transition building a program for adolescents and young adults with chronic illness and disability* (pp. 191-200). Springer International Publishing.

Farrell, K., Fernandez, R., Salamonson, Y., Griffiths, R., & Holmes-Walker, D. J. (2018). Health outcomes for youth with type 1 diabetes at 18months and 30months post transition from pediatric to adult care. *Diabetes Research and Clinical Practice, 139*, 163-169. https://doi.org/10.1016/j.diabres.2018.03.013

Fazeli Farsani, S., Souverein, P. C., van der Vorst, M. M., Knibbe, C. A., Herings, R. M., de Boer, A., & Mantel-Teeuwisse, A. K. (2016). Increasing trends in the incidence and prevalence rates of type 1 diabetes among children and adolescents in the Netherlands. *Pediatric Diabetes, 17*(1), 44-52. https://doi.org/10.1111/pedi.12232

Fegran, L., Hall, E. O., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. *International Journal of Nursing Studies, 51*(1), 123-135. https://doi.org/10.1016/j.ijnurstu.2013.02.001

Foster, H. E., Minden, K., Clemente, D., Leon, L., McDonagh, J. E., Kamphuis, S., Berggren, K., Van Pelt, P., Wouters, C., Waite-Jones, J., Tattersall, R., Wyllie, R., Stones, S. R., Martini, A., Constantin, T., Schalm, S., Fidanci, B., Erer, B., Demirkaya, E., . . . Carmona, L. (2017). EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Annals of the Rheumatic Diseases, 76*(4), 639-646. https://doi.org/10.1136/annrheumdis-2016-210112

Gabriel, P., McManus, M., Rogers, K., & White, P. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *Journal of Pediatrics, 188*, 263-269. https://doi.org/10.1016/j.jpeds.2017.05.066

Garvey, K. C., Beste, M. G., Luff, D., Atakov-Castillo, A., Wolpert, H. A., & Ritholz, M. D. (2014). Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study. *Adolescenth Health, Medicine and Therapeutics, 5*, 191-198. https://doi.org/10.2147/AHMT.S67943

Garvey, K. C., Foster, N. C., Agarwal, S., DiMeglio, L. A., Anderson, B. J., Corathers, S. D., Desimone, M. E., Libman, I. M., Lyons, S. K., Peters, A. L., Raymond, J. K., & Laffel, L. M. (2017). Health care transition preparation and experiences in a U.S. national sample of young adults with type 1 diabetes. *Diabetes Care, 40*(3), 317-324. https://doi.org/10.2337/dc16-1729

Goralski, J. L., Nasr, S. Z., & Uluer, A. (2017). Overcoming barriers to a successful transition from pediatric to adult care. *Pediatric Pulmonology, 52*(S48), S52-S60. https://doi.org/10.1002/ppul.23778

Gray, S., Cheetham, T., McConachie, H., Mann, K. D., Parr, J. R., Pearce, M. S., Colver, A., & Transition Collaborative Group. (2018). A longitudinal, observational study examining the relationships of patient satisfaction with services and mental well-being to their clinical course in young people with Type 1 diabetes mellitus during transition from child to adult health services. *Diabetic Medicine, 35*(9), 1216-1222. https://doi.org/10.1111/dme.13698

Hanghoj, S., & Boisen, K. A. (2014). Self-reported barriers to medication adherence among chronically ill adolescents: a systematic review. *Journal of Adolescent Health, 54*(2), 121-138. https://doi.org/10.1016/j.jadohealth.2013.08.009

Heery, E., Sheehan, A. M., While, A. E., & Coyne, I. (2015). Experiences and outcomes of transition from pediatric to adult health care services for young people with congenital heart disease: A systematic review. *Congenital Heart Disease, 10*(5), 413-427. https://doi.org/10.1111/chd.12251

Hergenroeder, A. C., & Wiemann, C. M. (2018). *Health care transition: building a program for adolescents and young adults with chronic illness and disability*. Springer Publishing Inc.

Iyengar, J., Thomas, I. H., & Soleimanpour, S. A. (2019). Transition from pediatric to adult care in emerging adults with type 1 diabetes: a blueprint for effective receivership. *Clinical Diabetes and Endocrinology, 5*, 3. https://doi.org/10.1186/s40842-019-0078-7

Kennedy, A., & Sawyer, S. (2008). Transition from pediatric to adult services: are we getting it right? *Current Opinion in Pediatrics, 20*(4), 403-409. https://doi.org/10.1097/MOP.0b013e328305e128

Kirk, S. (2008). Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development, 34*(5), 567-575. https://doi.org/10.1111/j.1365-2214.2008.00862.x

Ladouceur, M., Calderon, J., Traore, M., Cheurfi, R., Pagnon, C., Khraiche, D., Bajolle, F., & Bonnet, D. (2017). Educational needs of adolescents with congenital heart disease: Impact of a transition intervention programme. *Archives of Cardiovascular Diseases, 110*(5), 317-324. https://doi.org/10.1016/j.acvd.2017.02.001

Le Roux, E., Mellerio, H., Guilmin-Crepon, S., Gottot, S., Jacquin, P., Boulkedid, R., & Alberti, C. (2017). Methodology used in comparative studies assessing programmes of transition from paediatrics to adult care programmes: a systematic review. *BMJ Open, 7*(1), e012338. https://doi.org/10.1136/bmjopen-2016-012338

López-Bastida, J., López-Siguero, J. P., Oliva-Moreno, J., Perez-Nieves, M., Villoro, R., Dilla, T., Merino, M., Jiang, D., Aranda-Reneo, I., Reviriego, J., & Vazquez, L. A. (2017). Social economic costs of type 1 diabetes mellitus in pediatric patients in Spain: CHRYSTAL observational study. *Diabetes Research and Clinical Practice, 127*, 59-69. https://doi.org/10.1016/j.diabres.2017.02.033

Lotstein, D. S., McPherson, M., Strickland, B., & Newacheck, P. W. (2005). Transition planning for youth with special health care needs: results from the national survey of children with special health care needs. *Pediatrics, 115*(6), 1562-1568. https://doi.org/10.1542/peds.2004-1262

Mackie, A. S., Rempel, G. R., Kovacs, A. H., Kaufman, M., Rankin, K. N., Jelen, A., Yaskina, M., Sananes, R., Oechslin, E., Dragieva, D., Mustafa, S., Williams, E., Schuh, M., Manlhiot, C., Anthony, S. J., Magill-Evans, J., Nicholas, D., & McCrindle, B. W. (2018). Transition intervention for adolescents with congenital heart disease. *Journal of the American College of Cardiology, 71*(16), 1768-1777. https://doi.org/10.1016/j.jacc.2018.02.043

Maurice-Stam, H., Nijhof, S. L., Monninkhof, A. S., Heymans, H. S. A., & Grootenhuis, M. A. (2019). Review about the impact of growing up with a chronic disease showed delays achieving psychosocial milestones. *Acta Paediatrica, 108*(12), 2157-2169. https://doi.org/10.1111/apa.14918

Mazur, A., Dembinski, L., Schrier, L., Hadjipanayis, A., & Michaud, P. A. (2017). European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Paediatrica, 106*(8), 1354-1357. https://doi.org/10.1111/apa.13901

Meleis, A. I. (2010). *Transitions theory: middle range and situation specific theories in nursing research and practice*. Springer Publishing Company.

Michaud, P. A., Schrier, L., Ross-Russel, R., van der Heijden, L., Dossche, L., Copley, S., Alterio, T., Mazur, A., Dembinski, L., Hadjipanayis, A., Del Torso, S., Fonseca, H., & Ambresin, A. E. (2018). Paediatric departments need to improve residents' training in adolescent medicine and health: a position paper of the European Academy of Paediatrics. *European Journal of Pediatrics, 177*(4), 479-487. https://doi.org/10.1007/s00431-017-3061-2

Monaghan, M., Helgeson, V., & Wiebe, D. (2015). Type 1 diabetes in young adulthood. *Current Diabetes Reviews, 11*(4), 239-250. https://doi.org/10.2174/1573399811666150421114957

Mubanga, N., Baumgardner, D. J., & Kram, J. J. F. (2017). Health care transitions for adolescents and young adults with special health care needs: Where are we now? *Journal of Patient-Centered Research and Reviews, 4*(2), 90-95. https://doi.org/10.17294/2330-0698.1406

National Institute for Health and Care Excellence. (2016). *Transition from children's to adults' services for young people using health or social care services, Guideline 43.* NICE.

Netherlands' Ombudsman for Children. (2021). *Mijn Zorg Mijn Zaak: Kinderen over hun betrokkenheid bij beslissingen tijdens hun ziekte [My Care My Business: Children about their involvement in decisions during their illness]*. Netherlands'Ombudsman for Children.

Oram, R. A., & Redondo, M. J. (2019). New insights on the genetics of type 1 diabetes. *Current Opinion in Endocrinology, Diabetes, and Obesity, 26*(4), 181-187. https://doi.org/10.1097/MED.0000000000000489

Patterson, C. C., Dahlquist, G. G., Gyurus, E., Green, A., Soltesz, G., & Eurodiab Study Group. (2009). Incidence trends for childhood type 1 diabetes in Europe during 1989-2003 and predicted new cases 2005-20: a multicentre prospective registration study. *Lancet, 373*(9680), 2027-2033. https://doi.org/10.1016/S0140-6736(09)60568-7

Patton, G. C., Sawyer, S. M., Santelli, J. S., Ross, D. A., Afifi, R., Allen, N. B., Arora, M., Azzopardi, P., Baldwin, W., Bonell, C., Kakuma, R., Kennedy, E., Mahon, J., McGovern, T., Mokdad, A. H., Patel, V., Petroni, S., Reavley, N., Taiwo, K., . . . Viner, R. M. (2016). Our future: a Lancet commission on adolescent health and wellbeing. *Lancet, 387*(10036), 2423-2478. https://doi.org/10.1016/S0140-6736(16)00579-1

Peeters, M. A. C., Sattoe, J. N. T., Bronner, M. B., & Van Staa, A. L. (2017). *Ervaringen van jongeren met diabetes mellitus type 1 met de huidige transitiezorg: Resultaten van een quick scan onder jongeren met diabetes mellitus type 1 [Experiences with current transitional care of young people with type 1 diabetes mellitus: Results of a quick scan among young people with type 1 diabetes mellitus]*. Rotterdam University of Applied Sciences, Research Center Innovations in Care.

Pyatak, E. A., Sequeira, P. A., Vigen, C. L., Weigensberg, M. J., Wood, J. R., Montoya, L., Ruelas, V., & Peters, A. L. (2017). Clinical and psychosocial outcomes of a structured transition program among young adults with type 1 diabetes. *Journal of Adolescent Health, 60*(2), 212-218. https://doi.org/10.1016/j.jadohealth.2016.09.004

Quas, J. A. (2014, December). *Adolescence: A unique period of challenge and opportunity for positive development.* https://www.apa.org/pi/families/resources/newsletter/2014/12/adolescence-development

Rapley, T., Farre, A., Parr, J. R., Wood, V. J., Reape, D., Dovey-Pearce, G., McDonagh, J., & Transition Collaborative Group. (2019). Can we normalise developmentally appropriate health care for young people in UK hospital settings? An ethnographic study. *BMJ Open, 9*(9), e029107. https://doi.org/10.1136/bmjopen-2019-029107

Sattoe, J. N. T. (2015). *Growing up with a chronic condition: Challenges for self-management and self-management support*. Erasmus University Rotterdam.

Sawyer, S. M., Azzopardi, P. S., Wickremarathne, D., & Patton, G. C. (2018). The age of adolescence. *Lancet Child and Adolescent Health, 2*(3), 223-228. https://doi.org/10.1016/S2352-4642(18)30022-1

Sawyer, S. M., Drew, S., Yeo, M. S., & Britto, M. T. (2007). Adolescents with a chronic condition: challenges living, challenges treating. *Lancet, 369*(9571), 1481-1489. https://doi.org/10.1016/S0140-6736(07)60370-5

Schultz, A. T., & Smaldone, A. (2017). Components of interventions that improve transitions to adult care for adolescents with type 1 diabetes. *Journal of Adolescent Health, 60*(2), 133-146. https://doi.org/10.1016/j.jadohealth.2016.10.002

Schumacher, K. L., & Meleis, A. I. (1994). Transitions: a central concept in nursing. *Image – The Journal of Nursing Scholarship, 26*(2), 119-127. https://doi.org/10.1111/j.1547-5069.1994.tb00929.x

Sequeira, P. A., Pyatak, E. A., Weigensberg, M. J., Vigen, C. P., Wood, J. R., Ruelas, V., Montoya, L., Cohen, M., Speer, H., Clark, S., & Peters, A. L. (2015). Let's Empower and Prepare (LEAP): Evaluation of a structured transition program for young adults with type 1 diabetes. *Diabetes Care, 38*(8), 1412-1419. https://doi.org/10.2337/dc14-2577

Sheehan, A. M., While, A. E., & Coyne, I. (2015). The experiences and impact of transition from child to adult healthcare services for young people with type 1 diabetes: a systematic review. *Diabetic Medicine, 32*(4), 440-458. https://doi.org/10.1111/dme.12639

Skinner, T. C., Joensen, L., & Parkin, T. (2020). Twenty-five years of diabetes distress research. *Diabetic Medicine, 37*(3), 393-400. https://doi.org/10.1111/dme.14157

Surís, J. C., & Akré, C. (2015). Key elements for, and indicators of, a successful transition: an international Delphi study. *Journal of Adolescent Health, 56*(6), 612-618. https://doi.org/10.1016/j.jadohealth.2015.02.007

Surís, J. C., Michaud, P. A., & Viner, R. (2004). The adolescent with a chronic condition. Part I: developmental issues. *Archives of Disease in Childhood, 89*(10), 938-942. https://doi.org/10.1136/adc.2003.045369

Tauschmann, M., & Hovorka, R. (2018). Technology in the management of type 1 diabetes mellitus - current status and future prospects. *Nature Reviews Endocrinology, 14*(8), 464-475. https://doi.org/10.1038/s41574-018-0044-y

Vallis, M., Willaing, I., & Holt, R. I. G. (2018). Emerging adulthood and type 1 diabetes: insights from the DAWN2 study. *Diabetic Medicine, 35*(2), 203-213. https://doi.org/10.1111/dme.13554

Van der Lee, J. H., Mokkink, L. B., Grootenhuis, M. A., Heymans, H. S., & Offringa, M. (2007). Definitions and measurement of chronic health conditions in childhood: a systematic review. *JAMA, 297*(24), 2741-2751. https://doi.org/10.1001/jama.297.24.2741

Van Hal, L., Tierolf, B., van Rooijen, M., & van der Hoff, M. (2019). *Een actueel perspectief op kinderen en jongeren met een chronische aandoening in Nederland: Omvang, samenstelling en participatie [A current perspective on children and young people with a chronic condition in the Netherlands: Extent, composition and participation]*. Verwey-Jonker Insitute.

Van Staa, A. L. (2012). *On Your Own Feet: Adolescents with chronic conditions and their preferences and competencies for care*. Erasmus University Rotterdam.

Van Staa, A. L. (2018). *Achtergronddocument: Nederlands onderzoek rond transitie in zorg van adolescenten met chronische aandoeningen in de somatische zorg en revalidatie (2000-2018) [Background paper: Dutch research on transition in care of adolescents with chronic conditions in somatic care and rehabilitation (2000-2018)]*. Rotterdam University of Applied Sciences, Research Center Innovations in Care.

Van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development, 37*(6), 821-832. https://doi.org/10.1111/j.1365-2214.2011.01261.x

Van Staa, A. L., Peeters, M. A. C., & Sattoe, J. N. T. (2020). On Your Own Feet: A practical framework for improving transitional care and young people's self-management. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An international perspective on nurses' roles and interventions* (pp. 191-228). Springer Nature. https://doi.org/10.1007/978-3-030-23384-6

Van Staa, A. L., Sattoe, J. N. T., & Strating, M. M. (2015). Experiences with and outcomes of two interventions to maximize engagement of chronically ill adolescents during hospital consultations: A mixed methods study. *Journal of Pediatric Nursing, 30*(5), 757-775. https://doi.org/10.1016/j.pedn.2015.05.028

Viner, R. M. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood, 81*(3), 271-275. https://doi.org/10.1136/adc.81.3.271

Viner, R. M. (2008). Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Archives of Disease in Childhood, 93*(2), 160-163. https://doi.org/10.1136/adc.2006.103721

Volksgezondheidszorg.info. (2021, June 18). *Preventie van diabetes [Prevention of diabetes]*. https://www.volksgezondheidenzorg.info/onderwerp/diabetes-mellitus/preventie-zorg/preventie

Wafa, S., & Nakhla, M. (2015). Improving the transition from pediatric to adult diabetes healthcare: A literature review. *Canadian Journal of Diabetes, 39*(6), 520-528. https://doi.org/10.1016/j.jcjd.2015.08.003

Weissberg-Benchell, J., Wolpert, H., & Anderson, B. J. (2007). Transitioning from pediatric to adult care: a new approach to the post-adolescent young person with type 1 diabetes. *Diabetes Care, 30*(10), 2441-2446. https://doi.org/10.2337/dc07-1249

Wentzell, K., Vessey, J. A., & Laffel, L. M. B. (2020). How do the challenges of emerging adulthood inform our understanding of diabetes distress? An integrative review. *Current Diabetes Reports, 20*(6), 21. https://doi.org/10.1007/s11892-020-01301-3

White, P. H., Cooley, W. C., Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 142*(5). https://doi.org/10.1542/peds.2018-2587

White, P. H., Schmidt, A., Shorr, J., Ilango, S., Beck, D., & McManus, M. (2020). *Six Core Elements of Health Care Transition™ 3.0.* Got Transition, The National Alliance to Advance Adolescent Health.

World Health Organization. (1986). Young people's health: a challenge for society. Report of a study group on young people and 'health for all by the year 2000'. *World Health Organization technical report series, 731,* 1–117.

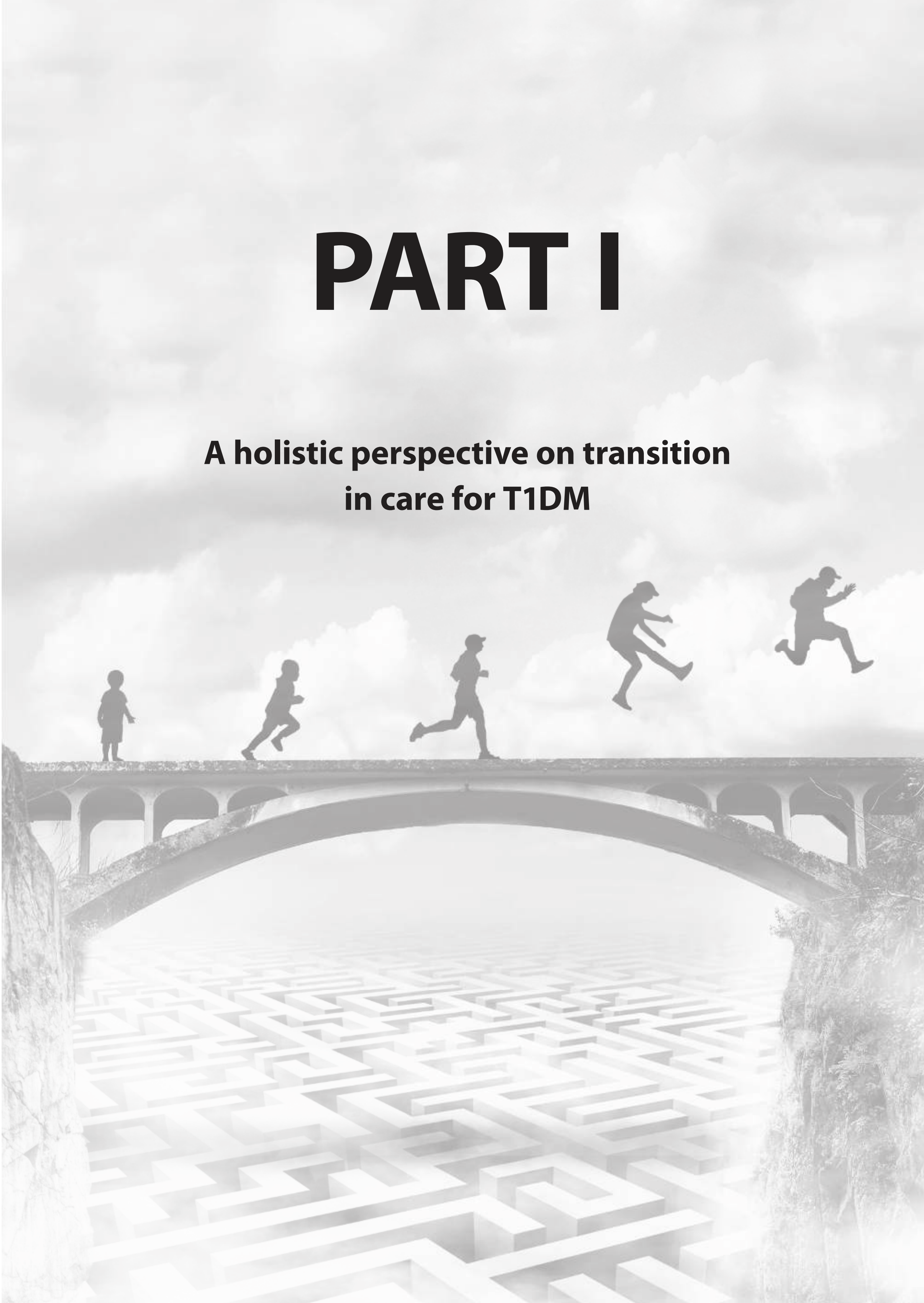
Ying, A. K., Lairson, D. R., Giardino, A. P., Bondy, M. L., Zaheer, I., Haymond, M. W., & Heptulla, R. A. (2011). Predictors of direct costs of diabetes care in pediatric patients with type 1 diabetes. *Pediatric Diabetes, 12*(3 Pt 1), 177-182. https://doi.org/10.1111/j.1399-5448.2010.00680.x

Young, V., Eiser, C., Johnson, B., Brierley, S., Epton, T., Elliott, J., & Heller, S. (2013). Eating problems in adolescents with type 1 diabetes: a systematic review with meta-analysis. *Diabetic Medicine, 30*(2), 189-198. https://doi.org/10.1111/j.1464-5491.2012.03771.x

Zhou, H., Roberts, P., Dhaliwal, S., & Della, P. (2016). Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services - an integrative review. *Journal of Clinical Nursing, 25*(21-22), 3113-3130. https://doi.org/10.1111/jocn.13326

PART I

A holistic perspective on transition in care for T1DM



2

The impact of type 1 diabetes on young adults' health-related quality of life

Madelon B. Bronner
Mariëlle A.C. Peeters
Jane N.T. Sattoe
AnneLoes van Staa

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ABSTRACT

Background

Young adulthood is a challenging period for people with diabetes mellitus type 1 (T1DM) as they are facing multiple life transitions while managing a demanding disease. This poses a risk for impaired health-related quality of life (HRQOL). We assessed HRQOL in a cohort of young adults with T1DM in the Netherlands, and compared outcomes with those of Dutch norm groups of healthy young adults and young adults with a chronic disease.

Methods

We analyzed data collected in a larger evaluation study on transitional care for young adults with T1DM in a nationwide sample in the Netherlands, including twelve participating hospitals. These data had been obtained from online questionnaires completed by young adults with T1DM after they had transferred to adult care. HRQOL was self-reported with the Pediatric Quality of Life Inventory for young adults (PedsQL-YA).

Results

One hundred and sixty-five young adults with T1DM participated (44.2% response); and they scored significantly worse than did healthy peers on all domains of HRQOL, except social functioning. Particularly, functioning at school or work was worse than that of the norm group. The study group's HRQOL-scores were comparable to norm scores of young adults with chronic diseases, although the physical and social functioning of young people with T1DM was better. One quarter (26.1%) of all young adults with T1DM reported fatigue.

Conclusions

During transition to adulthood, young adults with T1DM struggle to maintain a balance between the demands of managing a disease and their life. Many of them encounter problems at work or school, and suffer from fatigue. These findings underscore the need to regularly assess HRQOL, and to discuss work- and education-related issues in clinical practice.

BACKGROUND

Young adults with type 1 diabetes mellitus (T1DM) not only face developmental milestones, but also are expected to take over full responsibility for managing the disease. A high degree of self-control is needed, with the main goal to maintain optimal glycemic control (Murillo et al., 2017). Optimal glycemic control reduces the risk of disease progression and complications (Bryden et al., 2003; DiMeglio et al., 2018). In an American study on continuous glucose monitoring, only 17% of early young adults (18–25 years) and 30% of late young adults (26–30 years) met recommendations from the American Diabetes Association for glycemic control (Beck et al., 2012). Those not meeting the recommendations are at risk for developing diabetes-related complications, like retinopathy or hypertension (Bryden et al., 2003; Dabelea et al., 2017; James et al., 2014). These findings taken together make clear that young adulthood represents a critical period for people with T1DM.

Moreover, the process of transition from pediatric to adult health services in this period may result in a gap in services that negatively affects the health of young people with a chronic condition (Campbell et al., 2016). While multidisciplinary pediatric care for diabetes is often extensive and child-centered, adult care services expect their patients to be more independent and responsible for their own treatment (Viner, 2008). A review study concluded that more than 25% of young adults had reported a more than 6 months' gap in medical care during transition to adult health care services (Monaghan et al., 2015). Young adults often show poor clinic attendance or may even become lost to follow-up, which features have been associated with serious and costly medical consequences, such as diabetic ketoacidosis (Mazur et al., 2017). Therefore, poor transition to adult care may further contribute to adverse health outcomes.

Facing multiple life transitions while coping with a demanding disease can understandably impact one's health-related quality of life (HRQOL). Previous research has shown that T1DM is associated with impaired HRQOL and loss of utilities (Braga de Souza et al., 2015; Smith-Palmer et al., 2016). International diabetes guidelines therefore increasingly recommend the use of HRQOL measurement instruments to guide routine care (Delamater et al., 2014). The vast majority of HRQOL studies so far have been performed in children or adolescents with T1DM (Cruz et al., 2018; Lukacs et al., 2018; Murillo et al., 2017; Nieuwesteeg et al., 2012), while reports regarding HRQOL in young adults are scarce (Anderson et al., 2017; Kent & Quinn, 2018; Monaghan et al., 2015; Varni et al., 2018). In a study in a large global cohort of youth with T1DM (8–25 years), the 19–25 age group reported poorer HRQOL than did the younger age groups (Anderson et al., 2017). Young adults with T1DM may have age-specific worries that affect their HRQOL, such as concerns about being denied insurance, getting the job they wanted, living independently, future complications and having children (Kent & Quinn, 2018;

Monaghan et al., 2015). Research on HRQOL in this vulnerable group of young adults is scarce, however, and comparisons with healthy young adults are currently lacking.

The aim of this study was to assess HRQOL in a national cohort of young adults with T1DM in the Netherlands, and to compare their HRQOL scores with those of Dutch norm groups of healthy young adults (aged 18–25) and young adults with different chronic health conditions. This comparison may provide more insight in the impact of T1DM on young adults' quality of life.

METHODS

Participants and settings

The data presented in this paper have been collected in a larger evaluation study of transitional care for young adults with T1DM in a nationwide sample in the Netherlands. The study was conducted between April 2016 and October 2018 with the participation of twelve different hospitals, and used a mixed-methods design. The study protocol has been described elsewhere (Sattoe et al., 2016). The present paper deals with the results from an online questionnaire about HRQOL and transfer experiences. Patients were eligible to participate in the study if they had a confirmed diagnosis of T1DM – irrespective of the time elapsed since the diagnosis, – had made the transfer to adult services in 2012–2014, had no cognitive impairment, and were able to speak and read Dutch.

Measures

Socio-demographic variables collected in the online questionnaire included age, gender, educational level, educational status, employment status and living situation. Educational level was categorized as low (primary education, lower or middle general secondary education), middle (higher secondary education, middle vocational education) and high (higher vocational education, university) education (Schneider, 2013). Educational status was dichotomized as still studying or doing an internship (1) vs. not studying (0). Employment status was dichotomized as having paid work (1) vs. not having paid work (0). Living situation was dichotomized as living independently (1) vs. living with parents (0).

HRQOL was self-reported with the Dutch version of the Pediatric Quality of Life Inventory for young adults (PedsQL-YA) (Varni & Limbers, 2009). The scale contains 23 items in four subscales: 'physical health', 'emotional functioning', 'social functioning' and 'school/work functioning'. Items are scored on a five-point Likert scale from 'never' (0) to 'almost always' (4). Each answer is reversely scored and rescaled to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0). Higher scores indicate better reported HRQOL. Cronbach's α for the different scales in this study sample ranged from 0.80 to 0.94. Furthermore, minimal clinically important differences range between a 4.4 and 9.1 change in scores on the different scales (Varni et al., 2003). Dutch PedsQL-YA norm data of young adults were used for comparisons. In this study population, the self-reported prevalence of chronic health conditions was 21.1%. Most common conditions were asthma (34.3%), psychiatric disorders (10.9%), digestive disorders and gastrointestinal diseases (10.2%), and skin diseases (5.8%) (Limperg et al., 2014).

Design and procedure

In January 2018, the twelve participating hospitals invited via e-mail eligible patients who had made the transfer to adult services in 2012, 2013 or 2014 to complete an online questionnaire. Five of these hospitals also invited patients who had made the transfer in 2015 and 2016. Reminders were sent by e-mail after two and four weeks. To boost participation, every third respondent was to receive a €20 gift voucher. Those who eventually participated provided online consent to use the collected data for scientific research. The Medical Ethics Review Board of Erasmus MC approved the original study protocol (MEC-2014-246), and ethical approval was obtained from all local hospital review boards.

Statistical analyses

All analyses were conducted using SPSS 22.0 (Field, 2018). First, preparatory and descriptive analyses were performed (e.g. scale scores, Cronbach's alpha, distributions of scores, socio-demographics, effect sizes (Cohen, 1988)). Second, differences on socio-demographics (age and gender) between non-responders and comparison groups were calculated using *t*-tests, ANOVA, and Chi-square ($\chi 2$) tests. Next, differences on the PedsQL-YA scale scores between the study group and norm groups (healthy and chronic) were examined with multiple regression analysis, corrected for age and gender. These are potential confounders for HRQOL (Limperg et al., 2014). The group variable (T1DM, healthy, chronic) was coded into dummy variables with diabetes as reference group. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. Then, a regression model for the PedsQL-YA total scale was built to compare group differences, using the T1DM group as reference group, and age and gender as confounders. Subsequently, multivariate regression analyses were performed for PedsQL-YA subscales.

Exploratory analyses were performed on HRQOL-scores by examining on which items the study group and the norm groups reported most problems. Chi-square tests were used to analyze differences on the items between the study group and the norm groups.

RESULTS

Three hundred seventy-three eligible patients with T1DM were invited to fill out the online questionnaire, of whom 165 completed the questionnaire (response rate 44.2%). Their mean age was 22.6 years (*SD* = 1.6, range 19.0–28.0) and 60.0% was female. Most (69.5%) had middle level education and a paid job (78.0%). Half of the whole group was still studying or had an internship, and 61.0% lived with their parents (Table 1). The mean age at transfer was 18.4 years (*SD* = 1.2); the mean time elapsed between transfer and completing the questionnaire was 4.7 years (*SD* = 1.1). Non-response data were available only with regard to gender and age for young adults who had made the transfer to adult services in 2012–2014. Data showed that 36.9% of the non-responders was female and had an average age of 23.6 (*SD* = 1.4). Thus, non-responders were more often male ($\chi 2 = 21.814$, $p < 0.000$) and statistically significantly older than the participating young adults ($t = 6.337$, $p < 0.000$).

Table 1
Characteristics of 165 young adults with T1DM participating in the study

	N (%)
Age, years ± *SD*	22.7 ± 1.6
Female	99 (60.0)
Education	
Low	12 (7.3)
Middle	115 (69.7)
High	38 (23.0)
Studying or internship	83 (50.3)
Paid work	128 (77.6)
Living with parents	99 (60.0)

Dutch PedsQL-YA norm data of 310 healthy young adults and 75 young adults with a chronic disease were used for comparisons. The average age of the healthy group was 22.2 (*SD* = 2.4); 51.3% was female. In the chronic disease group the average age was 22.0 (*SD* = 2.4); 62.7% was female. Age ($F = 2.740$, $df = 2$, $p = 0.065$) and gender ($\chi 2 = 5.135$, $p = 0.077$) did not significantly differ from our study group (Table 2).

Multivariate regression analyses were used to compare HRQOL-scores between the different groups, controlling for gender and age. The model for the total PedsQL-score was statistically significant, F (4, 545) = 19.237, $p < 0.000$, and accounted for 12.4% of the variance. The T1DM study group had significantly different HRQOL-scores compared to both norm groups (healthy and chronic disease). HRQOL-scores in the study group were lower than in the healthy norm group ($\beta = 0.228$, $p = 0.000$), and higher than in the chronic disease group ($\beta = -0.101$, $p = 0.026$). This difference (-4.015) was too small to be of clinical relevance. Age ($\beta = -0.085$, $p = 0.036$) and gender ($\beta = -0.148$, $p = 0.000$) were significantly related to HRQOL. Males and younger participants had better HRQOL-scores.

Table 2
PedsQL-YA scores and effect sizes (Cohen's *d*) for young adults with T1DM compared to two norm groups (healthy and chronic disease) for age group 18-25

	Diabetes	Healthy	*d*	Chronic disease	*d*
	N = 165	*N* = 310		*N* = 75	
	M (SD)	*M (SD)*		*M (SD)*	
Total	79.0 (15.3)	85.9 (11.2)	0.6	75.2 (15.1)	-0.2
Physical	84.5 (15.9)	90.2 (12.5)	0.5	77.8 (20.5)	-0.3
Emotional	70.9 (21.9)	78.4 (17.7)	0.4	69.7 (18.1)	-0.1
Social	86.2 (15.1)	88.4 (13.7)	0.2	79.2 (17.4)	-0.4
School	71.0 (19.0)	84.0 (14.3)	0.9	72.7 (16.9)	0.1

Note. Higher scores indicate better HRQOL; Norm data (healthy and chronic disease) taken from Limperg et al. (2014).

To further explore the differences on HRQOL-scores, multivariate regression analyses were used to compare HRQOL-scores between the different groups, controlling for gender and age. Data are presented in Table 3. Compared to their healthy peers, young adults with T1DM scored significantly worse on all domains of HRQOL except social functioning. Particularly, functioning at school or work was worse than that of the healthy norm group. This difference (-13.0) could be considered clinically significant. The HRQOL-scores of the T1DM study group were comparable to the scores of the chronic disease group on emotional and school/work functioning. Scores on physical and social functioning were significantly better than the norm scores of young adults with a chronic disease. However, these statistically significant differences were of minimal clinical relevance.

The young adults with diabetes experienced most problems on the following three PedsQL-YA items: 'I have low energy', 'I forget things' and 'It is hard to pay attention at work or study'. More than a quarter (26.1%) of the young adults with diabetes was 'almost always' or 'often' low in energy, 17.0% forgot things and 13.3% had a hard time paying attention. In comparison with the healthy norm group, relatively more young adults with T1DM reported low energy (healthy norm: 4.8%; $\chi2 = 45.242$, $p = 0.000$), forgot things (healthy norm: 1.6%; $\chi2 = 39.283$, $p = 0.000$), and had problems paying attention (healthy norm: 4.5%; $\chi2 = 11.952$, $p = 0.001$). There were no significant differences between the T1DM group and the chronic disease group.

Table 3

Multivariate regression analysis for groups comparisons (diabetes, healthy and chronic disease group) on the PedsQL-YA scales, corrected for age and gender

		Unstandardized coefficients		Standardized coefficients		
		B	*SE*	*β*	*t*	*p*-value
Total	Diabetes	reference				
	Healthy	6.294	1.248	0.228	5.042	0.000
	Chronic disease	-4.015	1.801	-0.101	-2.229	0.026
	Age	-0.533	0.254	-0.085	-2.103	0.036
	Gender	-4.069	1.116	-0.148	-3.645	0.000
Physical	Diabetes	reference				
	Healthy	5.007	1.411	0.161	3.549	0.000
	Chronic disease	-6.986	2.035	-0.155	-3.433	0.001
	Age	-0.682	0.287	-0.097	-2.379	0.018
	Gender	-4.862	1.261	-0.157	-3.854	0.000
Emotional	Diabetes	reference				
	Healthy	6.399	1.794	0.163	3.568	0.000
	Chronic disease	-1.484	2.587	-0.026	-0.573	0.567
	Age	-0.875	0.364	-0.098	-2.402	0.017
	Gender	-8.592	1.604	-0.220	-5.357	0.000
Social	Diabetes	reference				
	Healthy	1.938	1.418	0.064	1.367	0.172
	Chronic disease	-7.140	2.045	-0.164	-3.491	0.001
	Age	-0.237	0.288	-0.035	-0.822	0.411
	Gender	-1.797	1.268	-0.060	-1.417	0.157
School	Diabetes	reference				
	Healthy	12.742	1.571	0.366	8.111	0.000
	Chronic disease	1.459	2.266	0.029	0.644	0.520
	Age	-0.251	0.319	-0.032	-0.788	0.431
	Gender	-0.606	1.405	-0.017	-0.432	0.666

Note. Higher scores indicate better HRQOL; Norm data (healthy and chronic disease) taken from Limperg et al. (2014); Gender is coded as male = 0, female = 1.

DISCUSSION

This unique nationwide study in the Netherlands shows that the surveyed young adults with T1DM had a good social life, but performed worse on physical, emotional, and school/work functioning than do their healthy counterparts. Particularly functioning at school or work was impaired. HRQOL of young adults with T1DM was comparable to norm scores of young adults with chronic diseases, as the differences were too small to be of clinical relevance. In addition, a quarter of young adults with T1DM reported fatigue.

Earlier studies in young adults with chronic diseases also showed the negative impact of the condition on social participation and work. For example, Sattoe et al. (2014) found four patterns of social participation among young adults with a chronic condition. Those with a social participation pattern similar to that of healthy agemates reported lower HRQOL. Keeping up with social demands might be challenging for young adults with a chronic condition. A recent review on the impact of growing up with a chronic disease on psychosocial outcomes showed a lower likelihood of having a paid job (Maurice-Stam et al., 2019). Similarly, a study in adults with T1DM showed higher unemployment and sick leave rates among this group compared to the general population – while they were slightly better educated (Monaghan et al., 2015; Nielsen et al., 2016). Extra guidance for finding the right balance between social life and work could be beneficial for these young adults.

One quarter of our study population reported fatigue, compared to only 4.8% of the healthy norm group. Fatigue is a prevalent and burdensome complaint of patients with T1DM (Menting et al., 2018; Menting et al., 2017), and is generally found in childhood chronic disease (Nap-van der Vlist et al., 2019). Research shows that these patients' fatigue is not simply explained by somatic processes such as suboptimal glycemic control, but that cognitions and behaviors also play an important role in the perpetuation of fatigue (Menting et al., 2018). Therefore, young adults with T1DM could probably benefit from cognitive-behavioral therapy (CBT) to manage their fatigue – as shown in a large multicenter, randomized controlled trial (Menting et al., 2017).

All in all, growing into adulthood with T1DM may go hand-in-hand with impaired HRQOL and with fatigue. Young adulthood represents a vulnerable period with high health risks, even higher than in childhood or adolescence. This is confirmed by a large global study among youth (8–25 years) with T1DM, in which the young adult age group reported the lowest HRQOL (Anderson et al., 2017). Therefore, it is important to monitor their HRQOL from childhood into adulthood. Regular assessments in outpatient clinics provide the opportunity to discuss health-related topics (Haverman et al., 2017), like functioning at school or work and to detect problems during transition. A smooth transition to adult health care services – preferably with the use of a structured transition program – is critical (Schultz & Smaldone, 2017). However, the appropriate ingredients and outcomes of such a program have not yet been detailed (Sattoe et al., 2017). In a study of Fair et al. (2016), achieving optimal quality of life was rated as the most important outcome for successful transition.

The present study has several strengths, including the relatively large sample size, the comparison with Dutch norm scores for the PedsQL-YA controlling for age and gender, a nationwide representation of young adults with T1DM, and the bridging of a significant gap in knowledge on quality of life among young adults with T1DM. Limitations include the suboptimal response rate (44.2%), although this is comparable with that in other post-transition diabetes studies (Garvey et al., 2013), as well as the significant differences in gender and age between responders and non-responders. Non-responders were more often male and significantly older than respondents. As men tend to report higher HRQOL (Limperg et al., 2014), this could have led to an overestimation of problems in HRQOL. However, health surveys in adolescents generally show that non-response bias leads to a substantial underestimation of health problems (Cheung et al., 2017). Therefore, it is difficult to estimate the size and the direction of non-response bias in our sample. Furthermore, the cross-sectional design precluded us from examining causality. Longitudinal studies are necessary to understand the causal underpinnings of HRQOL. Additionally, we did not study what variables contributed to better or worse HRQOL. Our primary aim was to explore the impact of T1DM on young adults' quality of life. For future studies, examining predictors for HRQOL would be of interest. Candidate predictors include worries about the future, level of physical activity, and clinical parameters such as HbA1c, BMI, time-in-range, and fear of complications like hypoglycemia (Kent & Quinn, 2018). More research on chronic fatigue in T1DM is also needed, as this is an understudied complaint (Jensen et al., 2017).

CONCLUSION

The impact of T1DM on young adults' quality of life is substantial. These young adults with T1DM may be socially active, but as a downside they may suffer from fatigue and experience problems at work. Finding the right balance between personal and professional life while managing a demanding disease is not easy for these young adults. This underscores the desirability of regular assessing HRQOL, including work- and study-related issues, in clinical practice. Particularly, functioning at school or work was worse than that of the norm group.

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REFERENCES

Anderson, B. J., Laffel, L. M., Domenger, C., Danne, T., Phillip, M., Mazza, C., Hanas, R., Waldron, S., Beck, R. W., Calvi-Gries, F., & Mathieu, C. (2017). Factors associated with diabetes-specific health-related quality of life in youth with type 1 diabetes: The global TEENs study. *Diabetes Care, 40*(8), 1002-1009. https://doi.org/10.2337/dc16-1990

Beck, R. W., Calhoun, P., & Kollman, C. (2012). Use of continuous glucose monitoring as an outcome measure in clinical trials. *Diabetes Technology & Therapeutics, 14*(10), 877-882. https://doi.org/10.1089/dia.2012.0079

Braga de Souza, A. C., Felício, J. S., Koury, C. C., Neto, J. F., Miléo, K. B., Santos, F. M., Negrato, C. A., Motta, A. R., Silva, D. D., Arbage, T. P., Carvalho, C. T., de Rider Brito, H. A., Yamada, E. S., Cunha de Melo, F. T., Resende Fde, S., Ferreira, J. C., & Gomes, M. B. (2015). Health-related quality of life in people with type 1 diabetes mellitus: data from the Brazilian type 1 diabetes study group. *Health and Quality of Life Outcomes, 13*, 204. https://doi.org/10.1186/s12955-015-0396-0

Bryden, K. S., Dunger, D. B., Mayou, R. A., Peveler, R. C., & Neil, H. A. (2003). Poor prognosis of young adults with type 1 diabetes: a longitudinal study. *Diabetes Care, 26*(4), 1052-1057. https://doi.org/10.2337/diacare.26.4.1052

Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., While, A., & Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews, 4*, CD009794. https://doi.org/10.1002/14651858.CD009794.pub2

Cheung, K. L., Ten Klooster, P. M., Smit, C., de Vries, H., & Pieterse, M. E. (2017). The impact of non-response bias due to sampling in public health studies: A comparison of voluntary versus mandatory recruitment in a Dutch national survey on adolescent health. *BMC Public Health, 17*(1), 276. https://doi.org/10.1186/s12889-017-4189-8

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Lawrence Erlbaum Associates.

Cruz, D., Collet, N., & Nobrega, V. M. (2018). Quality of life related to health of adolescents with dm1: an integrative review. *Ciencia & Saude Coletiva, 23*(3), 973-989. https://doi.org/10.1590/1413-81232018233.08002016

Dabelea, D., Stafford, J. M., Mayer-Davis, E. J., D'Agostino, R., Jr., Dolan, L., Imperatore, G., Linder, B., Lawrence, J. M., Marcovina, S. M., Mottl, A. K., Black, M. H., Pop-Busui, R., Saydah, S., Hamman, R. F., Pihoker, C., & SEARCH for Diabetes in Youth Research Group. (2017). Association of type 1 diabetes vs type 2 diabetes diagnosed during childhood and adolescence with complications during teenage years and young adulthood. *JAMA, 317*(8), 825-835. https://doi.org/10.1001/jama.2017.0686

Delamater, A. M., de Wit, M., McDarby, V., Malik, J., Acerini, C. L., & International Society for Pediatric and Adolescent Diabetes. (2014). ISPAD Clinical Practice Consensus Guidelines 2014. Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes, 15*(Suppl. 20), 232-244. https://doi.org/10.1111/pedi.12191

DiMeglio, L. A., Acerini, C. L., Codner, E., Craig, M. E., Hofer, S. E., Pillay, K., & Maahs, D. M. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Glycemic control targets and glucose monitoring for children, adolescents, and young adults with diabetes. *Pediatric Diabetes, 19*(Suppl. 27), 105-114. https://doi.org/10.1111/pedi.12737

Fair, C., Cuttance, J., Sharma, N., Maslow, G., Wiener, L., Betz, C., Porter, J., McLaughlin, S., Gilleland-Marchak, J., Renwick, A., Naranjo, D., Jan, S., Javalkar, K., Ferris, M., & International and Interdisciplinary Health Care Transition Research Consortium. (2016). International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatrics, 170*(3), 205-211. https://doi.org/10.1001/jamapediatrics.2015.3168

Field, A. P. (2018). *Discovering statistics using IBM SPSS* (5th ed.). Sage Publications Ltd.

Garvey, K. C., Finkelstein, J. A., Laffel, L. M., Ochoa, V., Wolfsdorf, J. I., & Rhodes, E. T. (2013). Transition experiences and health care utilization among young adults with type 1 diabetes. *Patient Preference and Adherence, 7*, 761-769. https://doi.org/10.2147/PPA.S45823

Haverman, L., Limperg, P. F., Young, N. L., Grootenhuis, M. A., & Klaassen, R. J. (2017). Paediatric health-related quality of life: what is it and why should we measure it? *Archives of Disease in Childhood, 102*(5), 393-400. https://doi.org/10.1136/archdischild-2015-310068

James, S., Gallagher, R., Dunbabin, J., & Perry, L. (2014). Prevalence of vascular complications and factors predictive of their development in young adults with type 1 diabetes: systematic literature review. *BMC Research Notes, 7*, 593. https://doi.org/10.1186/1756-0500-7-593

Jensen, O., Bernklev, T., & Jelsness-Jorgensen, L. P. (2017). Fatigue in type 1 diabetes: A systematic review of observational studies. *Diabetes Research and Clinical Practice, 123*, 63-74. https://doi.org/10.1016/j.diabres.2016.11.002

Kent, D. A., & Quinn, L. (2018). Factors that affect quality of life in young adults with type 1 diabetes. *Diabetes Educator, 44*(6), 501-509. https://doi.org/10.1177/0145721718808733

Limperg, P. F., Haverman, L., van Oers, H. A., van Rossum, M. A., Maurice-Stam, H., & Grootenhuis, M. A. (2014). Health related quality of life in Dutch young adults: psychometric properties of the PedsQL generic core scales young adult version. *Health and Quality of Life Outcomes, 12*, 9. https://doi.org/10.1186/1477-7525-12-9

Lukacs, A., Mayer, K., Sasvari, P., & Barkai, L. (2018). Health-related quality of life of adolescents with type 1 diabetes in the context of resilience. *Pediatric Diabetes, 19*(8), 1481-1486. https://doi.org/10.1111/pedi.12769

Maurice-Stam, H., Nijhof, S. L., Monninkhof, A. S., Heymans, H. S. A., & Grootenhuis, M. A. (2019). Review about the impact of growing up with a chronic disease showed delays achieving psychosocial milestones. *Acta Paediatrica, 108*(12), 2157-2169. https://doi.org/10.1111/apa.14918

Mazur, A., Dembinski, L., Schrier, L., Hadjipanayis, A., & Michaud, P. A. (2017). European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Paediatrica, 106*(8), 1354-1357. https://doi.org/10.1111/apa.13901

Menting, J., Tack, C. J., Donders, R., & Knoop, H. (2018). Potential mechanisms involved in the effect of cognitive behavioral therapy on fatigue severity in Type 1 diabetes. *Journal of Consulting and Clinical Psychology, 86*(4), 330-340. https://doi.org/10.1037/ccp0000290

Menting, J., Tack, C. J., van Bon, A. C., Jansen, H. J., van den Bergh, J. P., Mol, M., Goedendorp, M. M., Donders, R., & Knoop, H. (2017). Web-based cognitive behavioural therapy blended with face-to-face sessions for chronic fatigue in type 1 diabetes: a multicentre randomised controlled trial. *Lancet Diabetes & Endocrinology, 5*(6), 448-456. https://doi.org/10.1016/S2213-8587(17)30098-0

Monaghan, M., Helgeson, V., & Wiebe, D. (2015). Type 1 diabetes in young adulthood. *Current Diabetes Reviews, 11*(4), 239-250. https://doi.org/10.2174/1573399811666150421114957

Murillo, M., Bel, J., Perez, J., Corripio, R., Carreras, G., Herrero, X., Mengibar, J. M., Rodriguez-Arjona, D., Ravens-Sieberer, U., Raat, H., & Rajmil, L. (2017). Health-related quality of life (HRQOL) and its associated factors in children with type 1 diabetes mellitus (T1DM). *BMC Pediatrics, 17*(1), 16. https://doi.org/10.1186/s12887-017-0788-x

Nap-van der Vlist, M. M., Dalmeijer, G. W., Grootenhuis, M. A., van der Ent, C. K., van den Heuvel-Eibrink, M. M., Wulffraat, N. M., Swart, J. F., van Litsenburg, R. R. L., van de Putte, E. M., & Nijhof, S. L. (2019).

Fatigue in childhood chronic disease. *Archives of Disease in Childhood, 104*(11), 1090-1095. https://doi.org/10.1136/archdischild-2019-316782

Nielsen, H. B., Ovesen, L. L., Mortensen, L. H., Lau, C. J., & Joensen, L. E. (2016). Type 1 diabetes, quality of life, occupational status and education level - A comparative population-based study. *Diabetes Research and Clinical Practice, 121*, 62-68. https://doi.org/10.1016/j.diabres.2016.08.021

Nieuwesteeg, A., Pouwer, F., van der Kamp, R., van Bakel, H., Aanstoot, H. J., & Hartman, E. (2012). Quality of life of children with type 1 diabetes: a systematic review. *Current Diabetes Reviews, 8*(6), 434-443. https://doi.org/10.2174/157339912803529850

Sattoe, J. N. T., Hilberink, S. R., van Staa, A. L., & Bal, R. A. (2014). Lagging behind or not? Four distinctive social participation patterns among young adults with chronic conditions. *Journal of Adolescent Health, 54*(4), 397-403. https://doi.org/10.1016/j.jadohealth.2013.09.017

Sattoe, J. N. T., Hilberink, S. R., & van Staa, A. L. (2017). How to define successful transition? An exploration of consensus indicators and outcomes in young adults with chronic conditions. *Child: Care, Health and Development, 43*(5), 768-773. https://doi.org/10.1111/cch.12436

Sattoe, J. N. T., Peeters, M. A. C., Hilberink, S. R., Ista, E., & van Staa, A. L. (2016). Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open, 6*(8), e011926. https://doi.org/10.1136/bmjopen-2016-011926

Schneider, S. L. (2013). The International Standard Classification of Education 2011. In G. Elisabeth Birkelund (Ed.), *Class and stratification analysis* (Vol. 30, pp. 365-379). Emerald Group Publishing Limited. https://doi.org/10.1108/S0195-6310(2013)0000030017

Schultz, A. T., & Smaldone, A. (2017). Components of interventions that improve transitions to adult care for adolescents with type 1 diabetes. *Journal of Adolescent Health, 60*(2), 133-146. https://doi.org/10.1016/j.jadohealth.2016.10.002

Smith-Palmer, J., Bae, J. P., Boye, K. S., Norrbacka, K., Hunt, B., & Valentine, W. J. (2016). Evaluating health-related quality of life in type 1 diabetes: a systematic literature review of utilities for adults with type 1 diabetes. *ClinicoEconomics and Outcomes Research, 8*, 559-571. https://doi.org/10.2147/CEOR.S114699

Varni, J. W., Burwinkle, T. M., Seid, M., & Skarr, D. (2003). The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambulatory Pediatrics, 3*(6), 329-341. https://doi.org/10.1367/1539-4409(2003)003<0329:tpaapp>2.0.co;2

Varni, J. W., Delamater, A. M., Hood, K. K., Raymond, J. K., Driscoll, K. A., Wong, J. C., Adi, S., Yi-Frazier, J. P., Grishman, E. K., Faith, M. A., Corathers, S. D., Kichler, J. C., Miller, J. L., Doskey, E. M., Aguirre, V. P., Heffer, R. W., Wilson, D. P., & Pediatric Quality of Life Inventory 3.2 Diabetes Module Testing Study Consortium. (2018). Diabetes symptoms predictors of health-related quality of life in adolescents and young adults with type 1 or type 2 diabetes. *Quality of Life Research, 27*(9), 2295-2303. https://doi.org/10.1007/s11136-018-1884-6

Varni, J. W., & Limbers, C. A. (2009). The PedsQL 4.0 generic core scales young adult version: feasibility, reliability and validity in a university student population. *Journal of Health Psychology, 14*(4), 611-622. https://doi.org/10.1177/1359105309103580

Viner, R. M. (2008). Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Archives of Disease in Childhood, 93*(2), 160-163. https://doi.org/10.1136/adc.2006.103721

3

Transfer in care and diabetes distress in young adults with type 1 diabetes mellitus

Jane N.T. Sattoe
Mariëlle A.C. Peeters
Madelon B. Bronner
AnneLoes van Staa

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ABSTRACT

Introduction

Diabetes distress (DD) is a serious problem in many people with diabetes and is associated with unfavorable clinical and psychosocial outcomes in children and adults. Little is known about DD in young adults (YAs) with type 1 diabetes mellitus (T1DM) who transferred to adult care. This study aimed to explore the differences between YAs with/without DD regarding transfer experiences, self-management and health-related quality of life (HRQOL).

Research design and methods

Cross-sectional online questionnaire completed by YAs with T1DM after transfer. DD was measured with the short-form Problem Areas in Diabetes (PAID) scale. Descriptive analyses were followed by *t*-tests and *χ2*-tests to explore differences between the groups with/without DD. Effect sizes were calculated.

Results

Of 164 respondents with mean age 22.7 (± 1.56) years, 60.7% was female. The total sample scored low on DD (6.52 ± 4.67; range: 0-17), but 57 (34.8%) had a score ≥ 8, indicating DD. YAs with DD felt less ready to transfer to adult care than those without DD and scored lower on alliance between pediatric and adult care and reception in adult care. They also reported poorer self-management skills and lower HRQOL in all domains of functioning.

Conclusions

More than one-third YAs experienced DD after transfer; this was associated with less favorable transition, self-management and psychosocial outcomes. Transfer in care seems to be a source of DD. Systematic screening on DD and attention for YAs' worries is recommended in both pediatric and adult care.

SIGNIFICANCE OF THE STUDY

What is already known about this subject?

The few studies that explored diabetes distress in young adults with T1DM, showed that diabetes distress is significantly more present in the young adult group compared to other age groups and that more diabetes distress in young adults with T1DM is associated with impaired health outcomes and less frequent blood monitoring by young adults.

What are the new findings?

- More than one-third of the young adults with T1DM experienced diabetes distress after transfer to adult care.
- Having diabetes distress was associated with less favorable transition experiences, self-management outcomes and psychosocial outcomes.
- Transfer in care may be a source of diabetes distress in young adults.

How might these results change the focus of research or clinical practice?

Systematic screening on diabetes distress and attention for young adults' worries is recommended. Building positive relationships and adopting motivating communication styles may help clinicians to reduce diabetes distress in this population.

INTRODUCTION

Emerging adulthood is a critical period with increased risk of acute and even chronic health complications, psychological problems and psychosocial issues for young adults with type 1 diabetes mellitus (T1DM) (Iyengar et al., 2019). Young people growing up with T1DM go through various transitions while transitioning from childhood to adulthood. Next to the developmental milestones they are expected to achieve, they are required to transfer to adult care and take up self-management of their chronic condition, which can be challenging (Babler & Strickland, 2015; Monaghan et al., 2015). Young adults are underrepresented in research on living with T1DM, although they have unique views, challenges and needs (Monaghan et al., 2015; Weissberg-Benchell et al., 2007). The regular developmental tasks of young adults in emerging adulthood may influence and be influenced by T1DM (Babler & Strickland, 2015). Diabetes management, for instance, is often a lower priority for young adults with T1DM during important life transitions (Vallis et al., 2018), and glycemic control of this group is less optimal compared to other age groups (Iyengar et al., 2019).

Studies repeatedly show that living with diabetes comes with a profound emotional burden (Wentzell et al., 2020). Consequently, young people with T1DM are at significant risk for psychological comorbidity: high prevalence of depressive symptoms, anxiety and eating disorders have been reported in this group (Buchberger et al., 2016; De Wit & Snoek, 2011; Delamater, 2009; Young et al., 2013). Apart from these clinically defined psychological diagnoses, diabetes distress is more and more recognized as an important indicator for mental health (Balfe et al., 2013; Delamater et al., 2018). Diabetes distress is defined as "the negative emotional or affective experience resulting from the challenge of living with the demands of diabetes…" (Skinner et al., 2020). It is associated with unfavorable clinical and psychosocial outcomes and lower levels of self-management (Delamater et al., 2018). Different studies found the number of people experiencing diabetes distress to be higher than the number of people experiencing clinically established psychological disorders such as depression (Esbitt et al., 2013; Skinner et al., 2020). Therefore, diabetes distress can be a more useful indicator to gain insight into wellbeing and needs of (young) people with diabetes, and to prevent further deterioration of mental health in this group. This is why international diabetes guidelines recommend regular screening on diabetes distress in clinical practice (Delamater et al., 2018).

Diabetes distress has been topic of research for at least 25 years now (Skinner et al., 2020), but relatively little research has specifically addressed young adults (Stahl-Pehe et al., 2019; Wentzell et al., 2020). The few studies that explored this area, showed that diabetes distress is significantly more present in the young adult group compared to other age groups (Vallis et al., 2018; Wentzell et al., 2020) and that more diabetes distress in young adults with T1DM is associated with impaired health outcomes (e.g., higher hemoglobin A1c (HbA1c) levels) (Stahl-Pehe et al., 2019; Tanenbaum et al., 2017) and less frequent blood monitoring by young adults (Downie et al., 2021). Garvey et al. (2017) found that feeling prepared for transition to adult care was associated with lower diabetes distress in young adults with T1DM. However, this is the only study that addressed transition and diabetes distress. Since transition is an important phase to support the development of self-management skills and to prepare young people for adult life while maintaining good quality of life, it is useful to further explore the differences between young people with and without diabetes distress regarding transfer experiences, self-management and health-related quality of life. Such insights could help to tailor self-management support to the needs of young adults. This study aimed to explore these differences in a sample of Dutch young adults (aged 18-25 years) with T1DM.

RESEARCH DESIGN AND METHODS

Participants and setting

This study used data from a larger evaluation study of transitional care for young adults with T1DM in the Netherlands (Peeters et al., 2021; Van Staa et al., 2020). The study involved twelve hospitals and was conducted between April 2016 and October 2018; its study protocol has already been published (Sattoe et al., 2016), as is the evaluation study itself (Peeters et al., 2021). In the current study, results from an online questionnaire on diabetes distress, health-related quality of life, self-management, and transfer experiences were explored. Participants were young adults (aged 18-25 years) with a confirmed diagnosis of T1DM who had made the transfer to adult services in 2012-2014, had no cognitive impairment, and were able to speak and read Dutch. In our evaluation study we found that the care facilities could be divided in two groups: HI-ATT (with high attention for transitional care and thus better alliance between pediatric and adult care settings) and LO-ATT (the opposite). We established that there were hardly any significant differences between the two groups related to outcomes in young adults, such as health-related quality of life and self-management. Extra analysis (not published) also showed that there were no differences in diabetes distress. That is why in this study, we did not differentiate between teams with more or less transitional care facilities.

Data collection

The participating hospitals invited potential respondents by e-mail in October 2017. They were asked to fill out an online questionnaire on diabetes distress, health-related quality of life, self-management and transfer experiences. Most invited people had transferred to adult services in the period 2012 to 2014, but five hospitals also invited young adults who had transferred in 2015-2016. Reminders were sent after two and four weeks. Every third respondent received a €20 gift voucher. Those who eventually participated, consented with the use of their data and linking these to data from their electronic charts for this study.

Measures

Background characteristics

The following sociodemographic characteristics were addressed in the questionnaire: age (years); gender (male/female); highest completed educational level at time of the study (low (i.e. junior vocational or secondary general low) and medium (i.e. secondary general high or senior vocational) versus high (higher educational institutions)); employment status (paid or volunteer job, yes versus no); and living status (with parents versus independent). Time since transfer (first consultation in adult care) had been collected in the overarching evaluation study from participants' medical records.

Diabetes distress

Diabetes distress was measured with the Dutch version of the validated 5-item Problem Areas in Diabetes (PAID-5) scale (McGuire et al., 2010; Snoek et al., 2000). Items are scored on a 5-point Likert scale: 0 = not a problem, 1 = minor problem, 2 = moderate problem, 3 = somewhat serious problem, 4 = serious problem. The theoretical range is 0-20; higher scores indicate more stress. Cronbach's α in the current study was .89. For the categorization of groups into 'with diabetes distress' and 'without diabetes distress', a score of eight points or higher on the sum score was classified as having diabetes distress (McGuire et al., 2010).

Transfer experiences

Transfer experiences were measured using the validated 20-item On Your Own Feet – Transfer Experiences Scale (OYOF-TES) (Van Staa & Sattoe, 2014). Items are scored on a 5-point Likert scale: 1 = strongly disagree, 2 = disagree, 3 = do not agree/do not disagree, 4 = agree, 5 = strongly agree. Higher scores indicate more positive transfer experiences. Cronbach's α for the total scale was .91 in the current study. Subscales included: reception in adult care (4 items, $\alpha = .88$, alliance between pediatric and adult care (5 items, $\alpha = .87$), preparation for the transfer (3 items, $\alpha = .70$), readiness to transfer (6 items, $\alpha = .81$), and youth involvement (2 items, $\alpha = .60$).

Self-management

Self-management skills were measured with the validated 12-item Partners in Health (PIH) scale (Petkov et al., 2010). Items are scored on a 9-point Likert scale, where a higher score indicates better self-management skills. Cronbach's α in the current study was .74.

Health-related quality of life

Health-related quality of life (HRQOL) was measured using the Dutch version of the validated 23-item Pediatric Quality of Life Inventory for Young Adults (PedsQL-YA) (Varni & Limbers, 2009). Items are scored on a 5-point Likert scale: 0 = never, 1 = almost never, 2 = sometimes, 3 = often, 4 = almost always. Each answer is reversely scored and rescaled to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0). Higher scores indicate better HRQOL. Cronbach's α for the total scale was .94 in the current study. Subscales included: physical health (8 items, $\alpha = .88$), emotional functioning (5 items, $\alpha = .86$), social functioning (5 items, $\alpha = .80$), and school/work functioning (5 items, $\alpha = .80$).

Data analysis

Descriptive analyses were performed to describe the study sample's background characteristics. Differences on background characteristics between non-responders and responders were calculated using *t*-tests and Pearson chi-square tests. The study sample was divided in two groups on the basis of the PAID-5 scale score: 1) with diabetes distress (score ≥ 8); and 2) without diabetes distress (score < 8). Differences between these two groups were explored with *t*-tests and Pearson chi-square tests and effect sizes (Cohen's *d*) were calculated; descriptive analyses (frequencies) were used to explore diabetes distress within these groups (at item level). Missing data was excluded listwise.

RESULTS

Response and background characteristics

Four hundred and thirty-five young adults with T1DM were invited to participate in the study. Of these, 177 (40.7%) filled out the questionnaire and 164 (37.7%) provided information about diabetes distress. Non-responders did not differ from the responders in age (mean ± *SD* in years: 23.6 ± 1.40 versus 23.9 ± 1.49; $p = .158$), but they were more often men (64.0% versus 39.3%; $p < .001$). A description of the study sample is given in Table 1.

Diabetes distress

The total study sample ($n = 164$) scored low on problem areas in diabetes (6.52 ± 4.67, range: 0-17); but 57 of them (34.8%) had a score ≥ 8, indicating diabetes distress. These young adults with diabetes distress had a mean distress score of 11.88 (± 2.99) versus 3.66 (± 2.27) in those without diabetes distress ($p < .001$). "Worrying about the future and the possibility of serious complications" was most often mentioned as a serious problem by those with diabetes distress (67%; Figure 1). Those without diabetes distress also worried about this, but only 5% considered it a serious problem. "Feeling that diabetes

Table 1
Background characteristics of total study sample (*n* = 164)

Characteristic	Mean (±*SD*) or frequency (%)
Age (years) (range 19-28 years)	22.7 (±1.56)
Time since transfer[1] (3-6 years)	4.7 (±1.13)
Gender[2]	
Female	99 (60.7%)
Male	64 (39.3%)
Educational level[2]	
Low/middle	125 (76.7%)
High	38 (23.3%)
Paid or volunteer job[2]	
Yes	137 (84.0%)
No	26 (16.0%)
Living[2]	
With parents	99 (60.7%)
Independent (on own)	64 (39.3%)

[1] *n*=112
[2] *n*=163

is taking up too much of your mental and physical energy every day" was relatively often mentioned as a serious problem as well by 58% of those with diabetes distress. Comparisons of those with and those without diabetes distress on the PAID-5 showed substantial and significant differences between both groups (Figure 1).

Differences on background characteristics and outcomes

Interestingly, there were hardly any differences in background characteristics between young adults with and without diabetes distress (Table 2). However, the latter were significantly younger ($p = .038$).

As for transfer experiences, young adults with diabetes distress overall had less positive experiences ($p = .002$). More specifically, they rated the reception in adult care ($p = .013$) and the alliance between pediatric and adult care ($p = .029$) lower and felt less ready to transfer to adult care ($p < .001$). They also reported worse outcomes on self-management ($p < .001$) and overall HRQOL ($p < .001$) compared to young adults without diabetes distress. HRQOL of those with diabetes distress was significantly lower on all domains, i.e. physical functioning, emotional functioning, social functioning, and school/work functioning. Effect sizes differed from medium to large for all outcome measures. Large effect sizes were particularly found for emotional, social, and school/work functioning (Table 2).

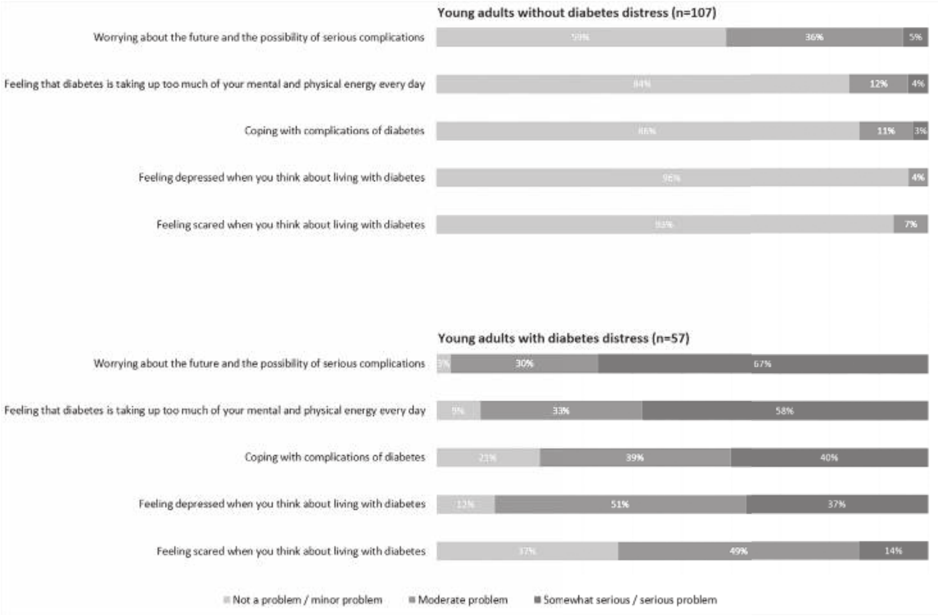

Figure 1. PAID-5 scores in young adults with and without diabetes distress

DISCUSSION

General discussion

This study found substantial differences in transfer experiences, self-management and HRQOL between young adults with T1DM with and without diabetes distress. Those without diabetes distress reported better transfer experiences and better self-management skills and higher HRQOL compared to those with diabetes distress. Young adults with diabetes distress were slightly older; no other differences in background characteristics were found.

Almost 35% of the participants reported diabetes distress. The estimated prevalence of diabetes distress in other studies is 28% in adolescents and emerging adults with T1DM (Lašaitė et al., 2016) and 32% in young adults with T1DM (Hislop et al., 2008), which is comparable to the present study. The outcome that those with diabetes distress were older than those without is congruent with the finding of Lašaitė et al. (2016) that emerging young adults more often experienced psychological distress compared to adolescents. A study in over 19-year-olds with T1DM found that younger adults more often experienced diabetes distress than older adults (Fisher et al., 2015). Probably, the developmental challenges of young adulthood add to the distress experienced from T1DM itself, which warrants specific attention from healthcare professionals.

Table 2
Differences between young adults with and without diabetes distress (mean (± *SD*) or frequency (%))

	Young adults with diabetes distress (*n* = 57)	Young adults without diabetes distress (*n* = 107)	Effect size	*p*-value
Background characteristics				
Age	23.00 (±1.67)	22.47 (±1.48)	.33	.038
Time since transfer (3-6 years)[1]	4.44 (±1.25)	4.82 (±1.03)	.33	.087
Gender[2]			-	
Female	39 (68.4%)	60 (56.6%)		.141
Male	18 (31.6%)	46 (43.4%)		
Educational level[3]			-	
Low/middle	44 (78.6%)	81 (75.7%)		.681
High	12 (21.4%)	26 (24.3%)		
Paid or volunteer job[3]			-	
Yes	46 (82.1%)	91 (85.0%)		.318
No	10 (17.9%)	16 (15.0%)		
Living[3]			-	
With parents	30 (53.6%)	69 (64.5%)		.188
On own	26 (46.4%)	38 (35.5%)		
Transfer experiences (OYOF-TES)*				
Reception in adult care	3.72 (±.993)	4.04 (±.675)	.38	.013
Alliance between pediatric and adult care	2.92 (±.899)	3.23 (±.857)	.35	.029
Preparation for the transfer	2.88 (±.925)	3.02 (±.931)	.15	.323
Readiness to transfer	3.76 (±.710)	4.19 (±.576)	.67	<.001
Youth involvement	3.12 (±1.02)	3.39 (±.955)	.27	.101
Total score	66.88 (±13.94)	73.35 (±11.25)	.51	.002
*Self-management (PIH**)*	76.09 (±8.81)	82.22 (±7.91)	.73	<.001
*HRQOL (PedsQL-YA***)*				
Physical functioning	79.11 (±15.30)	87.21 (±15.51)	.53	.002
Emotional functioning	52.81 (±17.70)	80.28 (±17.43)	1.56	<.001
Social functioning	78.51 (±16.26)	90.23 (±12.69)	.80	<.001
School/work functioning[2]	61.40 (±19.43)	75.99 (±16.70)	.81	<.001
Total score	69.41 (±14.35)	83.96 (±13.16)	1.06	<.001

[1] *n*=112: Young adults with diabetes distress *n*=41, without diabetes distress *n*=71
[2] *n*=163: Young adults with diabetes distress *n*=57, without diabetes distress *n*=106
[3] *n*=163: Young adults with diabetes distress *n*=56, without diabetes distress *n*=107
*OYOF-TES = On Your Own Feet Transfer Experiences Scale
**PIH = Partners in Health
***PedsQL-YA = Pediatric Quality of Life Inventory – Young Adult

Wentzell et al. (2020) indeed concluded in their integrative review that diabetes distress "is embedded within the developmental challenges specific to living with T1DM during this phase [i.e. emerging adulthood]". In this light, support of parents is also an important topic. Our study revealed that less young adults who still lived with their parents had diabetes distress compared to those who lived independently. Shaw et al. (2021) recently emphasized the (often overlooked) role of parents in promoting young adults' wellbeing.

Worrying about the future and the possibility of serious complications were most often reported as (serious) problems by people with T1DM, in our study and in previous studies as well (Skinner et al., 2020). In general, distress in people with T1DM seems to be related to emotions (worries, feelings etc.) rather than difficulties in practically managing the condition and its treatment (Sturt et al., 2015). However, insights into specific sources of distress in young adults with T1DM is lacking. In this study, the feeling that diabetes is taking up too much mental and physical energy every day, is the second most often mentioned problem, both by respondents with and those without diabetes distress. This problem was also highlighted in our study on HRQOL in these young adults, of whom one quarter reported fatigue due to T1DM (Bronner et al., 2020). Ways to counteract the feeling that diabetes management takes up too much mental and physical energy would benefit young adults with T1DM. Nevertheless, Barry-Menkhaus et al. (2020) recently emphasized that much work is still needed to find pragmatic and efficient ways to improve self-management of young adults with T1DM. Another systematic review also highlights the need to develop effective interventions for this group (Wong et al., 2020).

As for the differences in outcomes between young adults with and without diabetes distress, the latter reported more positive outcomes on all measures. They had better transfer experiences, more self-management skills and higher HRQOL. It is important to note that it is still not clear whether less positive transfer experiences add to diabetes distress or – vice versa – whether diabetes distress makes young adults more negative towards past experiences, including transfer. The only previous study that explored transition and diabetes distress, showed that feeling prepared for the transfer to adult care was associated with lower diabetes distress in young adults (Garvey et al., 2017). However, our results suggest that rather than preparation for transfer, reception in adult care, alliance between pediatric and adult care and readiness to transfer seem to be important for young people with T1DM. This suggests that the transfer in care adds to stress experiences by young adults. More research is needed to clarify the sources of diabetes distress in young adults with T1DM.

The finding that young adults without diabetes distress score significantly better on self-management than do those with diabetes distress is not surprising. Self-management encompasses three tasks: medical management, role management, and emotional management (Lorig & Holman, 2003). An association between lower self-care skills (medical management) and diabetes distress is consistently found in other age groups (Skinner et al., 2020). Less is known about the effect of diabetes distress on social participation (i.e., the degree to which someone takes up roles in society in different areas like school, work, relationships etc.), but we do know that young adults with social participation rates comparable to those of their healthy peers, generally report lower HRQOL (Sattoe et al., 2014). Social functioning and school/work functioning were indeed significantly and substantially lower in the group with diabetes distress in this study. More research is needed to further understand the relation between diabetes distress and social participation of young adults with T1DM. Emotional management involves, among other things, stress management, positive thinking and mental well-being (Sattoe et al., 2015). The largest negative effect of diabetes distress was indeed found for emotional functioning. More diabetes distress, therefore, could impair one's self-management skills.

The question is how to support young adults with T1DM who have diabetes distress. Apart from more insight into their sources of stress and support needs, studies researching distress in adults can provide recommendations that might be valid for young adults as well. First, as mentioned above, it is essential to regularly screen young adults for diabetes distress and have attention for and discuss any worries. Second, it is important to consider what healthcare professionals can do to counteract diabetes distress in young adults with T1DM (Skinner et al., 2020). A recent systematic review suggested that experiencing good communication and positive experiences with healthcare professionals is found to be associated with reduced diabetes distress and better self-management outcomes (Peimani et al., 2020). Previous studies in young people with chronic conditions have linked positive relationships with and trust in healthcare professionals with more positive outcomes as well (Fisher et al., 2019; Monaghan et al., 2013). Fisher et al. (2019) emphasize specific communication styles that healthcare professionals can apply to reduce diabetes distress. These recommendations are valid for both pediatric and adult care professionals. Transitional care based on good collaboration between pediatric and adult care and harboring a warm reception in adult care could contribute to alleviate the burden for young adults (Van Staa et al., 2020).

Strengths and limitations

This study addressed a gap in current literature and provided unique insights in diabetes distress around transfer in care. Another strength is the nationwide representation of young adults with T1DM. A possible limitation is that respondents were more often women; some studies suggest there is a significant association between higher diabetes distress and female gender in emerging adults, but the relationship between diabetes distress and gender is not clear (Wentzell et al., 2020). Therefore, we cannot tell if and how the underrepresentation of males in our study may have influenced our results.

Another limitation is that the cross-sectional study design did not allow for exploration of causality; longitudinal studies are needed to identify determinants of diabetes distress in young adults with T1DM. Also, while the response rate in this study was rather low, it appears to be comparable to similar (post transition) studies in young people with T1DM (Garvey et al., 2013). Finally, this study did not include any information about diabetes control and the impact on transfer, because the survey and available medical record data were collected in different time periods. Our evaluation study (Peeters et al., 2021) revealed that mean HbA1c scores did not change over time ($p = .836$); they were elevated across the whole study period with no significant differences between pediatric and adult care. It seems relevant to study the association between diabetes control and diabetes distress in future, longitudinal studies.

CONCLUSIONS

In this study, more than one-third of the young adults with T1DM experience diabetes distress after transfer to adult care. Differences in diabetes distress are substantial and so are the consequences of having diabetes distress. Those with diabetes distress had less positive transfer experiences, suggesting that the transfer in care could be a source of diabetes distress in young adults. Specific attention is required for reception in adult care, alliance between pediatric and adult care and readiness to transfer. Young adults with diabetes distress also reported less self-management skills and lower HRQOL compared to those without diabetes distress. Structured screening of diabetes distress and attention for and addressing young adults' worries is recommended in both pediatric and adult care.

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ETHICS APPROVAL

The Medical Ethics Review Board of Erasmus MC approved the original study protocol (MEC-2014-246), and ethical approval was obtained from all local hospital review boards. All participants gave informed consent before taking part in the study.

REFERENCES

Babler, E., & Strickland, C. J. (2015). Moving the journey towards independence: Adolescents transitioning to successful diabetes self-management. *Journal of Pediatric Nursing, 30*(5), 648-660. https://doi.org/10.1016/j.pedn.2015.06.005

Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D., & Conroy, R. (2013). What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *BMC Endocrine Disorders, 13*, 25. https://doi.org/10.1186/1472-6823-13-25

Barry-Menkhaus, S. A., Wagner, D. V., & Riley, A. R. (2020). Small Interventions for big change: Brief strategies for distress and self-management amongst youth with type 1 diabetes. *Current Diabetes Reports, 20*(1), 3. https://doi.org/10.1007/s11892-020-1290-7

Bronner, M. B., Peeters, M. A. C., Sattoe, J. N. T., & van Staa, A. (2020). The impact of type 1 diabetes on young adults' health-related quality of life. *Health and Quality of Life Outcomes, 18*(1), 137. https://doi.org/10.1186/s12955-020-01370-8

Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: A systematic review and meta-analysis. *Psychoneuroendocrinology, 70*, 70-84. https://doi.org/10.1016/j.psyneuen.2016.04.019

De Wit, M., & Snoek, F. J. (2011). Depressive symptoms and unmet psychological needs of Dutch youth with type 1 diabetes: results of a web-survey. *Pediatric Diabetes, 12*(3 Pt 1), 172-176. https://doi.org/10.1111/j.1399-5448.2010.00673.x

Delamater, A. M. (2009). Psychological care of children and adolescents with diabetes. *Pediatric Diabetes, 10*(Suppl. 12), 175-184. https://doi.org/10.1111/j.1399-5448.2009.00580.x

Delamater, A. M., de Wit, M., McDarby, V., Malik, J. A., Hilliard, M. E., Northam, E., & Acerini, C. L. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes, 19 Suppl 27*, 237-249. https://doi.org/10.1111/pedi.12736

Downie, G. A., Mullan, B. A., Boyes, M. E., & McEvoy, P. M. (2021). The effect of psychological distress on self-care intention and behaviour in young adults with type 1 diabetes. *Journal of Health Psychology, 26*(4), 543-555. https://doi.org/10.1177/1359105318824795

Esbitt, S. A., Tanenbaum, M. L., & Gonzalez, J. S. (2013). disentangling clinical depression from diabetes-specific distress: Making sense of the mess we've made. In: C. Lloyd, F. Pouwer, & N. Hermanns (Eds.), *Screening for Depression and Other Psychological Problems in Diabetes* (pp. 27-46). Springer-Verlag. https://doi.org/10.1007/978-0-85729-751-8_2

Fisher, L., Polonsky, W. H., & Hessler, D. (2019). Addressing diabetes distress in clinical care: a practical guide. *Diabetic Medicine, 36*(7), 803-812. https://doi.org/10.1111/dme.13967

Fisher, L., Polonsky, W. H., Hessler, D. M., Masharani, U., Blumer, I., Peters, A. L., Strycker, L. A., & Bowyer, V. (2015). Understanding the sources of diabetes distress in adults with type 1 diabetes. *Journal of Diabetes and its Complications, 29*(4), 572-577. https://doi.org/10.1016/j.jdiacomp.2015.01.012

Garvey, K. C., Finkelstein, J. A., Laffel, L. M., Ochoa, V., Wolfsdorf, J. I., & Rhodes, E. T. (2013). Transition experiences and health care utilization among young adults with type 1 diabetes. *Patient Preference and Adherence, 7*, 761-769. https://doi.org/10.2147/PPA.S45823

Garvey, K. C., Foster, N. C., Agarwal, S., DiMeglio, L. A., Anderson, B. J., Corathers, S. D., Desimone, M. E., Libman, I. M., Lyons, S. K., Peters, A. L., Raymond, J. K., & Laffel, L. M. (2017). Health care transition preparation and experiences in a U.S. national sample of young adults with type 1 diabetes. *Diabetes Care, 40*(3), 317-324. https://doi.org/10.2337/dc16-1729

Hislop, A. L., Fegan, P. G., Schlaeppi, M. J., Duck, M., & Yeap, B. B. (2008). Prevalence and associations of psychological distress in young adults with type 1 diabetes. *Diabetic Medicine, 25*(1), 91-96. https://doi.org/10.1111/j.1464-5491.2007.02310.x

Iyengar, J., Thomas, I. H., & Soleimanpour, S. A. (2019). Transition from pediatric to adult care in emerging adults with type 1 diabetes: a blueprint for effective receivership. *Clinical Diabetes and Endocrinology, 5*, 3. https://doi.org/10.1186/s40842-019-0078-7

Lašaitė, L., Dobrovolskiene, R., Danyte, E., Stankute, I., Razanskaite-Virbickiene, D., Schwitzgebel, V., Marciulionyte, D., & Verkauskiene, R. (2016). Diabetes distress in males and females with type 1 diabetes in adolescence and emerging adulthood. *Journal of Diabetes and its Complications, 30*(8), 1500-1505. https://doi.org/10.1016/j.jdiacomp.2016.08.013

Lorig, K. R., & Holman, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01

McGuire, B. E., Morrison, T. G., Hermanns, N., Skovlund, S., Eldrup, E., Gagliardino, J., Kokoszka, A., Matthews, D., Pibernik-Okanovic, M., Rodriguez-Saldana, J., de Wit, M., & Snoek, F. J. (2010). Short-form measures of diabetes-related emotional distress: the Problem Areas in Diabetes Scale (PAID)-5 and PAID-1. *Diabetologia, 53*(1), 66-69. https://doi.org/10.1007/s00125-009-1559-5

Monaghan, M., Helgeson, V., & Wiebe, D. (2015). Type 1 diabetes in young adulthood. *Current Diabetes Reviews, 11*(4), 239-250. https://doi.org/10.2174/1573399811666150421114957

Monaghan, M., Hilliard, M., Sweenie, R., & Riekert, K. (2013). Transition readiness in adolescents and emerging adults with diabetes: the role of patient-provider communication. *Current Diabetes Reports, 13*(6), 900-908. https://doi.org/10.1007/s11892-013-0420-x

Peeters, M. A. C., Sattoe, J. N. T., Bronner, M. B., Bal, R. A., & van Staa, A. (2021). The added value of transition programs in Dutch diabetes care: A controlled evaluation study. *Journal of Pediatric Nursing*. Advance online publication. https://doi.org/10.1016/j.pedn.2021.08.004

Peimani, M., Nasli-Esfahani, E., & Sadeghi, R. (2020). Patients' perceptions of patient-provider communication and diabetes care: A systematic review of quantitative and qualitative studies. *Chronic Illness, 16*(1), 3-22. https://doi.org/10.1177/1742395318782378

Petkov, J., Harvey, P., & Battersby, M. (2010). The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Quality of Life Research, 19*(7), 1079-1085. https://doi.org/10.1007/s11136-010-9661-1

Sattoe, J. N. T., Bal, M. I., Roelofs, P. D. D. M., Bal, R. A., Miedema, H. S., & van Staa, A. L. (2015). Self-management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counseling, 98*(6), 704-715. https://doi.org/10.1016/j.pec.2015.03.004

Sattoe, J. N. T., Hilberink, S. R., van Staa, A. L., & Bal, R. A. (2014). Lagging behind or not? Four distinctive social participation patterns among young adults with chronic conditions. *Journal of Adolescent Health, 54*(4), 397-403. https://doi.org/10.1016/j.jadohealth.2013.09.017

Sattoe, J. N. T., Peeters, M. A. C., Hilberink, S. R., Ista, E., & van Staa, A. L. (2016). Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open, 6*(8), e011926. https://doi.org/10.1136/bmjopen-2016-011926

Skinner, T. C., Joensen, L., & Parkin, T. (2020). Twenty-five years of diabetes distress research. *Diabetic Medicine, 37*(3), 393-400. https://doi.org/10.1111/dme.14157

Snoek, F. J., Pouwer, F., Welch, G. W., & Polonsky, W. H. (2000). Diabetes-related emotional distress in Dutch and U.S. diabetic patients: cross-cultural validity of the problem areas in diabetes scale. *Diabetes Care, 23*(9), 1305-1309. https://doi.org/10.2337/diacare.23.9.1305

Stahl-Pehe, A., Glaubitz, L., Bachle, C., Lange, K., Castillo, K., Tonnies, T., Yossa, R., Holl, R. W., & Rosenbauer, J. (2019). Diabetes distress in young adults with early-onset type 1 diabetes and its prospective relationship with HbA1c and health status. *Diabetic Medicine, 36*(7), 836-846. https://doi.org/10.1111/dme.13931

Sturt, J., Dennick, K., Due-Christensen, M., & McCarthy, K. (2015). The detection and management of diabetes distress in people with type 1 diabetes. *Current Diabetes Reports, 15*(11), 101. https://doi.org/10.1007/s11892-015-0660-z

Tanenbaum, M. L., Hanes, S. J., Miller, K. M., Naranjo, D., Bensen, R., & Hood, K. K. (2017). Diabetes device use in adults with type 1 diabetes: Barriers to uptake and potential intervention targets. *Diabetes Care, 40*(2), 181-187. https://doi.org/10.2337/dc16-1536

Vallis, M., Willaing, I., & Holt, R. I. G. (2018). Emerging adulthood and type 1 diabetes: insights from the DAWN2 study. *Diabetic Medicine, 35*(2), 203-213. https://doi.org/10.1111/dme.13554

Van Staa, A. L., Peeters, M. A. C., & Sattoe, J. N. T. (2020). On Your Own Feet: A practical framework for improving transitional care and young people's self-management. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An international perspective on nurses' roles and interventions* (pp. 191-228). Springer Nature. https://doi.org/10.1007/978-3-030-23384-6

Van Staa, A. L., & Sattoe, J. N. T. (2014). Young adults' experiences and satisfaction with the transfer of care. *Journal of Adolescent Health, 55*(6), 796-803. https://doi.org/10.1016/j.jadohealth.2014.06.008

Varni, J. W., & Limbers, C. A. (2009). The PedsQL 4.0 generic core scales young adult version: feasibility, reliability and validity in a university student population. *Journal of Health Psychology, 14*(4), 611-622. https://doi.org/10.1177/1359105309103580

Weissberg-Benchell, J., Wolpert, H., & Anderson, B. J. (2007). Transitioning from pediatric to adult care: a new approach to the post-adolescent young person with type 1 diabetes. *Diabetes Care, 30*(10), 2441-2446. https://doi.org/10.2337/dc07-1249

Wentzell, K., Vessey, J. A., & Laffel, L. M. B. (2020). How do the challenges of emerging adulthood inform our understanding of diabetes distress? An integrative review. *Current Diabetes Reports, 20*(6), 21. https://doi.org/10.1007/s11892-020-01301-3

Wong, S. K. W., Smith, H. E., Chua, J. J. S., Griva, K., Cartwright, E. J., Soong, A. J., Dalan, R., & Tudor Car, L. (2020). Effectiveness of self-management interventions in young adults with type 1 and 2 diabetes: a systematic review and meta-analysis. *Diabetic Medicine, 37*(2), 229-241. https://doi.org/10.1111/dme.14190

Young, V., Eiser, C., Johnson, B., Brierley, S., Epton, T., Elliott, J., & Heller, S. (2013). Eating problems in adolescents with type 1 diabetes: a systematic review with meta-analysis. *Diabetic Medicine, 30*(2), 189-198. https://doi.org/10.1111/j.1464-5491.2012.03771.x

4

Active involvement of young people with T1DM during outpatient hospital consultations: opportunities and challenges in transitional care services

Mariëlle A.C. Peeters
Hielke G. de Haan
Roland A. Bal
AnneLoes van Staa
Jane N. T. Sattoe

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ABSTRACT

Objective

Little is known about active involvement of young people (YP) with type 1 diabetes (T1DM) in transitional care. This study aims to gain insight into patient-provider interactions during outpatient hospital consultations.

Methods

Semi-structured observations (*n* = 61) of outpatient consultations with YP with T1DM (15-25 years) treated in 12 hospitals in the Netherlands. The consultations concerned pediatric care (*n* = 23), adult care (*n* = 17), and joint consultations (*n* = 21). Thematic data analysis focused on whether professionals engaged in open, in-depth conversations; used motivational interviewing techniques; involved YP in shared decision-making; and addressed non-medical topics.

Results

Apart from some good examples, the healthcare professionals generally had difficulty interacting adequately with YP. They paid little attention to the YP's individual attitudes and priorities regarding disease management; non-medical topics remained generally underexposed. Conversations about daily life often remained shallow, as YP's cues were not taken up. Furthermore, decisions about personal and health-related goals were often not made together.

Conclusion

By adopting a more person-centered approach, professionals could empower young people to take an active role in their diabetes management.

Practice implications

Using a structured conversation model combined with a tool to encourage YP's agenda-setting and shared decision-making is recommended for more person-centered transitional care in T1DM.

INTRODUCTION

Type 1 diabetes mellitus (T1DM) is a complex metabolic disorder characterized by lifelong demands of self-care and motivation to adhere to stringent treatment recommendations (Dovey-Pearce et al., 2007). The health risks of glycemic variability can be immediate and life threatening and could lead to long-term complications. For young people with T1DM, adolescence is a critical period in their lives, as they have to learn looking after their own healthcare needs. They must take up responsibility for day-to-day self-management (e.g., daily insulin injections and dietary restrictions) as well as the logistical aspects of diabetes care (e.g., follow-up in healthcare services) in the context of competing developmental life demands (Agarwal et al., 2017; Bronner et al., 2020; Dovey-Pearce et al., 2007; Sandler & Garvey, 2019; Saxby et al., 2020). For example, they are expected to become more confident and autonomous in managing their own concerns, establish relationships, and get actively involved in decisions affecting them. At the same time, transfer from pediatric to adult diabetes care is imminent, with its risks of fragmentation of care and adverse clinical and psychological outcomes (Cameron et al., 2018; Dovey-Pearce et al., 2007; Sandler & Garvey, 2019; White et al., 2018). Diabetes management is not the highest priority of most young people, compared to achieving developmental milestones in other life domains (Vallis et al., 2018). The process of moving from being a child to become a young adult between 15 and 25 years – known as the transition phase – can, therefore, bring unwanted effects. Studies have reported, for example, decreased outpatient clinic attendance, higher loss to follow-up rates in specialist adult care services, elevated glycosylated hemoglobin (HbA1c) levels, and inadequate self-efficacy and self-management skills (Clements et al., 2016; Farrell et al., 2018; Van Staa et al., 2011; White et al., 2017).

Given the vulnerability of young people with T1DM in the transition phase, fostering commitment to continuity of diabetes care in this period is an important task for both pediatric and adult care services (Sandler & Garvey, 2019). Current consensus recommendations in diabetes care articulate the importance of providing developmentally appropriate healthcare and active involvement of young people (Cameron et al., 2018; Farre & McDonagh, 2017; Dutch Diabetes Federation, 2021; National Institute for Health and Care Excellence, 2016; Peters et al., 2011; Sandler & Garvey, 2019; Sawyer, 2003; Saxby et al., 2020). This concept recognizes that young people develop understanding, coping and self-management skills at varying rates and intervals irrespective of their age, under the influence of individual experiences, capabilities and motivation (Farre & McDonagh, 2017; Modi et al., 2012; Saxby et al., 2020). One should consider that various aspects of development may impact on other life transitions (e.g., moving away from the family home, education, career, social and intimate relationships) and vice versa (Dovey-Pearce et al., 2005; Farre & McDonagh, 2017; Sandler & Garvey, 2019).

Professionals involved in transitional care are in a core position to set up young people for a lifetime of positive health-related behaviors and relationships with healthcare services (Sandler & Garvey, 2019). They can help young persons to meet the expectations that the healthcare system places upon them by modelling appropriate relationships, helping them acquiring skills and knowledge, and overcoming barriers to become active participants in care (Dovey-Pearce et al., 2005). Consultations in transitional care are crucial for facilitating a young person's autonomy, empowerment, and self-management (Manalastas et al., 2020). These consultations allow healthcare professionals and young people to build a shared understanding of how diabetes care is integrated with what else is going on in these young people's daily lives and what priorities they set at that particular point in their development (Dovey-Pearce et al., 2007; Dovey-Pearce et al., 2005; Manalastas et al., 2020). Person-centered communication facilitates this by empowering a patient to take an active role and express needs, preferences, values and concerns (Castro et al., 2016; Epstein et al., 2005; Epstein & Street, 2011; Levinson, 2011). Previous studies confirmed that providing care from a holistic perspective, investing in building positive relationships with young people, and facilitating an active role of the patients in care are conducive to positive health outcomes (Dovey-Pearce et al., 2007; Hibbard, 2017; Sacks et al., 2017).

Thus, healthcare professionals will be better equipped to engage with the young people and provide person-centered care when they take into account the young people's developmental context. This will allow to explore how T1DM is impacting on a young person's roles and responsibilities in the broader sense (Dovey-Pearce et al., 2005). However, the uptake of recommendations on developmentally appropriate healthcare remains unknown. Research showed that healthcare professionals still spend much time and effort on disease management; i.e., achieving control, minimizing disease progression, and reducing complications (Boisen et al., 2016; Dovey-Pearce et al., 2007; Suris et al., 2009). They would do well to pay more attention to person-centered care around transition and transfer (Manalastas et al., 2020). Apart from some studies (Betz et al., 2013; Van Staa & On Your Own Feet Research Group, 2011) – which both conclude that young people want to be more involved in their care, but also call for more research – little is known about patient-provider interactions in the transition phase (15-25 years).

Hence, this study is unique in that it aims to gain insight into the interactions between young people with T1DM and healthcare professionals during outpatient hospital consultations in the years before and after transfer to adult care. Deeper understanding of these interactions could help unravel how active involvement of young people with T1DM in their care can be promoted, thereby limiting unfavorable health outcomes.

METHODS

Design and setting

Within the framework of a Netherlands-based mixed-methods research and quality improvement program named *'Better Transition in Type 1 Diabetes'* (2016-2018), we carried out semi-structured participant observations with an overt approach – in which the researcher's role is to undertake research with brief exposure to collect observation data (i.e., "observer-as-participant" approach) (Jones & Smith, 2017). The improvement program aimed to advance transitional diabetes care (Van Staa et al., 2020) by supporting healthcare professionals to improve their transitional care arrangements based on findings from the literature, mirror meetings between young people and healthcare professionals, and research. The current observational study focused on gaining more insight into the interactions between young people with T1DM and healthcare professionals during the transition from pediatric to adult care. Professionals' actions, intentions and beliefs were explored in relation to existing knowledge about those young people's needs and preferences. We applied the focused ethnographic method, which is a pragmatic form of ethnography that intends to collect focused data based on a preliminary formulated central question and, therefore, concentrates on specific problem areas (Bikker et al., 2017; Lundin et al., 2007). Results on the pre-defined topics can be obtained within a short time span in several settings simultaneously (Bikker et al., 2017; Lundin et al., 2007).

Participants

The study population consisted of providers of transitional care to young people with T1DM, working in multidisciplinary diabetes teams in twelve regional and teaching hospitals participating in the *Better Transition in Type 1 Diabetes* program. Their self-selection for participation indicated that they were motivated to improve their transitional care. The sample size was not predetermined, but we invited professionals from different backgrounds, resulting in participation of pediatricians, internists, pediatric diabetes nurses, diabetes nurse specialists, dieticians, and psychologists. We aimed to reach variation in settings by studying three different types of consultations: 1) consultations in pediatric care, 2) consultations in adult care, and 3) joint consultations with professionals from pediatric and adult care. All patients involved were aged between 15 and 25 years and had been diagnosed with T1DM. They were asked to provide consent for observation in advance.

Data collection

We observed outpatient hospital consultations in which healthcare professionals, these young people, and in a number of cases parents as well participated. Consultations in each setting were observed for about 4 hours in total. The participants were told that the overall aim of the research was to gain a better impression of the working ways, procedures and routines in the consultation room for this specific age group, which might help to further improve transitional care processes. The application of a semi-structured protocol ensured that all these aspects were included in the observations (Table 1) (Sattoe et al., 2016). The grey marked boxes in Table 1 indicate the focus of the current study.

The observer – who was present in the consultation room but maintained a neutral stance – took field notes and wrote down the findings in narratives on the same day to ensure that the spoken words during the consultations were well captured. In addition, notes of informal talks with the healthcare professionals, alongside the observations were included in the narratives (Pope, 2005). The different observers all had a background in health sciences or nursing and were trained prior to conducting the observations. We have no indication that their presence disturbed the interactions.

Table 1
Observation guide (based on the study protocol of Sattoe et al. (2016))

Topic	Aspects addressed
*Background information**	Hospital
	Department
	Setting (pediatric care/adult care/joint care)
	Healthcare professionals present (disciplines)
	Young person (gender, age, presence of family)
What is going on in general	Activities
	Actions
	Interventions used
	Reporting
Environment and atmosphere	Process
	Consultation room layout
	Attitudes and involvement of attendees (verbal and non-verbal)
Diabetes team	Attendees
	Task division and coordination
	Communication between healthcare professionals (verbal and non-verbal)
*Interaction**	Division of roles
	How the young person behaves and how he/she experiences his/her involvement
	Parent's role and attitude (if present)
	Healthcare professional's role and attitude
	Communication (verbal and non-verbal)
	Topics addressed (content, by whom, and how extensively)
	Questions asked and how they are responded to (both ways)
	Shared decision-making

* Main focus of the current study.

Data analysis

Data were analyzed by using a constant comparative analysis method (Strauss & Corbin, 1998). Observation narratives were coded thematically by two researchers (MP & HH), of whom HH is a young person with T1DM who was a youth panel member in the *Better Transition in Type 1 Diabetes* program and participated in the mirror conversations with healthcare professionals (Van Staa et al., 2020). For optimal interpretation of the observation narratives, HH participated in the current study as a co-researcher.

MP and HH started by reading the narratives several times independently and considering what the interactions and field notes implied. They wrote memos about the essence of what was happening in the consultation room, and these were discussed within the entire research team, in the light of the central research question (Dierckx de Casterlé et al., 2012). Leading themes deriving from this discussion were focused on interactions between healthcare professionals and young people, and how this affects patient engagement; i.e., whether the healthcare professional: 1) engaged in open and in-depth conversations; 2) addressed psychosocial and other non-medical issues; 3) used motivational interviewing techniques; and 4) involved the young people in shared decision-making. Based on these themes, MP and HH pulled the data together and classified the findings into two contradictory categories: preferable practices versus non-preferable practices (Table 2). The results were discussed until consensus was reached on the final distribution among the categories.

Table 2

Clarification of preferable versus non-preferable practices in patient-provider interactions

Theme	Preferable	Non-preferable
Person-centered care	Attention to individual attitudes and priorities in diabetes management; open and in-depth conversations	No/little attention to individual attitudes and priorities; shallow conversations
Psychosocial aspects	Both medical and non-medical aspects are addressed	Strict focus on medical aspects
Motivational interviewing	Follow-up on the replies and signals given by the patients (patients' cues[1])	No follow-up on the replies and signals given by the patients
Shared decision-making	Involving patients in decisions about their care and treatment	Decisions about the patient's care and treatment are predominantly made by the healthcare professional, without patient involvement

[1] Defined as: *"a hint, which might be an expression or signal, mostly verbal but also nonverbal, which indirectly indicates an issue of presumed importance for the patient and implies an emotion, worry or uncertainty that the patient would like to bring up, or a move to another topic, that should demand an exploration from the provider"* (Piccolo et al., 2005).

Ethics approval

The Ethics Review Board of Erasmus MC approved the original study protocol as well as the updated addendum (MEC-2014-246). Ethics approval was also obtained from all local hospital review boards. All participating young people and their parents (in case of minors) had received an information letter about the goals of the study, and they were ensured complete confidentiality and anonymity. All participants provided written informed consent for observation during their consultation(s). Pseudonyms were used in the observation narratives.

RESULTS

Background characteristics

Sixty-one outpatient hospital consultations with young people with T1DM in the transition phase, with a mean age of 19 years, were observed. The consultations lasted between 15 and 30 minutes and included consultations in pediatric care ($n = 23$), adult care ($n = 17$), and joint consultations ($n = 21$). Involved professionals were pediatricians ($n = 25$), internists ($n = 17$), pediatric diabetes nurses ($n = 27$), diabetes nurse specialists ($n = 21$), dieticians ($n = 8$), and psychologists ($n = 3$). Parents were present in 23 of the consultations (38%); mostly in pediatric care ($n = 11$) and during joint consultations ($n = 9$). Two patients brought their partners to the consultation and one came with her grandmother (all in pediatric care).

General impression

Analysis of the observation narratives revealed different patterns of interaction. Some healthcare professionals took a directive attitude towards the young people and actually started the conversation without first asking them a question (non-preferable practice), while others adopted a coaching approach and made the young people active partners in their own care (preferable practice). The distribution among preferable and non-preferable practices was somewhat skewed. In most cases, an alternation of preferable and non-preferable examples on the themes mentioned in Table 2 was observed. This pattern was alike in the pediatric and adult care settings, and was also found in the setting of joint consultations.

Box 1 and Box 2 present composed cases illustrating the differences in preferable versus non-preferable patient-provider interaction in the transition phase. Both cases are intended to give an impression of how a consultation can proceed, from the beginning to the end.

Box 1

Composed case of non-preferable interactions in the consultation room

An 18-year-old girl, Lynn, has just made the transfer from pediatric to adult care and visits the internist for the first time. She has brought her mother. Right after they enter the consultation room and sit down, the internist starts talking about high blood glucose levels. She says: *"The values have never been so bad before!"* No further questions are asked about how Lynn is doing in daily life activities. On the contrary, the internist continues the conversation by asking her what she has done recently to prevent the "*bad*" values. She is also wondering whether the pediatrician's recommendations have been taken up and what she wants to do about the high values herself. Lynn seems to be uninterested; she does not really care. She says she has never had a really bad day and that she is not going to change anything. Her mother, who did not say much until then, looks somewhat frustrated and states that she almost hopes that things will go wrong so that her daughter finally becomes more alert about her condition. Then, the internist starts to explain the importance of structural measurements for a type 1 diabetes patient. However, she does not try to unravel the reasons behind Lynn's behavior. She urges her to measure more frequently and advises her to do this at fixed times. *"Blood sugar should be tested at least twice a day,"* the internist declares. Lynn shows little concern; she still seems to be uninterested and pays little attention to the doctor's instructions. She says that she never experiences hypos and has not been admitted to hospital in recent years: *"I am fine with that"*. Even when the internist explains that the consequences of poor therapy adherence may not become apparent until years later, Lynn remains indifferent. One last time, the doctor stresses the importance of behavior change, after which the consultation is over.

Box 2

Composed case of preferable interactions in the consultation room

A 22-year young man, Alex, has a regular follow-up visit with his diabetes nurse specialist. He came alone and the conversation starts with small talk about his study, internship, and future career goals. Then, the nurse asks Alex what he would like to discuss today, upon which he says that he's concerned about his high blood glucose values. Together they look at the Alex's pump details and glucose results and discuss how Alex deals with his values at work, in the evenings and on the weekends. The nurse asks about Alex's preferences in dealing with his high values. She suggests more physical activity, but Alex says that he is too busy with work at the moment. Therefore, a new insulin is proposed, and the nurse explains how this works. Alex responds openly. The nurse asks whether it would be helpful to write down what she has just explained, and Alex agrees. The conversation continues about Alex's eating habits and, especially, the carbohydrates intake. Alex says that he sometimes eats cookies in the evening, but that he wants to adjust his eating pattern. The nurse tries to gauge what is feasible for him. She explains that in case he does not want an extra insulin injection, he could opt for reducing his carbohydrates intake. Alex finds this is a good idea. *"The cookies are just for the hunger pangs,"* he says, after which the nurse explains what could cause these hunger pangs and how to prevent this. The nurse summarizes what has just been discussed and performs some medical checks. Finally, she asks Alex if there are any questions left and reminds him that it is always possible to contact her between the regular follow-up consultations that take place every six months, for example to adjust his insulin regimen.

Person-centered care

The central focus of many consultations appeared to lie on monitoring young people's diabetes management, so as to ensure that they follow the treatment recommendations. At the same time, the healthcare professionals often paid little attention to the young person's individual attitudes and priorities regarding his or her diabetes management (Box 1). It is evident that patients' priority given to the management of blood sugar levels widely differs. Although the importance of controlling values and preventing outliers is widely supported by both diabetes healthcare professionals and patients, it is not always the main priority in a young person's daily life. An 18-year-old patient illustrated this: *"It does not interest me that my values are high as long as I am feeling good."* General instructions and treatment recommendations did not seem fit into personal life goals of these patients and, therefore, did not make any sense to them (Table 3). In such cases, a more profound exploration of how patients dealt with the diabetes seems warranted, but such exploration was not often observed during the consultations.

Psychosocial aspects

To obtain a comprehensive view of the young patients, it is important for healthcare professionals to pay attention to psychosocial aspects such as school, work, social and intimate relationships, and leisure activities. For example, a 19-year-old woman asked her internist for advice on alcohol consumption, as this interferes with blood sugar levels. Together they explored the risks and a suitable solution (Table 3). Furthermore, showing interest in one's personal life instead of being asked questions about the diabetes at the beginning of a consultation can help to make the patient feel comfortable and to establish partnership (Box 2). Observations like these, however, were relatively exceptional. Psychosocial themes were often not addressed during the observed consultations.

Follow-up on the cues given

Although psychosocial aspects were not always addressed, most of the professionals did ask the young person how he/she was doing. However, these conversations often remained shallow, as professionals often did not follow-up on the cues given by the young person. Thus, the young person was generally not supported in integrating structural diabetes management into daily life. A more preferable situation is, for example, the conversation between an internist and a young adult, during which possible explanations for the patient's high HbA1c values were explored together (Table 3).

Shared decision-making

The young people's expected involvement in shared decision-making was often limited due to inadequate follow-up. Some professionals even stressed this explicitly, such as an internist did during his first contact with the patient in adult care: *"I will be a strict coach, I expect you to follow-up on my treatment recommendations as much as possible."* A more preferable practice in the light of shared decision-making was the conversation between a pediatrician and a patient about blood glucose monitoring. The pediatrician did not only provide information and advice, but also asked the patient about his own ideas to prevent outliers. The patient indicated that he should count carbohydrates better, upon which the pediatrician specifically asked how he was going to do this. In this way, the treatment decisions were not only supported, but even suggested by the young person himself.

Table 3
Examples of preferable versus non-preferable interaction between young people and healthcare professionals

Theme	Preferable	Non-preferable
Person-centered care	A patient visits her diabetes nurse in adult care for the first time after transfer. The nurse introduces herself and then asks the patient what she does in daily life; school, hobbies, holidays and sports are discussed. They talk about when the diabetes was diagnosed and how she has dealt with it in recent years. The patient seems to feel comfortable and continues to signal that it does not really interest her that her values are not good, as long as she feels good. They discuss about what the patient is doing about her diabetes so far. (F; 18 | AC*; nurse)	Directly at the start of the consultation, a dietician tells her patient: "A HbA1c of 60, last time it was 53. That's really high for someone who doesn't eat carbohydrates." Then, she asks the patient to take a look at his recent values and starts explaining about the working of glucose, fructose, and granulated sugar. (M; 22 | AC; dietician)
Psycho-social aspects	A patient asks her internist about drinking alcohol and how to prevent hypoglycemia. The internist emphasizes that she should be open about what and when she's consuming. Then, the internist can see when and how much her blood sugar levels drop, and then give adequate advice. The internist explains: "Of course it is better not to drink or to drink small amounts, but if you want to do so, we must discuss how this can be done as safely as possible." (F; 19 | AC; internist)	"How are you?" asks the diabetes nurse, who meets the patient for the first time in adult care. "Could be better," he answers. The nurse does not follow-up on this, but talks about adult care: "Consultations will be shorter, less frequent, and probably less personal here." Then the conversation continues with discussing medical aspects such as blood sugar levels, hypoglycemia, and measurements. Finally, she asks whether the patient smokes, drinks alcohol or uses drugs, and when the last eye and foot checks were performed. She writes everything down and, after asking the patient if he has any questions, the nurses end the consultation. (M; 22 | JC*; pediatric nurse & adult care nurse)
Follow-up on patients' cues	A patient shares his struggles with measuring, especially in combination with sports and work. The internist tries to gain more insight into this by asking: "What do you find difficult about it; do you mind that people see you measuring?" The patient answers that the problem is that he does not always remember to measure, after which the internist asks how he can help with this. He emphasizes that the young adult should do it on his own, but that he can take on a coaching and guiding role. (M; 19 | JC; pediatrician & internist)	A nurse asks his patient how often she measures her blood glucose levels, upon which the patient says: "That differs, I actually do not know." It turns out that the patient sometimes does not measure for a whole week. The nurse reports this in the patient's medical record but pays no further attention. He only asks: "Are you going to try to do better from now?" (F; 20 | AC; nurse)
Shared decision-making	During a joint consultation with two diabetes nurse specialists from pediatric and adult care, respectively, the conversation turns to the patient's wish to participate in Ramadan. The adult care nurse strongly discourages this, because of the high risks involved for people with T1DM. The pediatric nurse seems to be more open to the patient's values and religious considerations, although she recognizes the associated risks. She tries to think about solutions and suggests looking for alternatives that give a satisfying sense of participating; e.g., shorter fasting times or preparing different meals. In this way, the pediatric nurse tries to follow-up on the expressed wishes of the young person and involved her in shared decision-making. (F; 18 | JC; pediatric nurse & adult care nurse)	A young person visits the pediatrician for a regular follow-up consultation, together with his father who still plays a big role in his diabetes management. "Let us see how you can become more independent," says the pediatrician to the young person. She instructs him to measure every time before eating and before going to bed from now on. "That will give dad a better night's sleep," the pediatrician says. "And do not forget to send us your data more often. So, go for it!" (M; 17 | PC*; pediatrician)

[*] PC = pediatric care; AC = adult care; JC = joint care.

DISCUSSION AND CONCLUSION

Discussion

Our study revealed a wide variety in interactions between young people with T1DM and healthcare professionals during outpatient hospital consultations in the transition phase. We certainly observed good practices, but nevertheless also a variety of non-preferable practices, indicating that some healthcare professionals had difficulty to adequately interact with these young patients. In fact, we noticed that most of the observed consultations presented examples of both preferable and non-preferable practices. This would imply that there was often still room for improvement to actually get young people involved. Furthermore, parents' influential role in young people's health and development – and so the importance of appropriate parental support in transitional care – should not be underestimated (Heath et al., 2017). This was not the focus of our study, but future research into the parents' role during transition is recommended.

It is widely known that healthcare professionals treating adolescents and young adults do not always acknowledge and address their patients' development and health-related issues (Boisen et al., 2016; Van Staa et al., 2020). Our observations confirmed this medical focus in transitional care for young persons with T1DM, and revealed that the healthcare professionals often inadequately responded to the patient's replies and cues. Although routine attention for psychosocial aspects is identified as a core element in transitional care, these aspects are still not always covered in practice (Stinson et al., 2014; Van Staa et al., 2020). There even seems to be a significant discrepancy between professionals and young people regarding the discussion of psychosocial issues, raising the issue of the efficacy of the communication strategies being employed by professionals (Boisen et al., 2016).

In general, patients appear to assess the quality of their care largely through the perceived quality of the communication process; i.e., whether professionals listen to them carefully, understand their needs and preferences, and provide clear and sufficient information (Levinson, 2011). Especially in the care for young people with chronic conditions, a person-centered and holistic approach seems essential to support them in their transition towards independence, empowerment, and involvement (Van Staa et al., 2020). This requires professionals' attention to go beyond medical aspects, also addressing developmental and psychosocial challenges, so that these young patients can make choices in their care that best fit their individual circumstances (Levinson, 2011; Van Staa et al., 2020). Additionally, there is sufficient evidence for the importance of effective communication for patient outcomes (Dovey-Pearce et al., 2007; Hibbard, 2017; Sacks et al., 2017), also specifically for young people with diabetes (Dickinson et al., 2017; Manalastas et al., 2020).

Experienced gaps in transitional care following the principles of developmentally appropriate care, may be explained by the notion of epistemic injustice as a common, possibly pervasive feature of healthcare (Carel & Kidd, 2014). Based on this notion, young persons' experiences and interpretations may be heard and considered by professionals, but judged irrelevant or insufficiently articulated, as they do not always recognize that taking their young patients seriously is of potential therapeutic value. As a consequence, the improvement of communication skills as part of professionals' continuous learning process is not self-evident. Many professionals assume they are already performing well in this area and, consequently, focus on the acquisition of new technical information, insights and skills (Levinson, 2011). Furthermore, they are concerned that listening to patients' worries and addressing their individual difficulties and needs requires too much time, which they do not have because of the pressure to see as many patients as possible in a day (Levinson, 2011).

Another important aspect, specifically in diabetes care, are choices in language. Person-first, strengths-based, and empowering language is expected to improve patient-provider interaction and enhance a patient's motivation, health, and well-being (Dickinson et al., 2017). In contrast, words or phrases that have potentially negative connotations can contribute to stress and feelings of shame and judgement in T1DM patients – e.g. 'nonadherent', 'poorly controlled' and 'bad values' – and our observations confirm that this still occurs in daily practice.

To give healthcare professionals more insight into the potential therapeutic value and needed improvements of the transition and transfer experiences, mirror meetings with young people are highly recommended (De Wit et al., 2008). In the *Better Transition in Type 1 Diabetes* program, such group discussions with healthcare professionals served as an eye opener for diabetes teams on the different aspects of interaction (Table 2), and encouraged them to listen to young people's voices (Van Staa et al., 2020). Concrete preferences or recommendations appearing from these conversations, such as choices in language, are relatively easy to apply.

In addition to the individual factors associated with person-centered care, Luxford et al. (2011) argue for adopting a strategic organization-wide approach for successfully advancing person-centered care with a focus on patients as 'customers' of the healthcare service. It appeared from our study that the provision of person-centered care and the use of effective communication strategies still seems challenging for professionals from all diabetes teams, regardless of their organization of transitional care or whether they were working in the pediatric or the adult setting. Also in joint settings, healthcare professionals were still searching for best practices, which could be a consequence of poor collaboration and communication between pediatric and adult healthcare professionals (Zhou et al., 2016). Professionals sometimes appeared to feel a bit uncomfortable as such a joint setting is also new for them.

Implementing a structured conversation model, such as the diabetes consultation model of Rutten et al. (2018), which is supported by the Dutch Diabetes Federation (2018), could perhaps help improve interactions between young people and healthcare professionals. Figure 1 shows how this stepped model fits with the themes that emerged from our observations. In step 1, the diabetes healthcare professional addresses both medical and non-medical aspects with attention to individual attitudes and priorities of the young person. This means that the choice of topics to be discussed is not protocolled, but that the choice depends on the patient's actual situation and agenda-setting. In step 2, personal and health related goals are set together, where motivational interviewing techniques can be useful. In step 3, shared decisions related to personalized health goals and treatment options are made. Lastly, the consultation is completed in step 4 with an assessment of the experienced professional support. We hardly observed this step in our study, although it is considered important for follow-up. The model seems well applicable and is expected to result in more patient involvement including shared decision-making, which is appreciated from a patient perspective (Dutch Diabetes Federation, 2018; Rutten et al., 2018). In the end, a more person-centered approach is expected to facilitate patient empowerment and self-management (Castro et al., 2016). A possibly useful tool to bring the model into practice is the Self-Management Web, which facilitates an open and patient-led conversation about various life areas (Beck et al., 2019). The Self-Management Web ensures a holistic view and encourages shared decision-making between patients and healthcare professionals; the patient is in charge of selecting an area to work on if support is desired.

Strengths and limitations

A strength of this study is the participatory observational design that provided deep insights into patient-provider interactions during outpatient consultations in the transition phase. Furthermore, the study was conducted among members of fifteen diabetes teams in various outpatient settings (pediatric care, adult care, and joint care) and across a wide range of disciplines. Unfortunately, we could not make systematic comparisons

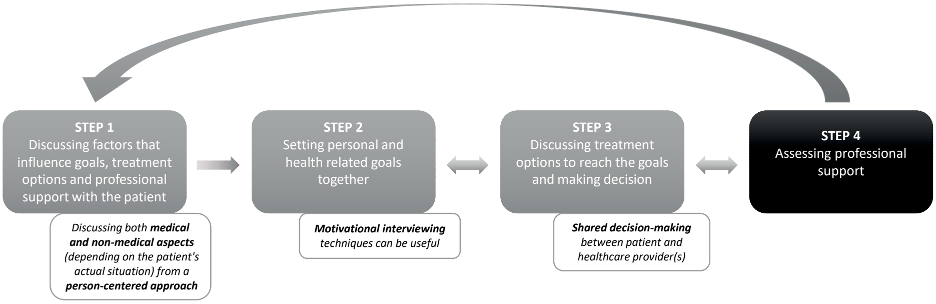

Figure 1. Structured conversation model of Rutten et al. (2018)

among these disciplines as they were not equally distributed in our data collection. Moreover, healthcare professionals were present in many different combinations during consultations. Apart from that, our study did not reveal any trends in performance, neither by type of professional (i.e., doctor, nurse, or allied healthcare professional) nor by setting (i.e., pediatric or adult care). Unique in our study was the participation of a young person with T1DM in our research team, which enabled to achieve optimal interpretation of the observation narratives.

Our study results were limited by its cross-sectional design, which could only provide a momentary snapshot of the interactions between young people with T1DM and their healthcare professionals in the transition phase. Longitudinal studies are required to facilitate a developmental perspective in research by gaining insight into follow-up and interactions over time; e.g., how personal and health related goals and decisions have been evaluated (Van Staa, 2012). Furthermore, since the observation narratives contained only limited direct quotations, we could not in all cases link findings to the actual data. Nevertheless, we preferred a participatory observational design above video recordings, because we wanted to disturb the natural process of interactions in the consultation room as little as possible. After all, it is not uncommon for others to be present during a consultation.

Conclusion

Healthcare professionals treating young people with T1DM in the transition phase are challenged to empower these young people to take an active role in their own treatment, by exploring their individual norms, values and priorities regarding the management of T1DM in daily life more in depth. Deeper understanding of attitudes and motivation may enable healthcare professionals to tailor self-management support and treatment recommendations. By adopting a more person-centered approach, young people are expected to become owners of their diabetes management and care. This might help to limit the risks of unfavorable health outcomes, thereby improving their future prospects.

Practice implications

First of all, encouragement of active patient involvement on a higher organizational level with a culture supportive of change and learning, can help diabetes teams to make their transitional care service more person-centered. On the healthcare team level, the use of a structured conversation model to support interactions between young people with T1DM and healthcare professionals could possibly contribute to more person-centered transitional care and is, therefore, highly recommended. Combined with the use of the Self-Management Web to facilitate patients' agenda setting and shared decision-making, the application of such a conversation model seems promising in advancing the quality of transitional care for young people with T1DM. In addition, systematic attention for judgmental versus non-judgmental language choices is required. Mirror meetings could be a valuable tool to reveal such hidden realities among young people with T1DM.

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REFERENCES

Agarwal, S., Raymond, J. K., Schutta, M. H., Cardillo, S., Miller, V. A., & Long, J. A. (2017). An adult health care-based pediatric to adult transition program for emerging adults with type 1 diabetes. *Diabetes Educator, 43*(1), 87-96. https://doi.org/10.1177/0145721716677098

Beck, D., Been-Dahmen, J., Peeters, M., Grijpma, J. W., van der Stege, H., Tielen, M., van Buren, M., Weimar, W., Ista, E., Massey, E., & van Staa, A. (2019). A nurse-led self-management support intervention (ZENN) for kidney transplant recipients using intervention mapping: Protocol for a mixed-methods feasibility study. *JMIR Research Protocols, 8*(3), e11856. https://doi.org/10.2196/11856

Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook, 61*(5), 311-336. https://doi.org/10.1016/j.outlook.2013.01.008

Bikker, A. P., Atherton, H., Brant, H., Porqueddu, T., Campbell, J. L., Gibson, A., McKinstry, B., Salisbury, C., & Ziebland, S. (2017). Conducting a team-based multi-sited focused ethnography in primary care. *BMC Medical Research Methodology, 17*(1), 139. https://doi.org/10.1186/s12874-017-0422-5

Boisen, K. A., Hertz, P. G., Blix, C., & Teilmann, G. (2016). Is HEADS in our heads? Health risk behavior is not routinely discussed with young people with chronic conditions. *International Journal of Adolescent Medicine and Health, 28*(4), 429-435. https://doi.org/10.1515/ijamh-2015-0015

Bronner, M. B., Peeters, M. A. C., Sattoe, J. N. T., & van Staa, A. (2020). The impact of type 1 diabetes on young adults' health-related quality of life. *Health and Quality of Life Outcomes, 18*(1), 137. https://doi.org/10.1186/s12955-020-01370-8

Cameron, F. J., Garvey, K., Hood, K. K., Acerini, C. L., & Codner, E. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Diabetes in adolescence. *Pediatric Diabetes, 19*(Suppl. 27), 250-261. https://doi.org/10.1111/pedi.12702

Carel, H., & Kidd, I. J. (2014). Epistemic injustice in healthcare: a philosophial analysis. *Medicine, Health Care, and Philosophy, 17*(4), 529-540. https://doi.org/10.1007/s11019-014-9560-2

Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling, 99*(12), 1923-1939. https://doi.org/10.1016/j.pec.2016.07.026

Clements, M. A., Foster, N. C., Maahs, D. M., Schatz, D. A., Olson, B. A., Tsalikian, E., Lee, J. M., Burt-Solorzano, C. M., Tamborlane, W. V., Chen, V., Miller, K. M., Beck, R. W., & T1D Exhange Clinic Network. (2016). Hemoglobin A1c (HbA1c) changes over time among adolescent and young adult participants in the T1D exchange clinic registry. *Pediatric Diabetes, 17*(5), 327-336. https://doi.org/10.1111/pedi.12295

De Wit, F., Mul, M., & Bal, R. A. (2008). Leren van patiënten: Spiegelbijeenkomsten leveren zorgverleners nuttige feedback [Learning from patients: Mirror meeting provide useful feedback to healthcare professionals]. *Medisch Contact, 63*(23), 990-993.

Dickinson, J. K., Guzman, S. J., Maryniuk, M. D., O'Brian, C. A., Kadohiro, J. K., Jackson, R. A., D'Hondt, N., Montgomery, B., Close, K. L., & Funnell, M. M. (2017). The use of language in diabetes care and education. *Diabetes Care, 40*(12), 1790-1799. https://doi.org/10.2337/dci17-0041

Dierckx de Casterlé, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: a guide for qualitative data analysis. *International Journal of Nursing Studies, 49*(3), 360-371. https://doi.org/10.1016/j.ijnurstu.2011.09.012

Dovey-Pearce, G., Doherty, Y., & May, C. (2007). The influence of diabetes upon adolescent and young adult development: a qualitative study. *British Journal of Health Psychology, 12*(Pt 1), 75-91. https://doi.org/10.1348/135910706X98317

Dovey-Pearce, G., Hurrell, R., May, C., Walker, C., & Doherty, Y. (2005). Young adults' (16-25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health & Social Care in the Community, 13*(5), 409-419. https://doi.org/10.1111/j.1365-2524.2005.00577.x

Dutch Diabetes Federation. (2018, Sept 6). *NDF Gespreksmodel Personalized DiabetesCare bruikbaar en toepasbaar [Dutch Diabetes Federation Conversation Model Personalized DiabetesCare feasible and applicable]*. https://diabetesfederatie.nl/nieuwsberichten/675-ndf-gespreksmodel-personalized-diabetescare-bruikbaar-en-toepasbaar

Dutch Diabetes Federation. (2021, March 12). *Zorgstandaard Diabetes [Healthcare Standard Diabetes]*. https://www.zorgstandaarddiabetes.nl/type-1/kind/inhoud/behandeling/transitiefase/

Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., & Duberstein, P. R. (2005). Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Social Science & Medicine, 61*(7), 1516-1528. https://doi.org/10.1016/j.socscimed.2005.02.001

Epstein, R. M., & Street, R. L., Jr. (2011). The values and value of patient-centered care. *Annals of Family Medicine, 9*(2), 100-103. https://doi.org/10.1370/afm.1239

Farre, A., & McDonagh, J. E. (2017). Helping health services to meet the needs of young people with chronic conditions: towards a developmental model for transition. *Healthcare (Basel), 5*(4). https://doi.org/10.3390/healthcare5040077

Farrell, K., Fernandez, R., Salamonson, Y., Griffiths, R., & Holmes-Walker, D. J. (2018). Health outcomes for youth with type 1 diabetes at 18months and 30months post transition from pediatric to adult care. *Diabetes Research and Clinical Practice, 139*, 163-169. https://doi.org/10.1016/j.diabres.2018.03.013

Heath, G., Farre, A., & Shaw, K. (2017). Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling, 100*(1), 76-92. https://doi.org/10.1016/j.pec.2016.08.011

Hibbard, J. H. (2017). Commentary on "Refining consumer engagement definitions and strategies". *Journal of Ambulatory Care Management, 40*(4), 265-269. https://doi.org/10.1097/JAC.0000000000000217

Jones, J., & Smith, J. (2017). Ethnography: challenges and opportunities. *Evidence-Based Nursing, 20*(4), 98-100. https://doi.org/10.1136/eb-2017-102786

Levinson, W. (2011). Patient-centred communication: a sophisticated procedure. *BMJ Quality & Safety, 20*(10), 823-825. https://doi.org/10.1136/bmjqs-2011-000323

Lundin, C. S., Danielson, E., & Ohrn, I. (2007). Handling the transition of adolescents with diabetes: participant observations and interviews with care providers in paediatric and adult diabetes outpatient clinics. *International Journal of Integrated Care, 7*, e05.

Luxford, K., Safran, D. G., & Delbanco, T. (2011). Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Internationl Journal for Quality in Health Care, 23*(5), 510-515. https://doi.org/10.1093/intqhc/mzr024

Manalastas, G., Noble, L. M., Viney, R., & Griffin, A. E. (2020). Patient autonomy in the consultation: How signalling structure can facilitate patient-centred care. *Patient Education and Counseling, 103*(11), 2269-2279. https://doi.org/10.1016/j.pec.2020.05.020

Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., Guilfoyle, S. M., Gray, W. N., & Drotar, D. (2012). Pediatric self-management: a framework for research, practice, and policy. *Pediatrics, 129*(2), e473-485. https://doi.org/10.1542/peds.2011-1635

National Institute for Health and Care Excellence. (2016). *Transition from children's to adults' services for young people using health or social care services, Guideline 43.* NICE.

Peters, A., Laffel, L., & the American Diabetes Association Transitions Working Group. (2011). Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). *Diabetes Care, 34*(11), 2477-2485. https://doi.org/10.2337/dc11-1723

Piccolo, L. D., Goss, C., & Zimmermann, C. (2005). The third meeting of the Verona Network on sequence analysis. finding common grounds in defining patient cues and concerns and the appropriateness of provider responses. *Patient Education and Counseling, 57*(2), 241-244. https://doi.org/10.1016/j.pec.2005.03.003

Pope, C. (2005). Conducting ethnography in medical settings. *Medical Education, 39*(12), 1180-1187. https://doi.org/10.1111/j.1365-2929.2005.02330.x

Rutten, G., van Vugt, H. A., de Weerdt, I., & de Koning, E. (2018). Implementation of a structured diabetes consultation model to facilitate a person-centered approach: Results from a nationwide Dutch study. *Diabetes Care, 41*(4), 688-695. https://doi.org/10.2337/dc17-1194

Sacks, R. M., Greene, J., Hibbard, J., Overton, V., & Parrotta, C. D. (2017). Does patient activation predict the course of type 2 diabetes? A longitudinal study. *Patient Education and Counseling, 100*(7), 1268-1275. https://doi.org/10.1016/j.pec.2017.01.014

Sandler, C. N., & Garvey, K. C. (2019). A practice in maturation: Current perspectives on the transition from pediatric to adult care for young adults with diabetes. *Current Diabetes Reports, 19*(11), 126. https://doi.org/10.1007/s11892-019-1247-x

Sattoe, J. N. T., Peeters, M. A. C., Hilberink, S. R., Ista, E., & van Staa, A. L. (2016). Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open, 6*(8), e011926. https://doi.org/10.1136/bmjopen-2016-011926

Sawyer, S. M. (2003). Developmentally appropriate healthcare for young people with chronic illness: questions of philosophy, policy, and practice. *Pediatric Pulmonology, 36*(5), 363-365. https://doi.org/10.1002/ppul.10369

Saxby, N., Beggs, S., Kariyawasam, N., Battersby, M., & Lawn, S. (2020). Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate chronic condition self-management in children? A systematic review. *Chronic Illness, 16*(4), 239-252. https://doi.org/10.1177/1742395318799844

Stinson, J., Kohut, S. A., Spiegel, L., White, M., Gill, N., Colbourne, G., Sigurdson, S., Duffy, K. W., Tucker, L., Stringer, E., Hazel, B., Hochman, J., Reiss, J., & Kaufman, M. (2014). A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *International Journal of Adolescent Medicine and Health, 26*(2), 159-174. https://doi.org/10.1515/ijamh-2013-0512

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Sage Publications.

Suris, J. C., Akre, C., & Rutishauser, C. (2009). How adult specialists deal with the principles of a successful transition. *Journal of Adolescent Health, 45*(6), 551-555. https://doi.org/10.1016/j.jadohealth.2009.05.011

Vallis, M., Willaing, I., & Holt, R. I. G. (2018). Emerging adulthood and type 1 diabetes: insights from the DAWN2 study. *Diabetic Medicine, 35*(2), 203-213. https://doi.org/10.1111/dme.13554

Van Staa, A. L. (2012). *On Your Own Feet: Adolescents with chronic conditions and their preferences and competencies for care.* Erasmus University Rotterdam.

Van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development, 37*(6), 821-832. https://doi.org/10.1111/j.1365-2214.2011.01261.x

Van Staa, A. L., & On Your Own Feet Research Group. (2011). Unraveling triadic communication in hospital consultations with adolescents with chronic conditions: the added value of mixed methods research. *Patient Education and Counseling, 82*(3), 455-464. https://doi.org/10.1016/j.pec.2010.12.001

Van Staa, A. L., Peeters, M. A. C., & Sattoe, J. N. T. (2020). On Your Own Feet: A practical framework for improving transitional care and young people's self-management. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An international perspective on nurses' roles and interventions* (pp. 191-228). Springer Nature. https://doi.org/10.1007/978-3-030-23384-6

White, M., O'Connell, M. A., & Cameron, F. J. (2017). Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *Lancet Child & Adolescent Health, 1*(4), 274-283. https://doi.org/10.1016/S2352-4642(17)30089-5

White, P. H., Cooley, W. C., Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 142*(5). https://doi.org/10.1542/peds.2018-2587

Zhou, H., Roberts, P., Dhaliwal, S., & Della, P. (2016). Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services - an integrative review. *Journal of Clinical Nursing, 25*(21-22), 3113-3130. H

PART II

Evaluating transitional care: a complex matter

5

Evaluating outpatient transition clinics: a mixed-methods study protocol

Jane N.T. Sattoe
Mariëlle A.C. Peeters
Sander R. Hilberink
Erwin Ista
AnneLoes van Staa

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ABSTRACT

Introduction

To support young people in their transition to adulthood and transfer to adult care, a number of interventions have been developed. One particularly important intervention is the transition clinic (TC), where pediatric and adult providers collaborate. TCs are often advocated as best practices in transition care for young people with chronic conditions, but little is known about TC models and effects. The proposed study aims to gain insight into the added value of a TC compared with usual care (without a TC).

Methods and analysis

We propose a mixed-methods study with a retrospective controlled design consisting of semi-structured interviews among healthcare professionals, observations of consultations with young people, chart reviews of young people transferred 2–4 years prior to data collection and questionnaires among the young people included in the chart reviews. Qualitative data will be analyzed through thematic analysis and results will provide insights into structures and daily routines of TCs, and experienced barriers and facilitators in transitional care. Quantitatively, within-group differences on clinical outcomes and healthcare use will be studied over the four measurement moments. Subsequently, comparisons will be made between intervention and control groups on all outcomes at all measurement moments. Primary outcomes are 'no-show after transfer' (process outcome) and 'experiences and satisfaction with the transfer' (patient-reported outcome). Secondary outcomes consider clinical outcomes, healthcare usage, self-management outcomes and perceived quality of care.

Ethics

The Medical Ethical Committee of the Erasmus Medical Center approved the study protocol (MEC-2014-246).

Dissemination

Study results will be disseminated through peer-reviewed journals and conferences. The study started in September 2014 and will continue until December 2016. The same study design will be used in a national study in 20 diabetes settings (2016–2018).

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The proposed study includes a controlled mixed-methods evaluation of process indicators, clinical and patient-reported outcomes. As such, it provides insights into the application and effects of a complex intervention.
- Based on the criteria of successful transition and an extensive literature research, we link possible outcomes to existing theory about the transition of young people with chronic conditions. This contributes to the development of a relevant evaluation framework for transitional care. In addition, we provide an approach that allows for comparisons between studies and even between disease groups.
- Some challenges associated with the design include the selection of control departments, response rates to the questionnaire and organizational issues around the chart reviews, particularly in case of transfer to other hospitals.

BACKGROUND

Successful transfer from pediatric to adult healthcare services is a crucial aspect of high-quality care, but also forms a major challenge for young people with chronic conditions (Viner, 2008). The gap between pediatric and adult healthcare services appears to be large (Van Staa et al., 2011). Studies showed that up to 25% of the young adults that have been transferred to adult healthcare services do not regularly attend follow-up visits in the hospital (Downing et al., 2013; Van Staa & Sattoe, 2014). Loss to follow-up may be a result of differences between pediatric and adult healthcare settings and a poor preparation for the transfer, but may also be affected by changes in social relationships and shifting roles (Fegran et al., 2014). While adolescents become increasingly responsible for their own health, they generally show poor treatment adherence, which puts them at risk for poor health outcomes (Sawyer et al., 2007) (e.g., deterioration of lung function in cystic fibrosis (CF)). They value being seen as a competent partner in care, but too often feel that they are not included in important decisions about their own lives (Betz et al., 2013; Fegran et al., 2014; Lugasi et al., 2011; Van Staa et al., 2011).

To support young people in their transition to adulthood and transfer to adult care, a number of interventions have been developed and implemented (Chu et al., 2015; Crowley et al., 2011; Sattoe et al., 2015). One particularly relevant intervention is the transition clinic (TC). TCs are often advocated as best practice in transition care for young people with chronic conditions (Camfield et al., 2012; Crowley et al., 2011; Davies & Jenkins, 2003; Viner, 1999). Although there is no common definition of a TC, the core principle is that professionals from pediatric and adult care are involved in the delivery of outpatient care in preparation for the upcoming transfer (Carrizosa et al., 2014; Crowley et al., 2011). While some TCs are focused on organizing a smooth transfer to adult care and on good clinical outcomes (Betz & Redcay, 2002), others have a broader focus including the transition to adulthood and associated psychosocial outcomes (Falcini & Nacci, 2007). Daily routines and used protocols differ considerably between TCs (Iyer & Appleton, 2013), and current literature lacks systematic descriptions of TCs' structures and working mechanisms (Crowley et al., 2011). In addition, little is known about the effects of this intervention. A review in 2011 identified four evaluation studies of TCs, but these were all diabetes oriented (Crowley et al., 2011). Although these studies found positive short-term health outcomes (better glycosylated hemoglobin (Hb1Ac) levels and less short-term complications) and follow-up rates, there is currently no evidence for (long-term) outcomes of TCs with regard to health outcomes, healthcare use, self-management and psychosocial functioning of young adults. Moreover, recent studies of TCs in other diagnostic groups did not include a controlled pre-post outcome evaluation (Cole et al., 2015; Geerlings et al., 2016; Gravelle et al., 2015; Jensen et al., 2015; Maturo et al., 2015; McQuillan et al., 2015; Mistry et al., 2015; Shalaby et al., 2015; Stringer et al., 2015; Timberlake et al., 2015; Tong et al., 2015; Uday et al., 2015), and as such could not provide sound evidence on outcomes of TCs.

In general, there is inconclusive evidence considering the effectiveness of transitional care. Also, although a large part of transition is generic and not disease specific, comparisons between disease groups and more general evaluations of interventions are rarely conducted. As pediatric or young adult diagnostic groups are often small, including more groups could be beneficial for effectiveness research. Moreover, a non-categorical approach would allow professionals of different disciplines to learn from each other (Sattoe et al., 2015). The recently formulated consensus indicators for successful transition (Surís & Akré, 2015) could be helpful for such comparisons and more generic evaluations. Furthermore, little information is provided about important elements of interventions used in transitional care (Chu et al., 2015; Watson et al., 2011), and there is still little research into young people's and healthcare professionals' experiences with such interventions (Nakhla et al., 2008; Prior et al., 2014; Van Staa & Sattoe, 2014).

METHODS AND ANALYSIS

Study aim

The proposed study evaluates the experiences with and outcomes of TCs. It aims to gain insight into the added value of a TC compared with usual care (without a TC) along the following research questions:

1. How do structures and daily routines differ between TCs and usual care?
2. What are healthcare professionals' experienced barriers and facilitators for the organization of a TC?
3. What are the differences in clinical outcomes and healthcare use of young people who were seen at a TC and those that received usual care?
4. What are the differences in self-management outcomes, experiences and satisfaction with the transfer to adult care and perceived quality of care of young people who were seen at a TC and those that received usual care?
5. What are the differences between TCs and usual care with respect to the criteria for successful transition? (Surís & Akré, 2015)

Study design

A TC is a complex intervention that cannot easily be evaluated through a randomized controlled trial. It is important to explore how complex interventions form a part of and work within their contexts, so that possible working mechanisms could be revealed and the eventual outcomes could be attributed to the intervention (Øvretveit et al., 2011). Therefore, the use of a mixed-methods design is advocated in the evaluation of complex interventions (Barlow et al., 2002; Tariq & Woodman, 2013). To answer the research questions, a mixed-methods study with a retrospective controlled design will be used. The TC will be compared with usual care, that is, transfer to adult care without the use of a TC. Elements studied considering the formats of transitional care will be as follows: TC setting, availability of a written transfer, involved professionals, age group seen at TC, number of TC visits young people have before transfer, presence of dedicated professionals in adult care, structure and content of the TC consultations (including subjects discussed), and use of other interventions to support transition such as individual transition plans.

The qualitative part of this study will be conducted first and is expected to provide insight into the development, underlying thoughts, organization, structure, team, facilitators and barriers of transitional care, both in the form of a TC and as standard care (without TC). Two data collection methods will be employed: *observations* during consultations with young people and *semi-structured interviews* with healthcare professionals. The quantitative part explores young people's experiences with transitional care and clinical, healthcare and self-management outcomes among those who received care at a TC and those who did not. Data collection methods will include *retrospective chart review* and *survey* among young adults transferred to adult care. An overview of the data collection methods per research question is presented in Table 1.

Table 1
Data collection methods per research question

	Data collection method	
Research questions	*Quantitative*	*Qualitative*
1. How do structures and daily routines differ between TCs and usual care?	Not applicable	Observations of healthcare practice and semi-structured interviews with healthcare professionals
2. What are healthcare professionals' experienced barriers and facilitators for the organization of a TC?	Not applicable	Observations of healthcare practice and semi-structured interviews with healthcare professionals
3. What are the differences in clinical outcomes and healthcare use of young people who were seen at a TC and those that received usual care?	Retrospective chart review of young people's medical records	Not applicable
4. What are the differences in self-management outcomes, experiences and satisfaction with the transfer to adult care, and perceived quality of care of young people who were seen at a TC and those that received usual care?	Survey among young people	Not applicable
5. What are the differences between TCs and regular transition care on the criteria for successful transition?	Retrospective chart review of young people's medical records and survey among young people	Not applicable

TC, transition clinic

Study setting

Purposive sampling will be used to select TCs in the Erasmus University Medical Center—Sophia Children's Hospital in Rotterdam. Previous research provided an overview of departments that have a TC in Erasmus University Medical Center (Van Hooft et al., 2012). TCs operating for 4 years or longer will be selected and invited to participate, because these are expected to have more or less embedded and standardized TC structures and routines. Also, selecting longer existing TCs would allow for larger study samples, because a larger number of young people would be treated at the TCs over time. For each participating TC, a control setting that provides usual care to the same diagnostic groups in one of the other University Medical Centers in the Netherlands will be selected. All departments will be contacted by e-mail to inform them about the study and to ask for their cooperation, followed by a phone call (in case of no reply). After consent, two researchers will visit the centers to explain the study in more detail. The teams will then be asked for suggestions for control settings that can be contacted to ask for participation. Based on the selection criteria and the previous overview of TCs in the Erasmus MC (Van Hooft et al., 2012), two pulmonology departments treating CF, two gastroenterology departments treating inflammatory bowel disease (IBD) (Crohn's disease and ulcerative colitis) and two endocrinology departments treating Turner syndrome (TS), congenital adrenal hyperplasia (CAH) and hypopituitarism will be invited to participate in the study.

Study procedures

Observations

Participant observations will be conducted at the TCs and at the outpatient control clinics. The aim is to observe about 8 hours in total at each setting. Young people and their parents will receive information about this study from their healthcare professional and all parties involved will be asked to provide written consent to the presence of the observer during their consultations. At the TCs, the consultations between young people, their parents and healthcare professionals will be observed, as well as the preparation of the professionals. In the control settings, regular consultations with young people and their parents will be observed. Attention will be paid to different themes including coordination of the transition process, structure, content of consultations and use of interventions. The researchers will take field notes and write down their findings in narratives.

Semi-structured interviews

Healthcare professionals from pediatric and adult care, working at all participating departments will be invited for semi-structured interviews by obtaining their e-mail addresses through the departments' heads, who are asked to inform their teams about the study on beforehand. Non-responders will be reminded by e-mail or a telephone call. Professionals from all relevant disciplines that participate in transitional care (e.g., doctors, nurses, psychologists, dieticians, social workers, physiotherapists, etc.) will be included.

Themes that will be addressed during the interviews are based on the literature, such as the validated 'You're welcome' quality criteria that determine whether a clinic can be typified young people-friendly (Hargreaves, 2011; Wilkinson & Robinson, 2009), the 'Mind the Gap' tool that is used to assess transfer readiness (Shaw et al., 2007), and experiences of young adults, parents and professionals (Betz et al., 2013; Fegran et al., 2014; Lugasi et al., 2011; Nehring et al., 2015; Sonneveld et al., 2013; Van Staa et al., 2011). Examples of topics are as follows: reasons for (not) setting up a TC, usefulness of the TC, barriers and facilitators, coordination of the TC, structure and content of transitional care and changes over time, involved healthcare professionals, use of interventions and added value of the TC for young people, their parents and healthcare professionals. Interviews will last for ~1 hour.

Retrospective chart review and survey

Of each outpatient department, all patients who have transferred to adult care 2–4 years prior to data collection will be selected for retrospective chart review and the survey. In case a patient has been transferred to adult care in another hospital, the clinician of the children's hospital will obtain contact details. Patients with severe intellectual disabilities or known psychiatric problems will be excluded. Information about such problems will be derived from the patient charts. An information letter accompanied by an invitation for participation in the survey and a consent form will be sent to all selected patients. A reminder letter will be sent to non-responders after 2 weeks, followed by a telephone call after 4 weeks. The survey will be sent to all patients that provided consent after chart review. For the chart review, both data from pediatric and adult care will be collected at four measurement moments: T-2, the second year before transfer; T-1, the year before transfer; T1, the year after transfer; and T2, the second year after transfer.

Process and outcome measures for chart review and survey

Although there are no agreed outcome measures for 'successful transition', several studies and study protocols for the evaluation of transitional care provide insights in important areas of outcome and process measures (Colver et al., 2013; Prior et al., 2014; Sharma et al., 2014; Tsybina et al., 2012). These include clinical outcomes, healthcare-related measures (medical follow-up) and psychosocial outcomes. Also, a recent international Delphi study provided insight into key indicators for successful transition (Surís

& Akré, 2015), while another one recently identified key transition outcomes (Fair et al., 2016). We differentiate between process and (patient-reported) outcome measures.

Since 'no-show after transfer' is seen as an important process measure for transitional care (Lugasi et al., 2011; Sharma et al., 2014; Surís & Akré, 2015), it is selected as a primary process outcome in this study. Information about no-show will be derived from the patient charts. In the chart review, the following secondary measures will be assessed: clinical outcomes, number of consultations and hospital admissions, therapeutic regimen, and if available quality of life. Specific measures are based on previous research (see references in the tables) and were discussed with professionals working in the specific fields of endocrinology, CF and IBD.

With respect to the outcome measures retrieved through the survey, young people's 'experiences and satisfaction with transfer' will be considered a primary patient-reported outcome in this study. In the survey, the following secondary outcomes will be assessed: healthcare-related and self-management outcomes, experiences with current care and quality of life. These outcome measures are based on literature around transfer of young people, both disease-specific and more generic (see references in the tables).

We categorized the variables into background, process and outcome variables. Table 2 presents an overview of relevant background variables to be collected; Table 3 explains the operationalization of included process measures; and Table 4 elaborates on the operationalization of the outcome measures.

Table 2
Relevant background variables

Variables	Operationalization	Data collection method
Date of birth	dd/mm/yyyy	Chart review
Date of diagnosis	dd/mm/yyyy	Chart review
Gender	Male/female	Chart review
Comorbidity	Yes/no	Chart review
Educational level	High/medium/low*	Survey
Type of education	Special education or not	Survey
Disability benefits	Yes/no	Survey

* Low: junior vocational or secondary general low; medium: secondary general high or senior vocational; high: higher educational institutions or university.

Table 3
Operationalization of process measures

Area*	Variable	Operationalization	Measurement moment†	Data collection method
Transfer	Date of transfer	dd/mm/yyyy	T0	Chart review
	Availability written transfer	Yes/no	T0	Chart review
	Written transfer recipient	Description	T0	Chart review
	Current healthcare provider	Center	T0	Chart review
Medical follow-up[1]	No-show at first appointment in adult care‡	Yes/no	T1	Chart review
	First appointment in adult care cancelled	Yes/no	T1	Chart review
	Scheduled consultations	Number per year	T-2, T-1, T1, T2	Chart review
	Missed consultations	Number per year	T-2, T-1, T1, T2	Chart review
	Time between last appointment in pediatric care and first appointment in adult care	Months	T-1, T1	Chart review
	Hospitalizations related to chronic condition	Number per year	T-2, T-1, T1, T2	Chart review
	Length of hospitalizations	Days	T-2, T-1, T1, T2	Chart review
	Emergency department visits	Number per year	T-2, T-1, T1, T2	Chart review
Healthcare	Topics discussed during consultations	The need for more attention for discussion of non-medical issues, and the frequency of communication about these topics during consultations	Not applicable	Survey

* References include general and disease-specific studies that included and/or recommended similar outcome measures to study transition.
† T-2: the second year before transfer; T-1: one year before transfer; T0: transfer; T1: the year after transfer; and T2: the second year after transfer.
‡ Primary measure.
[1] Bollegala et al., 2013; Bryant et al., 2013; Downing et al., 2013; Gleeson et al., 2013; Godbout et al., 2012; Goodhand et al., 2011; Goodhand et al., 2013; Leung et al., 2011; Lugasi et al., 2011; Okumura et al., 2014; Quon & Aitken, 2012; Sharma et al., 2014; Simmonds et al., 2009; Simmonds et al., 2010; Surís & Akré, 2015; Tuchman & Schwartz, 2013; Woodward et al., 2012; Zhang et al., 2014.

Table 4
Operationalization of outcome measures

Area*	Variable	Operationalization	Measurement moment† (for chart review data) or measurement scale and psychometrics (for survey data)	Data collection method
Clinical outcomes in CF[1]	Pulmonary functioning	FEV1 value	T-2, T-1, T1, T2	Chart review
	Acute pulmonary exacerbations	Use of antibiotics: yes/no, and frequency	T-2, T-1, T1, T2	Chart review
	Pseudomonas infection	Yes/no	T-2, T-1, T1, T2	Chart review
	Body mass index	Value	T-2, T-1, T1, T2	Chart review
Clinical outcomes in IBD[2]	Surgical treatments	Number per year	T-2, T-1, T1, T2	Chart review
	Medications	Use and type	T-2, T-1, T1, T2	Chart review
	Endoscopies	Number per year	T-2, T-1, T1, T2	Chart review
Clinical outcomes in endocrinology[3]	Body mass index	Value	T-2, T-1, T1, T2	Chart review
	Blood pressure	Systolic and diastolic	T-2, T-1, T1, T2	Chart review
	For those with TS: thyroid function	TSH/FT4 value	T-2, T-1, T1, T2	Chart review
	For those with CAH: androgens	17-OHP / androstenedione value	T-2, T-1, T1, T2	Chart review
	For those with Hypopituitarism: testosterone level	Value	T-2, T-1, T1, T2	Chart review
	For those with Hypopituitarism: insulin-like growth factor	IGF-1 level	T-2, T-1, T1, T2	Chart review
	For those with Hypopituitarism: FT4 level	Value	T-2, T-1, T1, T2	Chart review
	Medications	Use and type	T-2, T-1, T1, T2	Chart review
Healthcare-related outcomes	Experiences and satisfaction with transition to adult care‡[4]	Experiences on two domains: 1) organization of healthcare related to transition, and 2) satisfaction with preparation for transfer	On Your Own Feet Transfer Experiences Scale (OYOF-TES)[5] (validated 18-item scale with 5-point Likert scales, $\alpha = .92$) + self-reported satisfaction on a scale 1-10	Survey
	Perceived quality of care[6]	Patient-centeredness on five domains: 1) empowerment, 2) design of practice, 3) goal-setting/alignment, 4) problem-solving, 5) coordination / follow-up	Patient Assessment of Chronic Illness Care (PACIC) (validated 20-item scale with 5-point Likert scales)[7]	Survey

Table 4

Operationalization of outcome measures (*continued*)

Area*	Variable	Operationalization	Measurement moment† (for chart review data) or measurement scale and psychometrics (for survey data)	Data collection method
Self-management-related outcomes	Self-management[8]	Chronic condition self-management	Partners in Health scale (PIH) (validated 12-item scale with 9-point Likert scales)[9]	Survey
	Independence during consultations[10]	Self-reported independent behaviors during consultations with healthcare providers	Independent Behaviors During Consultations (IBDC) (validated 7-item scale with 5-point Likert scales, $\alpha = .79$)[11] + self-reported independence on a 1-10 scale	Survey
	Self-efficacy[12]	Disease-related self-efficacy on four domains: 1) knowledge about the condition, 2) coping, 3) competencies during consultations, 4) medication	On Your Own Feet Self-Efficacy Scale (OYOF-SES) (validated 16-item scale with 4-point Likert scales)[13]	Survey
	Adherence[14]	Self-reported adherence to medical treatment	Medication Adherence Rating Scale (MARS-5) (validated 5-item scale with 5-point Likert scales)[15] + self-reported adherence on a 1-10 scale	Survey
Quality of life	Quality of life[16]	Health-related quality of life on four domains: 1) physical, 2) emotional, 3) social, and 4) school/work	Pediatric Quality of Life Inventory Young Adult (PedsQL-YA) (validated 23-item scale with 5-point Likert scales)[17]	Survey

* References include general and disease-specific studies that included and/or recommended similar outcome measures to study transition.

† T-2: the second year before transfer; T-1: one year before transfer; T0: transfer; T1: the year after transfer; and T2: the second year after transfer.

‡ Primary outcome.

17-OHP, 17-hydroxyprgesterone; CAH, congenital adrenal hyperplasia; FEV1, forced expiratory volume in 1 second; FT4, free thyroxine; IBD, inflammatory bowel disease; IGF-1, insulin-like growth factor-1; TS, Turner syndrome; TSH, thyroid-stimulating hormone.

[1] Doull, 2013; Hodson et al., 2008; Okumura et al., 2014; Quon & Aitken, 2012; Simmonds, 2013; Simmonds et al., 2009; Suri et al., 2007

[2] Bollegala et al., 2013; Dabadie et al., 2008; Goodhand et al., 2013

[3] Gleeson et al., 2013; Kirk & Clayton, 2006

[4] Bishop et al., 2014; Bloom et al., 2012; Bryant et al., 2013; Colver et al., 2013; Dabadie et al., 2008; Escher, 2009; Godbout et al., 2012; Leung et al., 2011; Lugasi et al., 2011; McLaughlin et al., 2008; Okumura et al., 2014; Stanhope, 2004; Watson et al., 2011

[5] Van Staa & Sattoe, 2014

[6] Bishop et al., 2014; Bloom et al., 2012; Bryant et al., 2013; Colver et al., 2013; Dabadie et al., 2008; Escher, 2009; Godbout et al., 2012; Leung et al., 2011; Lugasi et al., 2011; McLaughlin et al., 2008; Okumura et al., 2014; Stanhope, 2004; Watson et al., 2011

[7] Glasgow et al., 2005; Wensing et al., 2008

[8] Sattoe et al., 2015

[9] Battersby et al., 2003; Petkov et al., 2010

[10] Strating et al., 2013

[11] Strating et al., 2013

[12] Bishop et al., 2014; Bryant et al., 2013; Dabadie et al., 2008; El-Matary, 2009; Escher, 2009; Fishman et al., 2010; Goodhand et al., 2013; Lugasi et al., 2011; Tsybina et al., 2012; Zhang et al., 2014

[13] Van Staa, 2012

[14] Bollegala et al., 2013; Bryant et al., 2013; Désir & Seidman, 2003; Goodhand et al., 2011; Goodhand et al., 2013; Leung et al., 2011; Lugasi et al., 2011; Morton, 2009; Quon & Aitken, 2012; Simmonds, 2013

[15] Mahler et al., 2010

[16] Bent et al., 2002; Bishop et al., 2014; Bloom et al., 2012; Bryant et al., 2013; Colver et al., 2013; Goodhand et al., 2013; Kirk & Clayton, 2006; Leung et al., 2011; Morton, 2009; Quon & Aitken, 2012; Sharma et al., 2014; Simmonds, 2013; Suri et al., 2007; Tsybina et al., 2012

[17] Limperg et al., 2014

Data analyses

Qualitative analyses

Interviews are audio taped, transcribed verbatim and imported into ATLAS.ti 7.0. Interview transcripts and observation narratives will be coded thematically by two researchers independently. Themes will be derived from the topic lists used during the interviews, and if applicable, subthemes will be derived from the data (Thomas, 2006). Details will be collected on the contents of the intervention, structure and working ways, and possible changes over time. Furthermore, healthcare professionals' experiences with transitional care, as well as experienced facilitators and barriers will be explored. As such, these analyses will provide answers on the first two research questions.

Quantitative analyses

First within-group differences on clinical outcomes and healthcare use will be studied over the four measurement moments with analysis of variance (ANOVA) tests (chart review data). Subsequently, comparisons will be made between intervention and control groups on clinical outcomes, healthcare use, self-management outcomes, experiences and satisfaction with the transfer to adult care and the perceived quality of current care. Independent samples t-tests and χ^2-tests will be used to do so. These analyses will provide answers on the third and fourth research questions. The fifth research question is based on criteria for successful transition. To establish these, we used the recently established indicators of successful transition (Surís & Akré, 2015). The indicators or criteria that reached international consensus on being essential or very important for a successful transition and our operationalization and data collection method per criteria are presented in Table 5. Again, comparisons will be made between intervention and control groups with χ^2-tests. Data per diagnostic group will be analyzed. For the overall analysis of the generic outcomes (all but the clinical outcomes), all data will be compiled. Quantitative analyses will be performed with IBM SPSS 21.0.

Sample size: In an IBD sample of young people, it was found that 78% of the young people who were directly transferred versus 29% of those transferred through a TC had at least one recorded non-attendance at clinic after transfer (Cole et al., 2015). Since attending scheduled visits in adult care is an indicator for a successful transition (Surís & Akré, 2015), and no other studies provided relevant information on any of the indicators, we performed a sample size calculation based on this indicator and the results found by Cole et al. (2015). Based on their numbers, an α of 0.05 and a power of 0.95, we calculated that in the intervention and control group, the sample size should be 72 or more. Sample size calculation was performed with G*Power 3.2.1.

Table 5

Operationalization of the criteria for successful transition (Surís & Akré, 2015)

	Original criteria	Operationalization: successful transfer if…	Data collection method
1	Patient not lost to follow-up	Young adult attended first planned consultation in adult care: *yes/no*	Chart review
2	Attending scheduled visits in adult care	Young adult has no missed consultations in the two years after transfer: *yes/no*	Chart review
3	Patient building a trusting relationship with adult provider	Young people trust their current healthcare provider: *a score higher than 6 points on a 10-point scale*	Survey among young people
4	Continuing attention for self-management	There is sufficient attention for self-management (including non-medical) topics: *average score of 3 or higher on 5-point scale*	Survey among young people
5	Patient's first visit in adult care no later than 3-6 months after transfer	The first consultation in adult care takes place within 6 months after transfer: *yes/no*	Chart review
6	Number of emergency room visits for regular care in the past year	There were no emergency room visits due to acute disruption of the disease in the two years after transfer: *yes/no*	Chart review
7	Patient and family satisfaction with transfer of care	Young people are satisfied with the transfer process: *a score higher than 6 points on a 10-point scale*	Survey among young people
8	Maintain/improvement of standard for disease control	The standard for disease control evaluation is met in the year after transfer: *yes/no*	Chart review

ETHICS AND DISSEMINATION

To ensure data confidentiality, the following procedures will be followed. Patients' personal identification information will only be available to the healthcare team and two researchers who are not part of the healthcare team. These researchers will sign a non-disclosure agreement (NDA). Other researchers will receive anonymized data. Patient numbers will be secured with passwords known by the researchers that signed the NDA and one member of the healthcare team. Young people and their parents (in case of minors who can be included in the observation part of the study) will receive an information letter from the doctor who is in charge of the treatment. They will be asked to provide written informed consent per study part. They are also asked to provide consent for matching the data from the surveys and chart reviews. Data will be processed anonymously and respondent numbers will be used to link data from the chart review to data from the survey. If applicable, pseudonyms will be used in the interview transcripts and observation narratives. The Medical Ethical Committee of the

Erasmus Medical Center approved the study protocol (MEC-2014-246). Study results will be published in international peer-reviewed journals, and will be presented at national and international conferences. The study started in September 2014 and is anticipated to continue until December 2016. The same study design will be used in a national study in 20 diabetes settings, starting in April 2016 until 2018.

DISCUSSION

Structuring the transition process by means of a TC is advocated to organize collaboration between pediatric and adult care and for better preparation of all parties involved (Camfield et al., 2012; Crowley et al., 2011; Davies & Jenkins, 2003; Viner, 1999). Apparently, this recommendation has been taken up by the field. While Crowley et al. (2011) found only four evaluation studies of TCs in 2011, there has been a marked increase in the publication of evaluation studies of TCs since 2015. We found new studies in the fields of epilepsy, urology, diabetes, CF, IBD, kidney disease, HIV and rheumatology (Cole et al., 2015; Geerlings et al., 2016; Gravelle et al., 2015; Jensen et al., 2015; Jurasek et al., 2010; Levy-Shraga et al., 2016; Maturo et al., 2015; McQuillan et al., 2015; Mistry et al., 2015; Shalaby et al., 2015; Stringer et al., 2015; Timberlake et al., 2015; Tong et al., 2015; Uday et al., 2015). Still, the proposed study is unique in its design. First, because only two published studies included a historical control group in the study design (Cole et al., 2015; McQuillan et al., 2015). Our approach goes even further by including similar controls in the same time frame, adding the patient questionnaire and employing a pre-post design.

Second, our proposed design includes a significant qualitative study part that is expected to provide important insights into the daily routines, structures and working elements of TCs. Only one existing study employs qualitative data collection methods. Still, this study included a prospective evaluation among young adults (Tong et al., 2015) and therefore provides no insights into the TC model. Therefore, it is still unclear what TC models are implemented and what the best model might be (Carrizosa et al., 2014; Geerlings et al., 2015). Our study could provide some answers to this question since we study components and outcomes of different TC models employing a standardized evaluation framework and the same data collection methods, which enables comparisons.

Finally, the evaluation studies we found vary in the outcome measures they use to evaluate the TC. While almost all evaluate whether or not young people attend adult care after transfer, some are interested in young people's satisfaction with the care delivered and program components (Jurasek et al., 2010; Shalaby et al., 2015; Stringer et al., 2015), and others look at disease-specific outcomes or adherence (Cole et al., 2015; Levy-Shraga et al., 2016; McQuillan et al., 2015; Tong et al., 2015; Uday et al., 2015). Still, none of the studies clarify why certain outcome measures were chosen. We selected our outcome measures after extensive literature research, linking possible outcomes to current ideas about the transition of young people with chronic conditions. By doing so, we provide a relevant approach allowing for comparisons of transitional care between disease groups (e.g., based on the criteria for successful transition (Surís & Akré, 2015)).

There are some challenges associated with our study design that need to be addressed. First, the current lack of insight into different TC models complicates the selection of outcome measures for the quantitative evaluation. We are not able to select these based on the content of the interventions. However, we view transition in the light of the definition proposed by Blum and colleagues in 1993 as ‘a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system’, and as such transition ‘implies an increase in independent behavior and personal autonomy’ (Blum et al., 1993). They further stated that ‘the optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive’ (Blum et al., 1993). Starting from this point of view, we conducted an extensive literature study and selected outcome measures that reflect these goals. Although not all TC models may include elements aimed at improving the whole transition process, we believe the selection of a wide variety of outcome measures may enable the comparisons of different TC models.

The second challenge, in connection with the lack of insight in TC models, considers the selection of control departments. The core principle of TCs is that healthcare professionals from pediatric and adult care are involved in the delivery of outpatient care in preparation for the upcoming transfer. However, the focus of this care (e.g., medical and/or psychosocial needs) differs between TCs. This means that when defining usual care, that is, selecting control departments, we can only select on whether or not professionals from pediatric and adult care actively collaborate in the delivery of transitional care. It might be that even in the control setting some sort of collaboration is established, diluting the differences between usual care and care at a TC. To cope with this issue, we will also conduct qualitative research at these control sites. As such, we can specifically define what usual care in the control departments entails and how this differs from care in the intervention departments.

Furthermore, the retrospective character of the quantitative data might be a limitation. As participants will be asked to think about their transfer experiences from 2–4 years ago, this might lead to recall bias. Finally, the chart review and survey carry operational challenges with them. Most hospitals use different electronic patient record systems, and charts from 4 years ago may not even be digitalized yet. Also, there are usually very general formats within record systems, making it unclear whether or where information is available. To overcome these challenges, there will be close collaboration with at least one healthcare professional from each participating department. This professional will help us to draft a grid for chart review, and will explain their patient record system to us and show us where to find the required information. Since chart reviews include a very precise task, these will be conducted in teams of two researchers (who both will be instructed by the healthcare professional). Another challenge is the fact that it is not uncommon for young people to transfer to other hospitals, including some that may not be included in the study. This complicates the retrieval of post-transfer data for that group. Still, in the Netherlands, information from patient charts may be requested from the information department in the hospitals after written consent from the patient. Consent from young people who transferred to other hospitals will be sought. As for the survey, the response rate of young adults may be a problem. It is well known that response rates to questionnaires in adolescents and young adults are usually low (Nieboer et al., 2014; Steinbeck et al., 2015). To anticipate this issue, all young people who fill out the questionnaire will be presented with a gift voucher of €10. Furthermore, parents are an important actor when it comes to transitional care, and it would be good to include them in the survey part. However, we anticipate difficulties in locating the parents of the young people, since we study a group of young adults transferred 2– 4 years ago. Therefore, we chose to focus on the young people alone.

Finally, the observations are current, while the quantitative evaluation is retrospective. This may complicate the use of the qualitative data from the observations to understand the outcomes of the evaluation. Still, we conduct qualitative interviews with professionals to gain insight into any changes that occurred in the working ways of the TC in the past 5 years. This will support the interpretation of the observational and quantitative data.

REFERENCES

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling, 48*(2), 177-187. https://doi.org/10.1016/s0738-3991(02)00032-0

Battersby, M. W., Ask, A., M Reece, M., J Markwick, M., & P Collins, J. (2003). The Partners in Health scale: The development and psychometric properties of a generic assessment scale for chronic condition self-management. *Australian Journal of Primary Health, 9*(3), 41-52. https://doi.org/https://doi.org/10.1071/PY03022

Bent, N., Tennant, A., Swift, T., Posnett, J., Scuffham, P., & Chamberlain, M. A. (2002). Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study. *Lancet, 360*(9342), 1280-1286. https://doi.org/10.1016/s0140-6736(02)11316-x

Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook, 61*(5), 311-336. https://doi.org/10.1016/j.outlook.2013.01.008

Betz, C. L., & Redcay, G. (2002). Lessons learned from providing transition services to adolescents with special health care needs. *Issues in Comprehensive Pediatric Nursing, 25*(2), 129-149. https://doi.org/10.1080/01460860290042549

Bishop, J., Lemberg, D., & Day, A. (2014). Managing inflammatory bowel disease in adolescent patients. *Adolescent Health, Medicine and Therapeutics, 5*, 1-13. https://doi.org/10.2147/AHMT.S37956

Bloom, S. R., Kuhlthau, K., Van Cleave, J., Knapp, A. A., Newacheck, P., & Perrin, J. M. (2012). Health care transition for youth with special health care needs. *Journal of Adolescent Health, 51*(3), 213-219. https://doi.org/10.1016/j.jadohealth.2012.01.007

Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 14*(7), 570-576. https://doi.org/10.1016/1054-139x(93)90143-d

Bollegala, N., Brill, H., & Marshall, J. K. (2013). Resource utilization during pediatric to adult transfer of care in IBD. *Journal of Crohn's and Colitis, 7*(2), e55-e60. https://doi.org/10.1016/j.crohns.2012.05.010

Bryant, R. V., Trott, M. J., Bennett, A., Bampton, P. A., Moore, D. J., & Andrews, J. M. (2013). Transition of care in inflammatory bowel disease: mind the gap! Theory, practice and recommendations for an Australian context. *Internal Medicine Journal, 43*(11), 1171-1176. https://doi.org/https://doi.org/10.1111/imj.12272

Camfield, P., Camfield, C., & Pohlmann-Eden, B. (2012). Transition from pediatric to adult epilepsy care: a difficult process marked by medical and social crisis. *Epilepsy Currents, 12*(Suppl. 4), 13-21. https://doi.org/10.5698/1535-7511-12.4s.13

Carrizosa, J., An, I., Appleton, R., Camfield, P., & Von Moers, A. (2014). Models for transition clinics. *Epilepsia, 55*(Suppl. 3), 46-51. https://doi.org/10.1111/epi.12716

Chu, P. Y., Maslow, G. R., von Isenburg, M., & Chung, R. J. (2015). Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *Journal of Pediatric Nursing, 30*(5), e19-27. https://doi.org/10.1016/j.pedn.2015.05.022

Cole, R., Ashok, D., Razack, A., Azaz, A., & Sebastian, S. (2015). Evaluation of outcomes in adolescent inflammatory bowel disease patients following transfer from pediatric to adult health care services: Case for transition. *Journal of Adolescent Health, 57*(2), 212-217. https://doi.org/10.1016/j.jadohealth.2015.04.012

Colver, A. F., Merrick, H., Deverill, M., Le Couteur, A., Parr, J., Pearce, M. S., Rapley, T., Vale, L., Watson, R., & McConachie, H. (2013). Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. *BMC Public Health, 13*, 675. https://doi.org/10.1186/1471-2458-13-675

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood, 96*(6), 548-553. https://doi.org/10.1136/adc.2010.202473

Dabadie, A., Troadec, F., Heresbach, D., Siproudhis, L., Pagenault, M., & Bretagne, J. F. (2008). Transition of patients with inflammatory bowel disease from pediatric to adult care. *Gastroenterologie Clinique et Biologique, 32*(5 Pt 1), 451-459. https://doi.org/10.1016/j.gcb.2008.01.044

Davies, I. H., & Jenkins, H. R. (2003). Transition clinics for adolescents with chronic gastrointestinal disease in the UK and Ireland. *Journal of Pediatric Gastroenterology and Nutrition, 36*(4), 505-506. https://doi.org/10.1097/00005176-200304000-00019

Désir, B., & Seidman, E. G. (2003). Transitioning the paediatric IBD patient to adult care. *Best Practice & Research Clinical Gastroenterology, 17*(2), 197-212. https://doi.org/10.1016/s1521-6918(02)00145-2

Doull, I. (2013). Cystic fibrosis papers of the year 2012. *Paediatric Respiratory Reviews, 14*, 28-30. https://doi.org/https://doi.org/10.1016/j.prrv.2013.02.006

Downing, J., Gleeson, H. K., Clayton, P. E., Davis, J. R. E., Wales, J. K., & Callery, P. (2013). Transition in endocrinology: the challenge of maintaining continuity. *Clinical Endocrinology, 78*(1), 29-35. https://doi.org/https://doi.org/10.1111/j.1365-2265.2012.04473.x

El-Matary, W. (2009). Transition of children with inflammatory bowel disease: big task, little evidence. *World Journal of Gastroenterology, 15*(30), 3744-3747. https://doi.org/10.3748/wjg.15.3744

Escher, J. C. (2009). Transition from pediatric to adult health care in inflammatory bowel disease. *Digestive Diseases, 27*(3), 382-386. https://doi.org/10.1159/000228578

Fair, C., Cuttance, J., Sharma, N., Maslow, G., Wiener, L., Betz, C., Porter, J., McLaughlin, S., Gilleland-Marchak, J., Renwick, A., Naranjo, D., Jan, S., Javalkar, K., & Ferris, M. (2016). International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatrics, 170*(3), 205-211. https://doi.org/10.1001/jamapediatrics.2015.3168

Falcini, F., & Nacci, F. (2007). Review: Systemic lupus erythematosus in the young: the importance of a transition clinic. *Lupus, 16*(8), 613-617. https://doi.org/10.1177/0961203307078973

Fegran, L., Hall, E. O., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. *International Journal of Nursing Studies, 51*(1), 123-135. https://doi.org/10.1016/j.ijnurstu.2013.02.001

Fishman, L. N., Barendse, R. M., Hait, E., Burdick, C., & Arnold, J. (2010). Self-management of older adolescents with inflammatory bowel disease: A pilot study of behavior and knowledge as prelude to transition. *Clinical Pediatrics, 49*(12), 1129-1133. https://doi.org/10.1177/0009922810379042

Geerlings, R. P. J., Aldenkamp, A. P., de With, P. H. N., Zinger, S., Gottmer-Welschen, L. M. C., & de Louw, A. J. A. (2015). Transition to adult medical care for adolescents with epilepsy. *Epilepsy & Behavior, 44*, 127-135. https://doi.org/10.1016/j.yebeh.2014.12.041

Geerlings, R. P. J., Aldenkamp, A. P., Gottmer-Welschen, L. M. C., de With, P. H. N., Zinger, S., van Staa, A. L., & de Louw, A. J. A. (2016). Evaluation of a multidisciplinary epilepsy transition clinic for adolescents. *European Journal of Paediatric Neurology, 20*(3), 385-392. https://doi.org/10.1016/j.ejpn.2016.01.003

Glasgow, R. E., Wagner, E. H., Schaefer, J., Mahoney, L. D., Reid, R. J., & Greene, S. M. (2005). Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). *Medical Care, 43*(5), 436-444. https://doi.org/10.1097/01.mlr.0000160375.47920.8c

Gleeson, H., Davis, J., Jones, J., O'Shea, E., & Clayton, P. E. (2013). The challenge of delivering endocrine care and successful transition to adult services in adolescents with congenital adrenal hyperplasia: experience in a single centre over 18 years. *Clinical Endocrinology, 78*(1), 23-28. https://doi.org/10.1111/cen.12053

Godbout, A., Tejedor, I., Malivoir, S., Polak, M., & Touraine, P. (2012). Transition from pediatric to adult healthcare: assessment of specific needs of patients with chronic endocrine conditions. *Hormone Research in Paediatrics, 78*(4), 247-255. https://doi.org/10.1159/000343818

Goodhand, J., Hedin, C. R., Croft, N. M., & Lindsay, J. O. (2011). Adolescents with IBD: The importance of structured transition care. *Journal of Crohn's and Colitis, 5*(6), 509-519. https://doi.org/10.1016/j.crohns.2011.03.015

Goodhand, J. R., Kamperidis, N., Sirwan, B., Macken, L., Tshuma, N., Koodun, Y., Chowdhury, F. A., Croft, N. M., Direkze, N., Langmead, L., Irving, P. M., Rampton, D. S., & Lindsay, J. O. (2013). Factors associated with thiopurine non-adherence in patients with inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics, 38*(9), 1097-1108. https://doi.org/10.1111/apt.12476

Gravelle, A. M., Paone, M., Davidson, A. G. F., & Chilvers, M. A. (2015). Evaluation of a multidimensional cystic fibrosis transition program: a quality improvement initiative. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 30*(1), 236-243. https://doi.org/10.1016/j.pedn.2014.06.011

Hargreaves, D. S. (2011). Revised You're Welcome criteria and future developments in adolescent healthcare. *Journal of Clinical Research in Pediatric Endocrinology, 3*(2), 43-50. https://doi.org/10.4274/jcrpe.v3i2.10

Hodson, M. E., Simmonds, N. J., Warwick, W. J., Tullis, E., Castellani, C., Assael, B., Dodge, J. A., & Corey, M. (2008). An international/multicentre report on patients with cystic fibrosis (CF) over the age of 40 years. *Journal of Cystic Fibrosis, 7*(6), 537-542. https://doi.org/10.1016/j.jcf.2008.06.003

Iyer, A., & Appleton, R. (2013). Transitional services for adolescents with epilepsy in the UK: A survey. *Seizure - European Journal of Epilepsy, 22*(6), 433-437. https://doi.org/10.1016/j.seizure.2013.02.014

Jensen, P. T., Karnes, J., Jones, K., Lehman, A., Rennebohm, R., Higgins, G. C., Spencer, C. H., & Ardoin, S. P. (2015). Quantitative evaluation of a pediatric rheumatology transition program. *Pediatric Rheumatology, 13*(1), 17. https://doi.org/10.1186/s12969-015-0013-0

Jurasek, L., Ray, L., & Quigley, D. (2010). Development and implementation of an adolescent epilepsy transition clinic. *Journal of Neuroscience Nursing, 42*(4), 181-189. https://doi.org/10.1097/jnn.0b013e3181e26be6

Kirk, J., & Clayton, P. (2006). Specialist services and transitional care in paediatric endocrinology in the UK and Ireland. *Clinical Endocrinology, 65*(1), 59-63. https://doi.org/10.1111/j.1365-2265.2006.02546.x

Leung, Y., Heyman, M. B., & Mahadevan, U. (2011). Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. *Inflammatory Bowel Diseases, 17*(10), 2169-2173. https://doi.org/10.1002/ibd.21576

Levy-Shraga, Y., Elisha, N., Ben-Ami, M., Boyko, V., Lerner-Geva, L., Ziv, T., Konvalina, N., Cohen, O., & Pinhas-Hamiel, O. (2016). Glycemic control and clinic attendance of emerging adults with type 1 diabetes at a transition care clinic. *Acta Diabetologica, 53*(1), 27-33. https://doi.org/10.1007/s00592-015-0734-z

Limperg, P. F., Haverman, L., van Oers, H. A., van Rossum, M. A., Maurice-Stam, H., & Grootenhuis, M. A. (2014). Health related quality of life in Dutch young adults: psychometric properties of the

PedsQL generic core scales young adult version. *Health and Quality of Life Outcomes, 12*, 9. https://doi.org/10.1186/1477-7525-12-9

Lugasi, T., Achille, M., & Stevenson, M. (2011). Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies. *Journal of Adolescent Health, 48*(5), 429-440. https://doi.org/10.1016/j.jadohealth.2010.10.016

Mahler, C., Hermann, K., Horne, R., Ludt, S., Haefeli, W. E., Szecsenyi, J., & Jank, S. (2010). Assessing reported adherence to pharmacological treatment recommendations. Translation and evaluation of the Medication Adherence Report Scale (MARS) in Germany. *Journal of Evaluation in Clinical Practice, 16*(3), 574-579. https://doi.org/10.1111/j.1365-2753.2009.01169.x

Maturo, D., Powell, A., Major-Wilson, H., Sanchez, K., De Santis, J. P., & Friedman, L. B. (2015). Transitioning adolescents and young adults with HIV infection to adult care: Pilot testing the "Movin' Out" transitioning protocol. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 30*(5), e29-e35. https://doi.org/10.1016/j.pedn.2015.06.013

McLaughlin, S. E., Diener-West, M., Indurkhya, A., Rubin, H., Heckmann, R., & Boyle, M. P. (2008). Improving transition from pediatric to adult cystic fibrosis care: Lessons from a national survey of current practices. *Pediatrics, 121*(5), e1160-e1166. https://doi.org/10.1542/peds.2007-2217

McQuillan, R. F., Toulany, A., Kaufman, M., & Schiff, J. R. (2015). Benefits of a transfer clinic in adolescent and young adult kidney transplant patients. *Canadian Journal of Kidney Health and Disease, 2*, 81. https://doi.org/10.1186/s40697-015-0081-6

Mistry, B., Van Blyderveen, S., Punthakee, Z., & Grant, C. (2015). Condition-related predictors of successful transition from paediatric to adult care among adolescents with type 1 diabetes. *Diabetic Medicine, 32*(7), 881-885. https://doi.org/https://doi.org/10.1111/dme.12746

Morton, A. M. (2009). Symposium 6: Young people, artificial nutrition and transitional care. The nutritional challenges of the young adult with cystic fibrosis: transition. *Proceedings of the Nutrition Society, 68*(4), 430-440. https://doi.org/10.1017/s0029665109990176

Nakhla, M., Daneman, D., Frank, M., & Guttmann, A. (2008). Translating transition: a critical review of the diabetes literature. *Journal of Pediatric Endocrinology & Metabolism, 21*(6), 507-516.

Nehring, W. M., Betz, C. L., & Lobo, M. L. (2015). Uncharted territory: Systematic review of providers' roles, understanding, and views pertaining to health care transition. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 30*(5), 732-747. https://doi.org/10.1016/j.pedn.2015.05.030

Nieboer, A. P., Cramm, J. M., Sonneveld, H. M., Roebroeck, M. E., van Staa, A., & Strating, M. M. H. (2014). Reducing bottlenecks: professionals' and adolescents' experiences with transitional care delivery. *BMC Health Services Research, 14*(1), 47. https://doi.org/10.1186/1472-6963-14-47

Okumura, M. J., Ong, T., Dawson, D., Nielson, D., Lewis, N., Richards, M., Brindis, C. D., & Kleinhenz, M. E. (2014). Improving transition from paediatric to adult cystic fibrosis care: programme implementation and evaluation. *BMJ Quality & Safety, 23*(Suppl. 1), i64-i72. https://doi.org/10.1136/bmjqs-2013-002364

Øvretveit, J. C., Shekelle, P. G., Dy, S. M., McDonald, K. M., Hempel, S., Pronovost, P., Rubenstein, L., Taylor, S. L., Foy, R., & Wachter, R. M. (2011). How does context affect interventions to improve patient safety? An assessment of evidence from studies of five patient safety practices and proposals for research. *BMJ Quality & Safety, 20*(7), 604-610. https://doi.org/10.1136/bmjqs.2010.047035

Petkov, J., Harvey, P., & Battersby, M. (2010). The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Quality of Life Research, 19*(7), 1079-1085. https://doi.org/10.1007/s11136-010-9661-1

Prior, M., McManus, M., White, P., & Davidson, L. (2014). Measuring the "Triple Aim" in transition care: A systematic review. *Pediatrics, 134*(6), e1648-e1661. https://doi.org/10.1542/peds.2014-1704

Quon, B. S., & Aitken, M. L. (2012). Cystic fibrosis: what to expect now in the early adult years. *Paediatric Respiratory Reviews, 13*(4), 206-214. https://doi.org/10.1016/j.prrv.2012.03.005

Sattoe, J. N. T., Bal, M. I., Roelofs, P. D. D. M., Bal, R. A., Miedema, H. S., & van Staa, A. L. (2015). Self-management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counseling, 98*(6), 704-715. https://doi.org/10.1016/j.pec.2015.03.004

Sawyer, S. M., Drew, S., Yeo, M. S., & Britto, M. T. (2007). Adolescents with a chronic condition: challenges living, challenges treating. *Lancet, 369*(9571), 1481-1489. https://doi.org/10.1016/S0140-6736(07)60370-5

Shalaby, M. S., Gibson, A., Granitsiotis, P., Conn, G., & Cascio, S. (2015). Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. *Journal of Pediatric Urology, 11*(2), 89.e81-89.e85. https://doi.org/10.1016/j.jpurol.2014.11.024

Sharma, N., O'Hare, K., Antonelli, R. C., & Sawicki, G. S. (2014). Transition care: future directions in education, health policy, and outcomes research. *Academic Pediatrics, 14*(2), 120-127. https://doi.org/10.1016/j.acap.2013.11.007

Shaw, K. L., Southwood, T. R., & McDonagh, J. E. (2007). Development and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care among adolescents with juvenile idiopathic arthritis. *Child: Care, Health & Development, 33*(4), 380-388. https://doi.org/10.1111/j.1365-2214.2006.00699.x

Simmonds, N. J. (2013). Ageing in cystic fibrosis and long-term survival. *Paediatric Respiratory Reviews, 14*(Suppl. 1), 6-9. https://doi.org/10.1016/j.prrv.2013.01.007

Simmonds, N. J., Cullinan, P., & Hodson, M. E. (2009). Growing old with cystic fibrosis - the characteristics of long-term survivors of cystic fibrosis. *Respiratory Medicine, 103*(4), 629-635. https://doi.org/10.1016/j.rmed.2008.10.011

Simmonds, N. J., MacNeill, S. J., Cullinan, P., & Hodson, M. E. (2010). Cystic fibrosis and survival to 40 years: a case–control study. *European Respiratory Journal, 36*(6), 1277-1283. https://doi.org/10.1183/09031936.00001710

Sonneveld, H. M., Strating, M. M., van Staa, A. L., & Nieboer, A. P. (2013). Gaps in transitional care: what are the perceptions of adolescents, parents and providers? *Child: Care, Health & Development, 39*(1), 69-80. https://doi.org/10.1111/j.1365-2214.2011.01354.x

Stanhope, R. (2004). Transition from paediatric to adult endocrinology: hypopituitarism. *Growth Hormone & IGF Research, 14*, 85-88. https://doi.org/https://doi.org/10.1016/j.ghir.2004.03.019

Steinbeck, K. S., Shrewsbury, V. A., Harvey, V., Mikler, K., Donaghue, K. C., Craig, M. E., & Woodhead, H. J. (2015). A pilot randomized controlled trial of a post-discharge program to support emerging adults with type 1 diabetes mellitus transition from pediatric to adult care. *Pediatric Diabetes, 16*(8), 634-639. https://doi.org/https://doi.org/10.1111/pedi.12229

Strating, M. M. H., Cramm, J. M., Sonneveld, H. M., van Staa, A. L., Roebroeck, M. E., & Nieboer, A. P. (2013). *Betere transitiezorg voor jongeren met chronische aandoeningen: Evaluatieonderzoek van het Actieprogramma Op Eigen Benen Vooruit! [Better transitional care for young people with chronic conditions: Evaluation study of the Action Program On Your Own Feet Ahead!]*. Erasmus School of Health Policy & Management.

Stringer, E., Scott, R., Mosher, D., MacNeill, I., Huber, A. M., Ramsey, S., & Lang, B. (2015). Evaluation of a rheumatology transition clinic. *Pediatric Rheumatology, 13*(1), 22. https://doi.org/10.1186/s12969-015-0016-x

Suri, R., Metcalfe, C., Wallis, C., & Bush, A. (2007). Assessing the usefulness of outcomes measured in a cystic fibrosis treatment trial. *Respiratory Medicine, 101*(2), 254-260. https://doi.org/10.1016/j.rmed.2006.05.012

Surís, J. C., & Akré, C. (2015). Key elements for, and indicators of, a successful transition: an international Delphi study. *Journal of Adolescent Health, 56*(6), 612-618. https://doi.org/10.1016/j.jadohealth.2015.02.007

Tariq, S., & Woodman, J. (2013). Using mixed methods in health research. *JRSM Short Reports, 4*(6), 2042533313479197. https://doi.org/10.1177/2042533313479197

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation, 27*(2), 237-246. https://doi.org/10.1177/1098214005283748

Timberlake, M. D., Corbett, S. T., Costabile, R. A., & Herndon, C. A. (2015). Identification of adolescent and adult patients receiving pediatric urologic care and establishment of a dedicated transition clinic. *Journal of Pediatric Urology, 11*(2), 62.e1-6.

Tong, A., Gow, K., Wong, G., Henning, P., & Carroll, R. (2015). Patient perspectives of a young adult renal clinic: a mixed-methods evaluation. *Nephrology, 20*(5), 352-359. https://doi.org/10.1111/nep.12396

Tsybina, I., Kingsnorth, S., Maxwell, J., Bayley, M., Lindsay, S., McKeever, P., Colantonio, A., Hamdani, Y., Healy, H., & Macarthur, C. (2012). Longitudinal evaluation of transition services ("LETS Study"): protocol for outcome evaluation. *BMC Pediatrics, 12*, 51. https://doi.org/10.1186/1471-2431-12-51

Tuchman, L., & Schwartz, M. (2013). Health outcomes associated with transition from pediatric to adult cystic fibrosis care. *Pediatrics, 132*(5), 847-853. https://doi.org/10.1542/peds.2013-1463

Uday, S., Campbell, F., Yong, J., & Ajjan, R. (2015). Transition and beyond in adolescents and young adults with type 1 diabetes mellitus. *International Journal of Endocrinlogy and Metabolic Disorders, 1*(2). http://dx.doi.org/10.16966/2380-548X.106

Van Hooft, S. M., Van der Knaap, L., Latour, J. M., Jedeloo, S., Sattoe, J. N. T., & van Staa, A. L. (2012). *Wat zijn de huidige werkwijzen rondom de ondersteuning van zelfmanagement in de zorg voor jongeren met een chronische aandoening binnen het Erasmus MC-Sophia? [What are the current methods for supporting self-management in care for young people with a chronic condition within Erasmus MC-Sophia?]*. Rotterdam University of Applied Sciences, Research Center Innovations in Care.

Van Staa, A. L. (2012). *On Your Own Feet: Adolescents with chronic conditions and their preferences and competencies for care*. Erasmus University Rotterdam.

Van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health & Development, 37*(6), 821-832. https://doi.org/10.1111/j.1365-2214.2011.01261.x

Van Staa, A. L., & Sattoe, J. N. T. (2014). Young adults' experiences and satisfaction with the transfer of care. *Journal of Adolescent Health, 55*(6), 796-803. https://doi.org/10.1016/j.jadohealth.2014.06.008

Viner, R. M. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood, 81*(3), 271-275. https://doi.org/10.1136/adc.81.3.271

Viner, R. M. (2008). Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Archives of Disease in Childhood, 93*(2), 160-163. https://doi.org/10.1136/adc.2006.103721

Watson, R., Parr, J. R., Joyce, C., May, C., & Le Couteur, A. S. (2011). Models of transitional care for young people with complex health needs: a scoping review. *Child: Care, Health & Development, 37*(6), 780-791. https://doi.org/10.1111/j.1365-2214.2011.01293.x

Wensing, M., van Lieshout, J., Jung, H. P., Hermsen, J., & Rosemann, T. (2008). The Patients Assessment Chronic Illness Care (PACIC) questionnaire in The Netherlands: a validation study in rural general practice. *BMC Health Services Research, 8*, 182. https://doi.org/10.1186/1472-6963-8-182

Wilkinson, D., & Robinson, A. J. (2009). You're Welcome quality criteria: making health services young-people-friendly. *Sexually Transmitted Infections, 85*(3), 233-234. https://doi.org/10.1136/sti.2009.037333

Woodward, J. F., Swigonski, N. L., & Ciccarelli, M. R. (2012). Assessing the health, functional characteristics, and health needs of youth attending a noncategorical transition support program. *Journal of Adolescent Health, 51*(3), 272-278. https://doi.org/10.1016/j.jadohealth.2011.12.016

Zhang, L. F., Ho, J. S. W., & Kennedy, S. E. (2014). A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatrics, 14*(1), 4. https://doi.org/10.1186/1471-2431-14-4

6

Controlled evaluation of a transition clinic for Dutch young people with cystic fibrosis

Mariëlle A.C. Peeters
Jane N.T. Sattoe
AnneLoes van Staa
Simone E. Versteeg
Inge Heeres
Niels W. Rutjes
Hettie M. Janssens

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ABSTRACT

Background

Transition clinics (TCs) are advocated as best practice to support young people with cystic fibrosis (CF) during transition to adulthood and adult care. We aimed to research the functioning of a TC for young people with CF compared with direct hand-over care and to evaluate whether those treated at the TC have better transfer experiences and outcomes compared with the control group.

Methods

Mixed-methods retrospective controlled design, including interviews with professionals, observations of clinics, chart reviews (at four measurement moments), and patient surveys. Qualitative data analysis focused on organization and daily routines, and barriers and facilitators experienced. Young people's transfer experiences, self-management, health care use, and clinical outcomes were assessed quantitatively.

Results

The most notable feature distinguishing the TC and direct hand-over care comprised joint consultations between pediatric and adult care professionals in the former. A transition coordinator was considered essential for the success of the TC. The main barriers were lack of time, planning, and reimbursement issues. Young people treated at the TC tended to have better transfer experiences and were more satisfied. They reported significantly more trust in their adult care professionals. Their self-management-related outcomes were less favorable.

Conclusions

The TC had several perceived benefits and showed positive trends in transfer experiences and satisfaction, but no differences in health-related outcomes. Structured preparation of young people, joint consultations with pediatric and adult care professionals, and better coordination were perceived as facilitating elements. Further improvement demands solutions for organizational and financial barriers, and better embedding of self-management interventions in CF care.

INTRODUCTION

In the Netherlands, around 1500 people live with cystic fibrosis (CF) and more than half are over 18 years of age (Dutch Cystic Fibrosis Foundation [NCFS], 2018). Their life expectancy has improved and is likely to improve further with the advent of CF transmembrane conductance regulator modulator therapies (Askew et al., 2017; NCFS, 2018). CF care in the Netherlands has been concentrated in seven centers, each with an adult and a pediatric department. Although treatment protocols are standardized across these centers (Dutch Insitute for Healthcare Improvement [CBO], 2007), differences in the organization of care continue to exist.

Young people with CF may experience difficulty entering into adulthood as developmental milestones can clash with the demands of the disease (Bowmer et al., 2018). Independence and autonomy are compromised by frequent pulmonary exacerbations and may accentuate the feeling of being different from healthy peers (Opoka-Winiarska et al., 2015). Patients should be made aware early on in life of fertility concerns, genetic implications of CF, and short life expectancy (Opoka-Winiarska et al., 2015). Young people with CF also need to prepare for the transfer from pediatric to adult-oriented health care, which means bridging the gap between these settings (Feinstein et al., 2017; Goralski et al., 2017; Okumura & Kleinhenz, 2016). Because this coincides with physical and psychosocial changes, therapy adherence may be threatened with risk of loss of pulmonary function, lowering of body mass index (BMI), and hospitalizations (Okumura et al., 2014; Patel et al., 2017; Quon & Aitken, 2012). It is widely acknowledged that young people with CF should receive the appropriate support during the transitional phase (Connett & Nagra, 2018; Coyne et al., 2017; Goralski et al., 2017; Patel et al., 2017).

A transition clinic (TC) is often advocated as best practice for this type of support (Crowley et al., 2011; West & Mogayzel, 2016). Although there is no shared model, the TC's core principle is that professionals from both pediatric care (PC) and adult care (AC) deliver outpatient care in preparation for the upcoming transfer (Crowley et al., 2011). Studies evaluating TCs in CF care have reported improved health status, self-care and self-advocacy skills, and more independence (Askew et al., 2017; Chaudhry et al., 2013; Coyne et al., 2017; Gravelle et al., 2015; Okumura et al., 2014; Tuchman & Schwartz, 2013). However, most studies did not include a controlled pre-post outcome evaluation, and the body of evidence for effects is still small. Also, daily routines and protocols differ considerably between TCs (Crowley et al., 2011; Patel et al., 2017). Despite the expected positive impact, the contributions of the different components and the experiences of young people and professionals are still unclear (Coyne et al., 2017). This study aimed to evaluate the functioning and outcomes of a TC compared with a control setting with direct hand-over care. Our hypothesis is that young people with CF treated at the TC will have more positive transfer experiences and will show better self-management, health care use, and clinical outcomes around the transfer.

MATERIALS AND METHODS

Setting and design

This study involved a retrospective, controlled mixed-methods evaluation of a TC for young people with CF. Two of the largest CF centers in university hospitals in the Netherlands, each treating 200 to 300 patients a year, participated. One had implemented a TC in 2009; the other served as control setting providing direct hand-over care. The settings were compared on structures and daily routines, health care use, clinical- and self-management outcomes, and experiences and satisfaction with the transfer. Experienced barriers and facilitators for the functioning of the TC and perceived benefits were also studied. The study protocol has been published elsewhere (Sattoe et al., 2016).

Participants

Health care professionals (HCPs) from relevant disciplines in both settings were interviewed. All young people who transferred between 2010 and 2013 (2-4 years before data collection) were included in a chart review and were asked to fill out a survey. Those with known intellectual disabilities or psychiatric conditions were excluded.

Data collection

Qualitative part

In semi-structured interviews, HCPs were encouraged to share their experiences and expectations regarding transitional care. Topics addressed were organization and structure, facilitators and barriers, content of consultations, use of interventions, and potential improvements. HCPs working at the TC were also asked about perceived benefits.

Non-participant observations of outpatient consultations between young people, their parents (if present), and HCPs were conducted at both settings. Two observations of 4 hours each were performed at the TC and two observations of, respectively, 3 and 2 hours in the control setting. In addition, a multidisciplinary meeting of pediatric and adult HCPs at the TC was observed, in which they discussed the patients' psychosocial status. In the control setting, a regular multidisciplinary meeting of pediatric HCPs was observed. The observers focused on coordination of the transition process, structure and content of consultations, interaction between involved parties, and use of interventions.

Quantitative part

A set of background, process, and outcome variables was selected that previously had been found essential for a successful transition (Sattoe et al., 2016). Table 1 provides an overview of our operationalization and data collection method per variable. Patient data from four measurement moments were collected: T1, the 2 years before transfer; T2, the 1 year before transfer; T3, the 1 year after transfer; and T4, the 2 years after transfer. The young people who provided consent for the chart review were invited to fill out an online survey. A reminder was sent to non-responders after 2 weeks, followed by a telephone call after 4 weeks.

Data analysis

Qualitative part

Interviews were audio-recorded and transcribed ad verbatim; observation field notes were recorded in narratives. ATLAS.ti 7.0 was used for data analysis. Two researchers (MP and JS) independently analyzed the data by using the framework approach, whereby themes addressed during the interviews and observations were leading in the coding process. If applicable, subthemes were derived from the data.

Quantitative part

Analysis of variance tests were used to investigate within-group differences on clinical outcomes and health care use over the four measurement moments. Independent samples t-tests and Pearson's χ^2-tests were performed to compare the TC and control setting on chart review and survey outcomes. Effect sizes were calculated to indicate the magnitude of the observed effects, as they are not affected by the sample sizes, unlike P-values (Cohen's $d = 0.2$ small effect, 0.5 medium, and 0.8 large). Spearman's tests were used to examine correlations. Statistical analyses were performed with IBM SPSS 26.0.

Ethical considerations

All young people provided written consent for the different study parts in which they were included after they received the appropriate information. Quantitative data were processed anonymously, and pseudonyms were used in the interview transcripts and observation narratives. The Medical Ethics Review Board of Erasmus Medical Center approved the study protocol (MEC-2014-246).

Table 1

Operationalization of background characteristics, process and outcome measures[a]

Theme	Variable	Operationalization	Method of data collection	Measurement moment (chart review)[b] or measurement tool used (survey)
Background characteristics				
	Gender	Male/female	Chart review	
	Ethnicity	Caucasian/mixed/African American	Chart review	
	Date of birth	dd/mm/yyyy	Chart review	
	Date of transfer	dd/mm/yyyy	Chart review	T3
	Transferred to	Internal/external	Chart review	T3
Process outcomes				
Health care use	No-show at first appointment in adult care	Yes/no	Chart review	T3
	Scheduled consultations	Number per year	Chart review	T1; T2; T3; T4
	Hospitalizations related to condition	Number per year	Chart review	T1; T2; T3; T4
	Emergency department visits related to condition	Number per year	Chart review	T1; T2; T3; T4
Outcome measures				
Clinical	Height	Value (cm)	Chart review	T1; T2; T3; T4
	Weight	Value (kg)	Chart review	T1; T2; T3; T4
	BMI	Value	Chart review	T1; T2; T3; T4
	Pulmonary functioning[c]	FEV1 value (L)	Chart review	T1; T2; T3; T4
	Acute pulmonary exacerbations	Use of antibiotics (yes/no, frequency per year)	Chart review	T1; T2; T3; T4
Health care-related	Transfer experiences and satisfaction with transition	Experiences on two domains: 1) organization of health care related to transition and 2) satisfaction with preparation to transfer	Survey	On Your Own Feet Transfer Experiences Scale (OYOF-TES) (validated 18-item scale with 5-point Likert scales, $\alpha = .93$) (Van Staa & Sattoe, 2014) + self-reported satisfaction on a 1-10 scale
	Trust in health care providers	Trust in pediatric and adult care providers	Survey	Self-reported trust on a 1-10 scale

Table 1

Operationalization of background characteristics, process and outcome measures[a] (*continued*)

Theme	Variable	Operationalization	Method of data collection	Measurement moment (chart review)[b] or measurement tool used (survey)
	Perceived patient-centeredness of care	Patient-centeredness of adult care providers	Survey	Subscale 'patient-centeredness' of the American Consumer Assessment of Health Plan Surveys (validated 5-item scale with 4-point Likert scales, $\alpha = .90$) (Arah et al., 2006; Van Staa & Sattoe, 2014)
Self-management-related	Self-management	Chronic condition self-management	Survey	Partners in Health Scale (PIH) (validated 12-item scale with 9-point Likert scales, $\alpha = .82$) (Petkov et al., 2010)
	Independence during consultations	Self-reported independent behavior during consultations with health care providers	Survey	Independent Behaviors During Consultations (IBDCS) (validated 7-item scale with 5-point Likert Scales, $\alpha = .79$) (Van Staa & Sattoe, 2014) + self-reported independence on a 1-10 scale
	Self-efficacy	Disease-related self-efficacy on four domains: 1) knowledge about the condition, 2) coping, 3) competencies during consultations, and 4) medication	Survey	On Your Own Feet Self-Efficacy Scale (OYOF-SES) (validated 16-item scale with 4-point Likert scales, $\alpha = .85$) (Van Staa, 2012)
	Adherence	Self-reported adherence to medical treatment	Survey	Medication Adherence Rating Scale (MARS-5) (validated 5-item scale with 5-point Likert scales, $\alpha = .77$) (Tommelein et al., 2014) + self-reported adherence on a 1-10 scale
Quality of life	Health-related quality of life	Health-related quality of life on four domains: 1) physical, 2) emotional, 3) social, and 4) school/work	Survey	Pediatric Quality of Life Inventory Young Adult (PedsQL-YA) (validated 23-item scale with 5-point Likert scales, $\alpha = .93$) (Limperg et al., 2014)

Abbreviation: BMI, body mass index.

[a] Based on previously published study protocol (Sattoe et al., 2016).

[b] T1: two years before transfer; T2: one year before transfer; T3: one year after transfer; and T4: two years after transfer.

[c] FEV1% predicted was calculated based on age, gender, ethnicity, height and FEV1 value by using the calculator of the Global Lung Function Initiative (http://gligastransfer.org.au/calcs/spiro.html).

RESULTS

Response

Ten HCPs were interviewed in the TC setting and 18 in the control setting. Table 2 provides a description of the study sample.

Table 2
Description of the total study sample

	Transition clinic	Direct hand-over care	*P*-value[a]
Professionals interviewed	*n* = 10	*n* = 18	
	Pediatric pulmonologists (3); pediatric nurses (2); pediatric psychologist; pediatric psychotherapist; pulmonologist adult care; nurse adult care; psychologist adult care	Pediatric pulmonologists (4); pediatric gastroenterologists (2); pediatric nurses (2); pediatric social workers (2); pediatric psychologist; pediatric dieticians (2); pediatric physiotherapists (2); pulmonologist adult care; nurses adult care (2)	NA
Young people with CF	*n* = 27	*n* = 19	
Gender (male)	13 (48.1%)	10 (52.6%)	.765
Age	22.56 (±1.22)	22.26 (±1.33)	.444
Age at transfer[b]	18.31 (±0.618)	18.36 (±0.633)	.812
Department to which young person transferred is recorded/known (yes)	27 (100%)	18 (94.7%)	.413

[a] Independent Samples *T*-test or Pearson χ^2-test / Fischer's exact test.
[b] *N* = 26 in the transition clinic group and *n* = 14 in the control setting, because respectively *n* = 1 and *n* = 5 respondents did not give permission for chart review.

Structure and organization

In the TC setting, young people were invited for a final visit to the pediatric clinic, including joint consultations with: (a) their current pediatric pulmonologist and their future adult care pulmonologist, and (b) the nurses from both settings. This one-time visit was additional to the regularly scheduled multidisciplinary outpatient visits (four times a year). In the control setting, no special transition arrangements were arranged apart from these regular visits. Here, young persons and their parents said farewell during the final consultation with the pediatric pulmonologist. In the period between the last appointment in PC and the first appointment in AC, the pediatric pulmonologist was in charge of treatment decisions in case of unforeseen circumstances. This was the case in both the TC and control setting. Table 3 provides more detailed information on the characteristics of care provision of these two centers and their pediatric and adult clinics, and presents the differences in structures and daily routines between both settings.

Table 3

Differences in structures and daily routines between transition clinic and control setting

Characteristics of care	Transition clinic	Control setting
Location	Pediatric and adult clinic are co-located on the same campus.	Pediatric clinic is located on two different campuses in the city, adult clinic is centralized on one of these campuses.
Electronic medical record system (EMR)	Pediatric and adult clinic use the same EMR.	Pediatric and adult clinic that are co-located on the same campus use the same EMR; the other pediatric clinic (located on a different campus) uses paper charts.
Transition		
Team of professionals	Pediatric pulmonologists, pediatric nurses, pediatric psychologist, pediatric psychotherapist, pulmonologist AC, nurse AC, and psychologist AC.	Pediatric pulmonologists, pediatric gastroenterologists, pediatric nurses, pediatric social workers, pediatric psychologist, pediatric dieticians, pediatric physiotherapists, pulmonologists AC, and nurses AC.
Start of the transition phase	From 12 years by using the Individual Transition Plan.	Stimulating self-management skills from 12 years, specific attention for transfer from around 16 or 17 years.
Use of self-management interventions	Knowledge tool, Cystic Fibrosis Questionnaire (CFQ), Individual Transition Plan, independent consultations with young people (without parents present).	Knowledge tool, Cystic Fibrosis Questionnaire (CFQ), KLIK PROfile (a web-based application for the use of patient reported outcomes), independent consultations with young people (without parents).
Transfer		
Setting of effectuation	Pediatric clinic.	Pediatric clinic (one of the two locations).
Visitors	Young people with CF aged 17 or 18 years, with or without their parents.	Young people with CF until age of 18, with or without their parents.
Working ways	TC with joint consultations, written transfer (EMR).	Written transfer (EMR or paper chart), multidisciplinary CF team meeting with professionals from pediatric and AC (doctors, nurses and paramedics; every month; alternately on each of the two campuses).
Structure and organization	1. Joint consultation with pediatric pulmonologist and adult pulmonologist. Just before young people entered the consultation room, the pulmonologists briefly talked about the patient's situation. 2. Joint consultation with pediatric nurse and adult nurse.	1. Multidisciplinary pediatric CF team meeting. 2. Consultation of the pediatric pulmonologist with young people.
Topics discussed (content)	*During preliminary discussion between pulmonologists:* Pediatric pulmonologist informs the adult pulmonologist about the young person and his/her situation. Themes addressed are the medical situation, independent behavior and (relation with) parents.	*During multidisciplinary team meeting:* Discussion of the most striking issues regarding patients' current situation and relevant historical occurrences, such as therapy adherence and clinical outcomes, hospital admissions, self-management skills, risk behavior and school situation. Not only about transferring patients, but about all children who are planned for an outpatient visit that day.

Table 3

Differences in structures and daily routines between TC setting and control setting (*continued*)

Characteristics of care	Transition clinic	Control setting
	During joint consultation of pediatric and AC pulmonologist with young person (with or without parents present): Young persons are asked about their disease and therapy adherence, and a physical examination is performed. Subsequently, the adult pulmonologist explains about structures and routines in AC (i.e. the outpatient clinic and the team of professionals) and differences with pediatric care are discussed. Attention is paid to young people's responsibility regarding therapy adherence and to social participation (e.g. sport, driving license, school and work). *During joint consultation of pediatric and AC nurse with young person (with or without parents present):* Focus is on preparing young persons and their parents for the transfer to AC. Practical things are discussed, such as the way outpatient visits are organized, logistics and attainability. Attention is also paid to differences with PC; young people receive an information bulletin about the AC setting. Moreover, the nurses suggest a guided tour to become familiar with the new setting. After providing information and instructions, the nurses inquire young people about their attitude towards the upcoming transfer. They are asked about their transfer readiness (possibly also of their parents), their experiences with taking up responsibility and self-management, for instance in self-care, therapy adherence, and social participation (school/work and future plans). The pediatric nurse also asks if the young person agrees with transferring the individual transition plan to AC.	*During individual consultation of pediatric pulmonologist with young person (with or without parents present):* Attention is paid to medical subjects (i.e. symptoms, treatment and adherence) and non-medical subjects (i.e. study, work, sport, transition in care and the importance of independent behavior). Sometimes other relevant professionals – like a physiotherapist or a psychologist – participate in the care process, dependent on the young person's individual situation and needs. The overall care trajectory is coordinated by the pediatric specialized nurse.
Follow-up after transfer within the same hospital	By an adult pulmonologist, the same who was involved in the TC.	By an adult pulmonologist, the same who was involved in monthly meetings and discussions about the CF patients.

Abbreviations: AC, adult care; EMR, electronic medical record system; PC, pediatric care; TC, transition clinic.

Interview results

Perceived benefits of a TC

Professionals at the TC perceived several benefits. In PC, HCPs appreciated the planned farewell moment. They found that preparation for transfer had improved:

> *"It really helps to prepare children. […] Now they know that something is going to happen which could have a high impact on them. That was not the case before, when it was abrupt and we got a lot of reactions afterwards. […] So, it is much better organized and less stressful for the patients than before." (TC; pulmonologist PC)*

> *"Professionals from adult care say: 'We see different young people and parents transferring.' That is nice to hear. I hear nurses and the doctor say that things went better last years. They see changes and the transfer goes more smoothly." (TC; nurse PC)*

The joint consultations provided HCPs from AC with a more holistic view of the transferring patient. The pulmonologist explained: "It is no longer the case that you just hand over the person. Instead, 'This is the patient as a whole: this is his disease, this is his personality and these are goals or concerns.' I think that's the secret of a good transition, that you know all these facets."

Moreover, using an Individual Transition Plan (ITP) from around the age of 12 creates structure and continuity in the preparation for transfer. "The ITPs are also transferred at the TC, so that we are fully aware of the young persons' preparation and information so far, and things that need special attention from us" (TC; nurse AC).

The TC also facilitates finetuning of the care trajectory between PC and AC: "Two distinct worlds have to communicate with each other, two settings. […] It is, of course, paramount that this runs smoothly and that we know what our colleagues from PC have done and how we can best continue" (TC; psychologist AC). HCPs in the control setting miss such joint care arrangements: "A transition clinic, where young people are seen by the pulmonologists and the nurses from PC and AC, would be really valuable […]. Such a transition process, with more intensive consultation between pediatric and adult professionals, would improve [the quality of] care" (control; nurse AC).

Facilitators and barriers for transitional care

Professionals in the TC setting considered intrinsic motivation and commitment as prerequisites for a successful TC.

> *"It is all about the willingness and the effort of a group of people to work together." (TC; psychotherapist PC)*

> *"Everyone is convinced that it is better to do it this way. Despite the busy schedules […], it's everyone's intention to make time for transition." (TC; pulmonologist AC)*

Starting paying attention to transition at an early stage is essential according to professionals from both settings. This helps to better prepare young people and their parents for their final visit to the pediatric clinic. Also, flexibility in the moment of transfer is required.

> *"We start at the age of 12: 'Listen, from now on you are going to manage your medication by yourself […] because when you reach 18, you should be able to do it on your own.' So, we emphasize that very often and it is no longer a surprise. I think it is important to announce [the transfer] far in advance and repeat it over and over." (TC; pulmonologist PC)*

> *"I think we need to be more alert. We only wake up when the date of transfer comes really close. Now it is like: 'Oh, he or she is 17, we have to get started with a number of things.' That should be earlier." (Control; pulmonologist PC)*

Several professionals pointed out that it helps when a member of the care team takes up a coordinating role in this process, preferably "a dedicated nurse specialist". This transition coordinator is not only important for logistics, but also to ensure an early start, to serve as a spokesperson for young people and parents, and to create a sense of urgency for adequate transitional care in both teams.

> *"The nurse is often easily accessible; patients dare to tell more to their nurse than to their doctor, also about non-medical issues. Nurses can act as a link between the patient and other professionals; so that a more holistic view of the patient can be established." (Control; pulmonologist AC)*

Professionals also reported several barriers to the organization and functioning of the TC. First, lack of time; their work schedules hardly left any room for extra or longer consultations or additional team meetings. Presently, the TC only involved one moment of joint care, which was not always enough.

> *"Time is always limited while the [transition] consultation has two goals, as we also use it for regular follow-up [next to preparation for the transfer]." (TC; pulmonologist PC)*

> *"Nowadays, everyone is too busy. […] I think that our collaboration suffers from that. Because there is just too little time to think about things quietly and to align or fine-tune things." (Control; social worker PC)*

Lack of financial support is another important barrier as transitional care is not reimbursed. One of the TC pediatric pulmonologists illustrates this: "At regular consultation hours you see ten children and at the transition clinic only four." Potential barriers may also lie within a setting's culture, policy, and ways of working.

> *"We are used to discuss and explain things, and to make shared decisions. In adult care, information is provided, but in the end the patient decides." (TC; nurse PC)*

> *"We always try to make it as easy as possible for our patients. So, when an appointment has to be rescheduled, I schedule a new one. […] When something is wrong with medication, we call the pharmacy. […] This is not how it works in adult care, where patients have to do it all by themselves." (Control; nurse PC)*

According to some adult HCPs, PC is made "too attractive," pointing at the high level of involvement and sense of responsibility for young persons' health. They think that this increases the gap and thus impedes the transfer to AC. About content of care at the TC, professionals mentioned lack of uniformity in the preparation trajectory, despite the use of the ITP. A pediatric pulmonologist said: "Regularly I have consultations with youth aged 12 to 18 in which I do not think about transition at all and no one points this out to me." Professionals in the control setting also did not always address transition, thereby leaving the young persons and their parents wondering what to expect from transition and when it was going to happen. Furthermore, professionals from both settings emphasized that their transitional care would benefit from more availability of allied health professionals, more attention for psychosocial aspects, and more independent consultations (without parents).

Transfer experiences and satisfaction with transition

Analysis revealed a trend of higher scores for transfer experiences among those treated at the TC compared with those treated in direct hand-over care. The difference was not statistically significant; the effect size was medium ($d = 0.48$). The same was the case for reported satisfaction with transition ($d = 0.68$) (Table 4). Looking at individual items of the Transfer Experiences Scale (5-point Likert scales; 1 = strongly disagree, 5 = strongly agree), young people treated at the TC had more often met their adult HCPs before transfer (3.73 ± 1.27 vs. 2.14 ± 1.23, $P < .01$; $d = 1.25$) and reported more trust in their adult HCPs (4.73 ± 0.467 vs. 4.21 ± 0.426, $P < .01$; $d = 1.11$). They assigned higher scores to the experienced alignment in the ways of working and dealings between PC and AC (3.45 ± 1.13 vs. 2.93 ± 0.917). This difference was not significant; the effect size was medium (*d* = 0.46). There was no difference in perceived patient-centeredness of adult HCPs.

Table 4
Differences in health care- and self-management-related outcomes

	Transition clinic (*n* = 11)[a]	Control setting (*n* = 14)[b]	Effect size[c]	*P*-value[d]
Health care-related				
Transfer experiences (OYOF-TES)	71.73 (±8.84)	67.50 (±7.83)	0.48	.218
Satisfaction with transition (VAS; range 1-10)	8.00 (±1.27)	7.14 (±1.03)	0.68	.074
Perceived patient-centeredness of care (CAHPS)	17.60 (±2.07)	17.57 (±2.74)	0.01	.978
Self-management-related				
Self-management skills (PIH)	78.00 (±8.41)[e]	83.29 (±6.43)	-0.63	.094
Independence during consultations (range 1-10) (IBDCS)	8.67 (±0.866)[f]	9.29 (±0.914)	-0.68	.121
Self-efficacy (OYOF-SES)	57.90 (±3.00)[e]	56.00 (±10.93)	0.17	.600
Adherence to treatment (MARS-5)	21.80 (±2.20)[e]	20.00 (±3.49)	0.52	.165
Health-related quality of life (PedsQL-YA)	72.17 (±14.44)[e]	73.84 (±18.53)	-0.09	.815

[a] *n* = 11 (40.7%) responded to the survey.
[b] *n* = 14 (73.7%) responded to the survey.
[c] Cohen's *d* (based on largest SD).
[d] Independent Samples *T*-test.
[e] *n* = 10.
[f] *n* = 9.

Self-management-related outcomes

There were no significant differences regarding self-management. Still, effect sizes show some trends. Young people in the TC setting tended to report better medication adherence than those in the control setting (*d* = 0.52) (Table 4). However, they also tended to report lower scores on self-management and independence during consultations; effect sizes were medium (respectively *d* = –0.63 and *d* = –0.68).

Differences in health care use and clinical outcomes

Young people who received care at the TC were significantly more often admitted to hospital in the two years after transfer than those in direct hand-over care (*P* = .045, *d* = 0.45) (Table 5). This may be related to poorer pulmonary functioning, as they had lower FEV1% predicted over the whole period compared with those in the control setting. Before transfer, these differences were not statistically significant; effect sizes were medium (T1: *P* = .173, *d* = –0.40; T2: *P* = .145, *d* = –0.49). After transfer, the differences were significant with large effect sizes (T3: $P = .003$, $d = -1.03$; T4: $P = .007$, $d = -1.06$). Within-subject analyses showed a significant linear decrease of FEV1% predicted over the four measurement moments in the TC group ($F(2.22, 40.03) = 5.89$, $P = .004$). There was no significant difference in FEV1% predicted over time within the control group. The correlation between pulmonary functioning and satisfaction with transition was not significant ($r_s = 0.298$, $P = .203$).

Table 5

Differences in health care use and clinical outcomes

	Transition clinic		Control setting		Effect size[a]	*P*-value[b]
No-show at first appointment in AC[c]						
	$n = 26$	1 (3.8%)	NA	NA	NA	NA
No. of hospital admissions						
T1	$n = 26$	0.65 (±1.13)	$n = 14$	0.36 (±0.842)	0.26	.395
T2	$n = 26$	0.58 (±1.10)	$n = 14$	0.43 (±1.09)	0.14	.686
T3	$n = 26$	0.54 (±0.811)	$n = 12$	0.50 (±0.798)	0.05	.892
T4[d]	$n = 26$	0.54 (±1.03)	$n = 12$	0.08 (±0.289)	0.45	.045
No. of emergency department visits						
T1	$n = 26$	0.23 (±0.815)	$n = 14$	0.07 (±0.267)	0.19	.484
T2	$n = 26$	0.31 (±1.05)	$n = 14$	0.21 (±0.579)	0.09	.760
T3	$n = 26$	0.04 (±0.196)	$n = 12$	0.58 (±0.996)	-0.54	.086
T4	$n = 26$	0	$n = 12$	0.08 (±0.289)	-0.28	.339
FEV1% predicted[e]						
T1	$n = 25$	78.11 (±18.54)	$n = 12$	88.41 (±25.84)	-0.40	.173
T2	$n = 23$	73.88 (±17.28)	$n = 12$	87.55 (±28.16)	-0.49	.145
T3	$n = 24$	70.48 (±19.07)	$n = 10$	94.89 (±23.59)	-1.03	.003
T4	$n = 22$	67.56 (±22.51)	$n = 10$	93.08 (±24.15)	-1.06	.007
No. of acute exacerbations						
T1	$n = 27$	0.67 (±0.832)	$n = 14$	1.29 (±1.98)	-0.31	.280
T2	$n = 23$	0.35 (±0.775)	$n = 14$	1.86 (±2.57)	-0.59	.050
T3	$n = 25$	0.76 (±1.27)	$n = 12$	0.75 (±1.49)	0.01	.983
T4	$n = 25$	0.72 (±1.28)	$n = 12$	0.50 (±0.798)	0.17	.588
BMI						
T1	$n = 25$	21.02 (±2.14)	$n = 12$	20.45 (±2.42)	0.24	.473
T2	$n = 24$	21.22 (±2.19)	$n = 12$	20.68 (±3.00)	0.18	.544
T3	$n = 16$	20.62 (±2.60)	$n = 6$	22.34 (±2.84)	-0.61	.193
T4	$n = 17$	20.94 (±3.04)	$n = 6$	22.36 (±2.62)	-0.47	.321

Abbreviations: BMI, body mass index; AC, adult care.

[a] Cohen's *d* (based on largest *SD*).

[b] Independent Samples *T*-test or Pearson χ^2-test.

[c] No data available from the control setting, except that we know that one of the patients was lost to follow-up after transfer.

[d] T1: two years before transfer; T2: one year before transfer; T3: one year after transfer; T4: two years after transfer.

[e] Calculation based on guidelines of the Global Lung Function Initiative (http://gligastransfer.org.au/calcs/spiro.html).

DISCUSSION

In this study, we found that joint consultations between professionals from PC and AC are generally preferred over direct hand-over transfer, and that having a dedicated transition coordinator is important in transitional care. This is confirmed in several other studies (Betz et al., 2013; Betz et al., 2018; Kirk, 2008). A coordinator at both sites of transition helps to secure organizational and health care-related issues, given the array of new services that were to be accessed (Betz et al., 2013). For successful transitional care, it also appears essential to address transition and self-management skills from an early age on. The interviewed professionals perceived several benefits of the TC, such as obtaining a holistic view of the transferring patient and fine-tuning of care between the settings. Professionals also noted that young people and their parents had more confidence in the transfer since they started seeing them at the TC. Indeed, the young people treated at the TC reported significantly more trust in their adult HCPs than those receiving direct hand-over care. This is probably because the former had met their new HCPs more often before transfer, which is considered one of the most effective mechanisms of transition programs (Coyne et al., 2017; Surís & Akré, 2015).

A contra-intuitive outcome of our study was that young people in the TC group had lower scores on self-management outcomes compared with those in the control group. The qualitative study revealed that self-management interventions (e.g., ITPs) are not always used as intended. When embedded in routine, ITPs can facilitate the discussion about patient's and parents' perceptions of transition readiness (Connett & Nagra, 2018). Besides this, it is important to provide young people with room for mastering self-management tasks, e.g., by organizing independent consultations with young people alone (without parents) more frequently during the transition phase (Van Staa et al., 2015). It remains a misconception, however, that young patients are all on their own when they transfer to AC. Our results showed that pediatric HCPs still take over young people's responsibilities, instead of encouraging them toward more independence. Pediatric HCPs may be projecting their own concerns onto their young patients, thereby hindering patient empowerment (Coyne et al., 2017; Flume et al., 2001).

Many professionals mentioned lack of time, planning difficulties, and reimbursement issues as barriers for the organization and functioning of a TC. These organizational barriers are not unique to the CF setting. The need to close the gaps in transitional care delivery and staff support is often mentioned (White et al., 2018). To optimize the organization and functioning of a TC, the microsystem level (patient, family, and the care team) should receive support from the mesosystem (hospital) and macrosystem level (governance) (Stern et al., 2014). In current daily practice, this higher-level support seems insufficient.

Looking at health care use and clinical outcomes, we found few significant results. However, most of these are probably not related to having a transition program in place. The lower FEV1% predicted values in the TC group compared with the control group hold for the entire study period, suggesting higher disease severity in the former. This could also explain the higher number of hospital admissions in the TC group in the second year after transfer. Also, other factors outside the scope of this study might have been of influence, such as differences in practice patterns and preferences despite widely utilized protocols.

Strengths and limitations

This evaluation study included a unique controlled pre-post design with a reasonably long study period. The mixed-methods approach helped gaining insight into the organization and functioning of the TC and perceived facilitators and barriers.

The relatively small number of participants may have negatively impacted the study's statistical power. Analysis showed some trends toward better transfer experiences in the TC setting, although few findings were statistically significant. Furthermore, the study was conducted in two academic medical centers in the Netherlands, using different electronic medical record systems. Insight into clinic attendance around the time of transfer was limited by the variation in registration of scheduled consultations and the lack of systematic recording of missed consultations. As both centers are following the Dutch Guideline Diagnostics and Treatment Cystic Fibrosis (CBO, 2007) recommending four multidisciplinary consultations a year, differences regarding scheduled consultations are not expected. We initially intended to compare both centers on the primary outcome of no-show after transfer (Sattoe et al., 2016), but unfortunately these data were not available for the control setting. What we do know, however, is that one patient in the control setting was lost to follow-up in the two years after transfer to AC.

CONCLUSION

We uncovered some benefits of an outpatient TC for young people with CF, from the perspective of the surveyed young people themselves and that of the interviewed professionals. No notable differences in health-related outcomes were found. Joint consultations in combination with a transition coordinator and an early started and structured process of preparation were considered facilitators for successful transitional care. For further improvement, organizational and financial barriers need to be addressed. This requires support from the meso and macro levels. It would be helpful to embed self-management interventions in routine transitional care.

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REFERENCES

Arah, O. A., ten Asbroek, A. H., Delnoij, D. M., de Koning, J. S., Stam, P. J., Poll, A. H., Vriens, B., Schmidt, P. F., & Klazinga, N. S. (2006). Psychometric properties of the Dutch version of the Hospital-level Consumer Assessment of Health Plans Survey instrument. *Health Services Research, 41*(1), 284-301. https://doi.org/10.1111/j.1475-6773.2005.00462.x

Askew, K., Bamford, J., Hudson, N., Moratelli, J., Miller, R., Anderson, A., Doe, S., & Bourke, S. J. (2017). Current characteristics, challenges and coping strategies of young people with cystic fibrosis as they transition to adulthood. *Clinical Medicine (London), 17*(2), 121-125. https://doi.org/10.7861/clinmedicine.17-2-121

Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook, 61*(5), 311-336. https://doi.org/10.1016/j.outlook.2013.01.008

Betz, C. L., Smith, K., Van Speybroeck, A., Jacobs, R. A., Rivera, N., Lee, J., Saghhafi, S., Nguyen, B., & Tu, H. (2018). Descriptive analysis and profile of health care transition services provided to adolescents and emerging adults in the Movin' On Up health care transition program. *Journal of Pediatric Health Care, 32*(3), 273-284. https://doi.org/10.1016/j.pedhc.2017.11.006

Bowmer, G., Sowerby, C., & Duff, A. (2018). Transition and transfer of young people with cystic fibrosis to adult care. *Nursing Children and Young People, 30*(5), 34-39. https://doi.org/10.7748/ncyp.2018.e1080

Chaudhry, S. R., Keaton, M., & Nasr, S. Z. (2013). Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatric Pulmonology, 48*(7), 658-665. https://doi.org/10.1002/ppul.22647

Connett, G. J., & Nagra, A. (2018). Ready, Steady, Go - Achieving successful transition in cystic fibrosis. *Paediatric Respiratory Reviews, 27*, 13-15. https://doi.org/10.1016/j.prrv.2018.05.007

Coyne, I., Sheehan, A. M., Heery, E., & While, A. E. (2017). Improving transition to adult healthcare for young people with cystic fibrosis: A systematic review. *Journal of Child Health Care, 21*(3), 312-330. https://doi.org/10.1177/1367493517712479

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood, 96*(6), 548-553. https://doi.org/10.1136/adc.2010.202473

Dutch Cystic Fibrosis Foundation. (2018). *Dutch Cystic Fibrosis Registry: Annual Report for 2017*. NCFS.

Dutch Institute for Healthcare Improvement. (2007). *Guideline Diagnostics and Treatment Cystic Fibrosis*. CBO.

Feinstein, R., Rabey, C., & Pilapil, M. (2017). Evidence supporting the effectiveness of transition programs for youth with special health care needs. *Current Problems in Pediatric and Adolescent Health Care, 47*(8), 208-211. https://doi.org/10.1016/j.cppeds.2017.07.005

Flume, P. A., Anderson, D. L., Hardy, K. K., & Gray, S. (2001). Transition programs in cystic fibrosis centers: perceptions of pediatric and adult program directors. *Pediatric Pulmonology, 31*(6), 443-450. https://doi.org/10.1002/ppul.1073

Goralski, J. L., Nasr, S. Z., & Uluer, A. (2017). Overcoming barriers to a successful transition from pediatric to adult care. *Pediatric Pulmonology, 52*(S48), S52-S60. https://doi.org/10.1002/ppul.23778

Gravelle, A. M., Paone, M., Davidson, A. G. F., & Chilvers, M. A. (2015). Evaluation of a multidimensional cystic fibrosis transition program: A quality improvement initiative. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 30*(1), 236-243. https://doi.org/10.1016/j.pedn.2014.06.011

Kirk, S. (2008). Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health & Development, 34*(5), 567-575. https://doi.org/10.1111/j.1365-2214.2008.00862.x

Limperg, P. F., Haverman, L., van Oers, H. A., van Rossum, M. A., Maurice-Stam, H., & Grootenhuis, M. A. (2014). Health related quality of life in Dutch young adults: psychometric properties of the PedsQL generic core scales young adult version. *Health and Quality of Life Outcomes, 12*, 9. https://doi.org/10.1186/1477-7525-12-9

Okumura, M. J., & Kleinhenz, M. E. (2016). Cystic Fibrosis transitions of care: Lessons learned and future directions for cystic fibrosis. *Clinics in Chest Medicine, 37*(1), 119-126. https://doi.org/10.1016/j.ccm.2015.11.007

Okumura, M. J., Ong, T., Dawson, D., Nielson, D., Lewis, N., Richards, M., Brindis, C. D., & Kleinhenz, M. E. (2014). Improving transition from paediatric to adult cystic fibrosis care: programme implementation and evaluation. *BMJ Quality & Safety, 23*(Suppl. 1), i64-i72. https://doi.org/10.1136/bmjqs-2013-002364

Opoka-Winiarska, V., Cofta, S., Mazurek, H., & Kozielski, J. (2015). Problems of patients with cystic fibrosis during transition to adulthood. *Pneumonologia i Alergologia Polska, 83*(5), 394-400. https://doi.org/10.5603/PiAP.2015.0064

Patel, A., Dowell, M., & Giles, B. L. (2017). Current concepts of transition of care in cystic fibrosis. *Pediatric Annals, 46*(5), e188-e192. https://doi.org/10.3928/19382359-20170425-02

Petkov, J., Harvey, P., & Battersby, M. (2010). The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Quality of Life Research, 19*(7), 1079-1085. https://doi.org/10.1007/s11136-010-9661-1

Quon, B. S., & Aitken, M. L. (2012). Cystic fibrosis: what to expect now in the early adult years. *Paediatric Respiratory Reviews, 13*(4), 206-214. https://doi.org/10.1016/j.prrv.2012.03.005

Sattoe, J. N. T., Peeters, M. A. C., Hilberink, S. R., Ista, E., & van Staa, A. L. (2016). Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open, 6*(8), e011926. https://doi.org/10.1136/bmjopen-2016-011926

Stern, M., Bertrand, D. P., Bignamini, E., Corey, M., Dembski, B., Goss, C. H., Pressler, T., Rault, G., Viviani, L., Elborn, J. S., & Castellani, C. (2014). European Cystic Fibrosis Society standards of care: Quality management in cystic fibrosis. *Journal of Cystic Fibrosis, 13*(Suppl. 1), S43-59. https://doi.org/10.1016/j.jcf.2014.03.011

Surís, J. C., & Akré, C. (2015). Key elements for, and indicators of, a successful transition: an international Delphi study. *Journal of Adolescent Health, 56*(6), 612-618. https://doi.org/10.1016/j.jadohealth.2015.02.007

Tommelein, E., Mehuys, E., Van Tongelen, I., Brusselle, G., & Boussery, K. (2014). Accuracy of the Medication Adherence Report Scale (MARS-5) as a quantitative measure of adherence to inhalation medication in patients with COPD. *Annals of Pharmacotherapy, 48*(5), 589-595. https://doi.org/10.1177/1060028014522982

Tuchman, L., & Schwartz, M. (2013). Health outcomes associated with transition from pediatric to adult cystic fibrosis care. *Pediatrics, 132*(5), 847-853. https://doi.org/10.1542/peds.2013-1463

Van Staa, A. L. (2012). *On Your Own Feet: Adolescents with chronic conditions and their preferences and competencies for care.* Erasmus University Rotterdam.

Van Staa, A. L., & Sattoe, J. N. T. (2014). Young adults' experiences and satisfaction with the transfer of care. *Journal of Adolescent Health, 55*(6), 796-803. https://doi.org/10.1016/j.jadohealth.2014.06.008

Van Staa, A. L., Sattoe, J. N. T., & Strating, M. M. (2015). Experiences with and outcomes of two interventions to maximize engagement of chronically ill adolescents during hospital consultations: A mixed methods study. *Journal of Pediatric Nursing, 30*(5), 757-775. https://doi.org/10.1016/j.pedn.2015.05.028

West, N. E., & Mogayzel, P. J., Jr. (2016). Transitions in health care: What can we learn from our experience with cystic fibrosis. *Pediatric Clinics of North America, 63*(5), 887-897. https://doi.org/10.1016/j.pcl.2016.06.010

White, P. H., Cooley, W. C., Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 142*(5). https://doi.org/10.1542/peds.2018-2587

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Value of an outpatient transition clinic for young people with inflammatory bowel disease: a mixed-methods evaluation

Jane N.T. Sattoe
Mariëlle A.C. Peeters
Jannie Haitsma
AnneLoes van Staa
Victorien M. Wolters
Johanna C. Escher

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ABSTRACT

Objective

Developing and evaluating effective transition interventions for young people (16–25 years) with inflammatory bowel disease (IBD) is a high priority. While transition clinics (TCs) have been recommended, little is known about their operating structures and outcomes. This study aimed to gain insight into the value of a TC compared with direct hand-over care.

Design

Controlled mixed-methods evaluation of process outcomes, clinical outcomes and patient-reported outcomes.

Setting

Two outpatient IBD clinics in the Netherlands.

Participants

Data collection included: semi-structured interviews with professionals (*n* = 8), observations during consultations with young people (5×4 hours), medical chart reviews of patients transferred 2 to 4 years prior to data collection (*n* = 56 in TC group; *n* = 54 in control group) and patient questionnaires (*n* = 14 in TC group; *n* = 19 in control group).

Outcomes

Data were collected on service structures and daily routines of the TC, experienced barriers, facilitators and benefits, healthcare use, clinical outcomes, self-management outcomes and experiences and satisfaction of young people with IBD.

Results

At the TC, multidisciplinary team meetings and alignment of care between pediatric and adult care providers were standard practice. Non-medical topics received more attention during consultations with young people at the TC. Barriers experienced by professionals were time restrictions, planning difficulties, limited involvement of adult care providers and insufficient financial coverage. Facilitators experienced were high professional motivation and a high case load. Over the year before transfer, young people at the TC had more planned consultations ($p = 0.015$, Cohen's $d = 0.47$). They showed a positive trend in better transfer experiences and more satisfaction. Those in direct hand-over care more often experienced a relapse before transfer ($p = 0.003$) and had more missed consultations ($p = 0.034$, Cohen's $d = -0.43$) after transfer.

Conclusion

A TC offers opportunities to improve transitional care, but organizational and financial barriers need to be addressed before guidelines and consensus statements in healthcare policy and daily practice can be effectively implemented.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This study is unique in its design, since it is the first transition clinic (TC) evaluation study to include a control group and similar controls, while employing a reasonably long monitoring period, covering the 2 years before transfer and the 2 years after transfer.
- The mixed-methods design is a strength, because it provided a more comprehensive interpretation of the results, for instance about the organization and interventions employed in the current TC model.
- A limitation of the study is the insufficient statistical power to demonstrate significant differences in patient-reported outcomes between settings, since the response rate on the questionnaires was low (37%–46%).
- In addition, patients transferred to other hospitals could not be included in the post-transfer measurements, despite repeated efforts to collect these.

INTRODUCTION

In recent years, much attention has been given to the development, implementation and evaluation of transition interventions for young people with inflammatory bowel disease (IBD). Two years ago, a national guideline on transition of young people with chronic digestive diseases, including IBD, was developed in the UK (Brooks et al., 2017). The need to improve care for these young people has been repeatedly emphasized (Philpott & Kurowski, 2019), for instance in a topical review on transitional care for young people with IBD by the European Crohn's and Colitis Organization (Van Rheenen et al., 2017) and in a position statement by the Italian Society of Gastroenterology (Elli et al., 2015).

IBD is a collective term for ulcerative colitis, Crohn's disease and IBD unclassified. While growing up, young people with IBD must learn to manage a very demanding and complex disease. For a correct diagnosis and treatment efficacy, repeat endoscopy is necessary as well as often lifelong treatment with a combination of medication and possibly surgery. Treatment is aimed at controlling inflammation and preventing exacerbations (Lindfred et al., 2012). In adolescents, IBD is more severe than in adults (Goodhand et al., 2011), showing an unpredictable pattern that is hard to adjust treatment and daily life to.

Next to physical complaints such as abdominal pain, fatigue and side effects of medication, IBD is associated with psychological and social problems in young people (Brooks et al., 2016; Kemp et al., 2012). Many young people with IBD must deal with stress, fear, depressive symptoms and school absenteeism more than their healthy age-mates (Bishop et al., 2014). As a result of all this, health-related quality of life is compromised (Lindfred et al., 2012). These young people are especially vulnerable when going through the overall transition from childhood to adulthood and being transferred from pediatric to adult healthcare. Research shows that during these transitions, young people may resist strict treatment regimens leading to non-adherence to medication and drop-out of healthcare. Consequently, they are at risk for complications and worsening health (Fegran et al., 2014). Indeed, adolescents with IBD are reported to have more missed consultations and more hospital admissions than adults with IBD (Goodhand et al., 2011).

To support young people with IBD during their transition from pediatric to adult care and to address both the physical and psychosocial burden of their disease, a profound recommendation made is to implement transition clinics (TCs) (Clarke & Lusher, 2016; Goodhand et al., 2011; Mazur et al., 2017; Van Rheenen et al., 2017). Although there is no common definition of a TC, the core principle is that professionals from pediatric care and adult care jointly deliver outpatient care (Carrizosa et al., 2014; Crowley et al., 2011; Philpott & Kurowski, 2019). While TCs are advocated as best practice in transitional care, clinical practice in this area is just emerging and there is still little understanding about service structures, experiences and outcomes of TCs. This is especially true for transitional care for young people with IBD (Gray & Maddux, 2016; Philpott & Kurowski, 2019). Also, it is important for evaluation studies to consider both patient satisfaction and clinical outcomes (Philpott & Kurowski, 2019). This study aimed to gain insight into the value of a TC compared with direct hand-over care for young people with IBD by employing a mixed-methods approach. This approach gave room for new insights into outcomes of a TC for young people with IBD while considering its context.

MATERIALS AND METHODS

Study design

The study included a controlled mixed-methods evaluation of process, clinical and patient-reported outcomes. The TC setting was compared with direct hand-over care for young people with IBD on service structures and daily routines, healthcare use, clinical outcomes, self-management outcomes and experiences and satisfaction with the transfer. Health professionals' experienced barriers and facilitators for the functioning of the TC and perceived benefits were also studied. The study was set in two clinics in university medical centers in the Netherlands, of which one was a TC. The full study protocol has been published before (Sattoe et al., 2016). The SQUIRE (Standards for Quality Improvement Reporting Excellence) reporting guidelines were used.

Data collection and study sample

Service structures and daily routines were studied with semi-structured interviews with healthcare professionals and observations during consultations with young people. The interviews also served to gain insight into experienced barriers, facilitators and benefits of the TC. Themes addressed during the interviews were based on relevant literature. These included the validated 'You're welcome' quality criteria that determine whether a clinic can be typified as young people-friendly (Hargreaves, 2011), the 'Mind the Gap' tool that is used to measure the difference between ideal and experienced transitional care (Shaw et al., 2007), and known experiences of young adults, parents and professionals (Betz et al., 2013; Fegran et al., 2014; Lugasi et al., 2011; Nehring et al., 2015; Sonneveld et al., 2013; Van Staa et al., 2011). Examples of topics are reasons for (not) setting up a TC, usefulness of the TC, barriers and facilitators, coordination of the TC, structure and content of transitional care and changes over time, composition of the healthcare team, use of specific interventions and the perceived value of the TC for young people, their parents and healthcare professionals. Interviews lasted for 45 to 60 min per respondent. Non-participant observations of outpatient consultations were conducted at both settings. In the control setting, regular consultations were observed. Researchers took field notes and wrote down their findings in narratives. The observers focused on coordination of the transition process, content of consultations, interaction between involved parties and use of transition interventions. Professionals from the TC were interviewed between May and July 2014 and those from the control setting between February and April 2015. Observations in the TC setting took place in the period May–July 2014, and in the control setting this was the case for the period June–August 2015.

All young people who had been transferred between 2010 and 2013 (2–4 years before data collection) were included in a chart review and were asked to fill out a survey. Those with severe intellectual disabilities or known psychiatric problems were excluded. Healthcare use and clinical outcomes were assessed through patient chart reviews, at four points in time: the second year before transfer = T1, the year before transfer = T2, the year after transfer = T3, and the second year after transfer = T4. Self-management outcomes, experiences and satisfaction were studied with online surveys among the young people, filled out between March and October 2015.

Since fully attending scheduled visits in adult care is an indicator for a successful transition (Surís & Akré, 2015), the primary outcome for the chart review was the number of missed consultations after transfer. The sample size calculation was based on this outcome and indicated we needed a sample size of 72 or more in each group (Sattoe et al., 2016). These sample sizes could not be achieved, however, since the populations that met the inclusion criteria at both sites numbered less than 72 per group. At both sites, all young people that met the inclusion criteria were included. The primary outcome for the survey was transfer experiences. Details on the quantitative data collection are presented in Table 1.

Data analyses

Interviews were audio taped and transcribed verbatim. Interview transcripts and observation narratives were coded thematically by two researchers (JNTS and MACP) independently. The research applied the framework approach, whereby themes addressed during the interviews and observations were leading in the coding process. If applicable, subthemes were derived from the data. ATLAS.ti 7.0 was used for qualitative data analysis.

Independent samples *t*-tests and χ^2-tests served to test differences between the intervention and control groups in chart review and survey outcomes, and effect sizes were calculated. Cases with missing data were omitted. IBM SPSS Statistics 25 was used for quantitative data analysis.

Ethical considerations

Young people and, if applicable, their parents received an information letter from the doctor in charge of treatment. They provided written informed consent per study part. Data were processed anonymously and pseudonyms were used in the interview transcripts and observation narratives.

Table 1

Quantitative data collection method, method description and outcome measures

Method	Description	Themes addressed or outcome measures
Chart review	Of each outpatient department, all charts were reviewed of patients who transferred to adult care 2–4 years prior to data collection. Data from chart reviews were collected for four moments over time: second year before transfer (T1), year before transfer (T2), year after transfer (T3) and second year after transfer (T4). T3 and T4 data were only available for young people who transferred to an adult department within the same hospital. Patients with severe intellectual disabilities or known psychiatric problems were excluded.	Background characteristics: Date of birth, date of diagnosis, gender, comorbidity. Transfer: Date of transfer, current healthcare provider (department to which young person transferred is recorded/known). Medical follow-up: No-show at first appointment in adult care, number of scheduled/missed consultations, number of planned and unplanned hospitalizations, emergency department visits. Clinical outcomes: • *Use of medications*, in four categories: 1=aminosalicylates; 2=corticosteroids; 3=immunomodulators; 4=biologicals/biosimilars. • *Disease activity during transfer*, measured by global physician assessment in four categories (remission, mild, moderate and severe) dichotomized as being active (moderate or severe) or not (remission or mild), or measured by the Pediatric Ulcerative Colitis Activity Index (PUCAI)/weighted Pediatric Crohn's Disease Activity Index (wPCDAI), where a score of 10 or higher indicated active disease during transfer. • Whether young people had a *relapse* in the year before transfer (T2) or after transfer (T3).
Survey	An invitation for a digital survey was sent to all patients whose charts were reviewed.	Background characteristics: Educational level, type of education, disability benefits. Healthcare-related outcomes: • *Transfer experiences* measured with the validated 18-item On Your Own Feet Transfer Experiences Scale with 5-point Likert scales (Van Staa & Sattoe, 2014). • Self-reported *satisfaction with transition* on a 1–10 scale. • Perceived *patient-centeredness* measured with a subscale of the American Consumer Assessment of Health Plan Surveys (validated 5-item scale with 4-point Likert scales (Arah et al., 2006). Self-management-related outcomes: • *Self-management* measured with the validated 12-item Partners in Health Scale with 9-point Likert scales (Battersby et al., 2003; Petkov et al., 2010). • *Independence during consultations* measured as self-reported independence on a 1–10 Visual Analogue Scale. • *Self-efficacy* measured with the validated 16-item On Your Own Feet Self-Efficacy Scale with 4-point Likert scales (Van Staa, 2012). • Adherence to treatment measured with the validated 5-item Medication Adherence Rating Scale with 5-point Likert scales (Mahler et al., 2010). • *Health-related quality of life* measured with the validated 23-item Pediatric Quality of Life Inventory Young Adult with 5-point Likert scales (Limperg et al., 2014).

Patient and public involvement

Patients or the public were not involved in the design, conduct, reporting or dissemination of our research.

RESULTS

Study setting and response

Two pediatric gastroenterology departments treating young people with IBD participated. One of these had implemented a TC in 2006. The other department had not (yet) implemented a transition program or TC and served as control setting.

In both settings, interviews were held with professionals involved in transitional care. Three observations of 4 hours of outpatient consultations were performed at the TC and two in the control setting. At the TC, 56 young people had been transferred to adult care 2 to 4 years prior to data collection. Twenty-five of these (44.6%) had been transferred to another hospital, implying that data after transfer were not readily available. In the control setting, the total study sample numbered 54, of whom 30 (55.6%) had been transferred to another hospital. Of the total groups, 21 of the young people in the TC setting (37.5%) and 25 of those in the control setting (46.3%) responded to the invitation for the survey. Eventually, 14 (25%) and 19 (35.2%) filled out the survey, respectively. The study response is summarized in Table 2. A description of the study sample is given in Table 3.

Table 2
Study response per data collection method per setting

Data collection method	Transition clinic	Control setting
Semi-structured interviews	5 interviews: pediatric IBD nurse specialist (*n*=1), pediatric gastroenterologists (*n*=2), adult gastroenterologist (*n*=1) and one family counsellor working in pediatric care (*n*=1).	3 interviews: pediatric gastroenterologist (*n*=1), adult care nurse (*n*=1) and adult gastroenterologist (*n*=1).
Observations	3×4 hours of clinical consultations before transfer.	2×4 hours of clinical consultations before transfer.
Chart reviews	*n*=56 (young people with IBD), of which 25 transferred to an adult department in another hospital. Number of charts per measurement moment were: T1, *n*=55; T2, *n*=56; T3, *n*=30; T4, *n*=30.	*n*=54 (young people with IBD), of which 30 transferred to an adult department in another hospital. Number of charts per measurement moment were: T1, *n*=44; T2, *n*=54; T3, *n*=24; T4, *n*=23.
Surveys	*n*=21 responded (37.5%); *n*=14 (25.0%) filled out the survey.	*n*=25 responded (46.3%); *n*=19 (35.2%) filled out the survey.

IBD, inflammatory bowel disease.

Table 3
Characteristics of the study samples of young people with IBD

	Transition clinic (*n*=56 before transfer; *n*=30 after transfer)	Control setting (*n*=54 before transfer; *n*=24 after transfer)	*P*-value*
Gender (male)	31 (55.4%)	30 (55.6%)	0.983
Age at time of survey (years)	20.89 (±0.908)	21.02 (±0.961)	0.482
Diagnosis			
Crohn's disease	29 (51.8%)	24 (44.4%)	0.701
Ulcerative colitis	24 (42.8%)	23 (42.6%)	
IBD unclassified	3 (5.4%)	6 (11.1%)	
Ulcerative proctitis	-	1 (1.9%)	
Timing of diagnosis			
Within two years before transfer	2 (3.6%)	11 (20.4%)	0.006
More than two years before transfer	54 (96.4%)	43 (79.6%)	
Age at transfer (years)	17.46 (±0.503)	17.26 (±0.589)	0.052

* Independent Samples *T*-test or Pearson χ^2-test.
IBD, inflammatory bowel disease.

Service structures and daily routines

Joint delivery of outpatient care between pediatric and adult professionals was the main difference between the TC setting and the direct hand-over transfer setting (control setting). The TC was organized in an adult care setting; the multidisciplinary team consisted of two pediatric gastroenterologists, one adult gastroenterologist, one pediatric nurse specialist and one family counsellor working in pediatric care. In the direct hand-over care setting, only one pediatric gastroenterologist was involved in care before transfer. At the TC, young people aged 16 to 18 years were seen. They visited every 3 months before actual transfer to adult care. Three out of the four consultations per year were held with pediatric care professionals; the other consultation was with the adult care professional. Although this TC did not provide joint consultations, there was intensive collaboration and alignment between pediatric and adult providers (joint care). Prior to each TC, the pediatric and adult team together discussed the patients.

In both settings, during consultations attention was given to the medical aspects of IBD, such as dealing with the treatment and with treatment side effects. Young people's own ideas and responsibilities were also discussed in both settings, as well as the upcoming transfer. However, at the TC, more attention was given to non-medical topics, such as leisure, sports, independent living, work, family situation and psychological counselling, as well as differences between the pediatric and adult healthcare setting. Table 4 provides a summary of the differences in service structures, daily routines, and content of consultations between the TC and control setting.

Interview results

Facilitators

The most important facilitators for the functioning of the TC are related to the healthcare team involved in transitional care. High engagement and motivation of healthcare professionals from both pediatric and adult care is essential according to all respondents at the TC. Pediatric and adult professionals should be willing to work together and perceive transitional care (and thus the TC) as important. The pediatric nurse explained: "What I noticed is that it is essential to have people who are enthusiastic, who think this is really important." The adult gastroenterologist seemed to agree: "You just need people who are enthusiastic and who can work together. We are doing this together." Another facilitator was the fact that the case load of patients seen at the TC was large enough for clinics to be structurally scheduled over the year.

Barriers

Barriers for the organization of a TC were: (1) lack of service structure and alignment in content of care between pediatric and adult care, and little attention given to transition-

Table 4
Differences in service structures and daily routines between the two settings

Characteristics of care	Transition clinic	Control setting (direct hand-over care)
Setting	Adult gastroenterology department.	Pediatric gastroenterology department.
Team of professionals	Pediatric IBD nurse specialist (n=1), pediatric gastroenterologists (n=2), adult gastroenterologist (n=1), and one family counsellor working in pediatric care (n=1).	Pediatric gastroenterologist (n=1).
Visitors	Young people with IBD aged 16-18 years with or without their parents.	Young people with IBD with or without their parents until age of 18.
Visits TC	Every 3 months.	-
Follow-up after transfer within the same hospital	By an adult gastroenterologist, but not necessarily the one involved at the TC.	By an adult gastroenterologist or IBD nurse.
Structure of care before transfer	1. Each clinic starts with 1-hour multidisciplinary team meeting of professionals, usually lead by the pediatric nurse specialist. 2. Consultation with pediatric gastroenterologist or pediatric nurse. 3. Consultation with adult gastroenterologist for selected young people who will soon transfer to adult care; all young people treated at the TC will see the adult care gastroenterologist at least once before actual transfer to adult care, and preferably once every year.	1. No multidisciplinary team or nurse involved. 2. Measurements of weight and length by a medical assistant. 3. Consultation with pediatric gastroenterologist.
Topics discussed (content of care)	During team meeting: medical history and status, treatment, and lifestyle of patients (e.g., smoking behavior); when pediatric nurse is in the lead extra topics are discussed: psychosocial topics (social participation, family situation, psychological counselling), treatment adherence, transfer to adult care (to which department/hospital). During consultation of pediatric healthcare professional with young person (with or without parents): how is your IBD, do you have complaints or symptoms you want to discuss, which medication do you use (directed to patient), how is this going, what are side effects, how is your eating behavior, smoking behavior, limitations in daily living (sports, hobby's, leisure, school, holidays), future plans, medication adherence, transfer to adult care, explaining TC, importance of becoming independent, and own responsibility. During consultation of adult gastroenterologist with young person (with or without parents): how is it going with the condition, do you have complaints or symptoms you want to discuss, which medication do you use (directed to patient), how is this going, what are side effects, importance of own responsibility (when taking medication), further treatment, explanation about TC, differences between pediatric and adult care, choice of department young person will be transferred to, activities of young person (school, work, living).	During consultation of pediatric gastroenterologist with young person (with or without parents): physical examination by healthcare professional, how is it going with the condition, do you have complaints or symptoms you want to discuss, how is it going with taking your medication (how will you do this during holidays), how are things going at school, school absenteeism, further treatment (endoscopy and importance of own voice in healthcare from 16 years and older, including transfer).

IBD, inflammatory bowel disease; TC, transition clinic.

specific topics; (2) time restrictions and planning difficulties; (3) limited involvement of professionals from adult care; (4) lack of financial coverage of the provided joint care. Professionals from both pediatric and adult care mentioned that they did not really coordinate who would discuss which topic with the young person (and his/her parents). Coordination could provide more structure in discussing important topics and preparing young persons for transition, but they feel that time is too short. The pediatric gastroenterologist explained: “So many things have to be done in so little time that often you don’t find the time to address all important topics. […] We need to bring more structure into the content discussed, because it can be valuable to discuss certain topics repeatedly.” The adult gastroenterologist also explained: “Being involved in transitional care takes time, and that is always the big problem. We do not have time.” In the control setting, time restrictions were an important reason for not organizing a TC and the TC time restrictions were also the reason that only one dedicated adult gastroenterologist was involved at the TC: the young people did not get to know the other adult providers before transfer. Another important barrier was related to financial coverage. The adult gastroenterologist clarified: “The only reason [the TC] is organized is because both the pediatric gastroenterologist and I want to do this. We think this is important, but I think others don’t find it as important as we do. No time and extra money are reserved for the TC. Although we provide joint care, my department doesn’t get paid for this. I’m doing a lot of voluntary work and have done so for years now. Now I don’t care, but my department doesn’t get paid. That means that there is no incentive to do this.” Financial support was also an issue according to the pediatric care professionals. A pediatric gastroenterologist explained: “The transition clinic is not financially supported by the hospital. All the extra work we do, is voluntary.” Lack of reimbursement was also mentioned in the control setting as an important reason for not having a TC.

Perceived benefits

Professionals stated that creating patient awareness about the transition process, making patients feel more prepared for treatment in an adult department and making them feel more confident about the transfer and self-management were the most important assets of a TC for young people. Parents could benefit from increased awareness about transition and feeling supported to help their children to become more independent. Professionals themselves benefitted because the TC encouraged them to work and learn together. By aligning treatment protocols across pediatric and adult care departments, quality of care was enhanced. Professionals thought the young people would feel safer because of this collaboration. A pediatric gastroenterologist added: “We also want the transition to go smoothly. We do not want our patients to get sicker after transfer. We want things to go well and want them to feel confident and safe.”

Differences in healthcare use

The young people who received care at the TC on average had significantly more planned consultations in the year before transfer than those in direct hand-over care (Table 5). As for missed consultations, those who received care at the TC had significantly fewer missed consultations in the second year after transfer. Over the whole period, young people treated at the TC had significantly fewer planned and unplanned hospital admissions related to IBD. For young people at the TC, the department and hospital they had been transferred to was more often recorded in the patient chart compared with those in direct hand-over care.

Table 5

Clinical and healthcare use outcomes of young people with IBD

Chart review results	Transition clinic	Control setting	Effect size*	*P*-value†
No. of charts reviewed‡				
T1	*n*=55	*n*=44		
T2	*n*=56	*n*=54		
T3	*n*=30	*n*=24		
T4	*n*=30	*n*=23		
Active disease during transfer (yes)§	5 (9.1%)	18 (34.0%)	-	0.002
Relapse in year before transfer (T2) (yes)§	13 (23.6%)	27 (50.9%)	-	0.003
Relapse in year after transfer (T3) (yes)¶	2 (6.9%)	6 (25.0%)	-	0.067
Use of aminosalicylates (yes)				
T1	22 (40.0%)	17 (40.5%)	-	0.962
T2	23 (41.1%)	21 (38.9%)	-	0.815
T3	8 (26.7%)	5 (20.8%)	-	0.618
T4	9 (30.0%)	5 (21.7%)	-	0.499
Use of corticosteroids (yes)				
T1	17 (30.9%)	9 (21.4%)	-	0.296
T2	15 (26.8%)	14 (25.9%)	-	0.919
T3	9 (30.0%)	4 (16.7%)	-	0.255
T4	10 (33.3%)	1 (4.3%)	-	0.010
Use of immunomodulators (yes)				
T1	40 (72.7%)	22 (52.4%)	-	0.039
T2	43 (76.8%)	31 (57.4%)	-	0.030
T3	23 (76.7%)	13 (54.2%)	-	0.081
T4	25 (83.3%)	11 (47.8%)	-	0.006
Use of biologics/biosimilars (yes)				
T1	4 (7.3%)	12 (28.6%)	-	0.005
T2	5 (8.9%)	20 (37.0%)	-	0.000
T3	2 (6.7%)	12 (50.0%)	-	0.000
T4	3 (10.0%)	11 (47.8%)	-	0.002

Table 5
Clinical and healthcare use outcomes of young people with IBD (*continued*)

Chart review results	Transition clinic	Control setting	Effect size*	*P*-value†
No. of planned consultations per year				
T1	3.33 (±1.75)	3.34 (±2.07)	-0.01	0.972
T2	4.71 (±2.08)	3.74 (±2.03)	0.47	0.015
T3	2.43 (±1.14)	2.71 (±1.12)	-0.25	0.378
T4	2.23 (±1.50)	1.96 (±1.26)	0.18	0.480
No. missed consultations per year				
T1	0.07 (±0.262)	0.07 (±0.334)	0	0.940
T2	0.20 (±0.519)	0.17 (±0.466)	0.06	0.753
T3	0.03 (±0.183)	0.13 (±0.338)	-0.30	0.208
T4	0.07 (±0.254)	0.35 (±0.647)	-0.43	0.034
No. unplanned hospital admissions per year				
T1	0.30 (±0.836)	0.43 (±0.846)	-0.15	0.472
T2	0.21 (±0.624)	0.41 (±0.858)	-0.32	0.179
T3	0	0.29 (±0.859)	-0.33	0.068
T4	0.17 (±0.461)	0	0.37	0.090
No. emergency department visits per year				
T1	0.24 (±0.838)	0.02 (±0.151)	0.26	0.099
T2	0.14 (±0.483)	0.02 (±0.136)	0.25	0.071
T3	0.03 (±0.183)	0.25 (±0.847)	-0.26	0.178
T4	0	0	-	-
Department to which young person transferred is recorded/known (yes)	55 (98.2%)	48 (88.9%)	-	0.045

* Cohen's *d* (based on largest *SD*).
† Independent samples *t*-test or Pearson χ^2-test.
‡ Second year before transfer=T1, year before transfer=T2, year after transfer=T3, second year after transfer=T4.
§ Control setting *n*=53, TC setting *n*=55.
¶ TC setting *n*=29.
IBD, inflammatory bowel disease; TC, transition clinic.

Differences in clinical measures

Significantly more young people in direct hand-over care had clinically active disease during transfer compared with those seen at the TC (Table 5). The young people in direct hand-over care also more often experienced a relapse in the year before transfer. Also, the use of medications differed significantly between both groups. In the direct hand-over group, more young people used biologics compared with the TC group. This difference was found at all data collection points.

Transfer experiences and satisfaction with transition

Regarding transition experiences, young people treated at the TC were more positive on whether their adult healthcare providers were familiar with their personal situation and whether they had met their adult healthcare provider(s) before transfer (Table 6). Overall, the young people treated at the TC tended to report higher scores for transition experiences compared with those treated in direct hand-over care. This difference was not statistically significant, but the effect size was medium. The same was the case for reported satisfaction with the transfer.

Healthcare-related and self-management-related outcomes (at the time of survey)

The perceived patient-centeredness score was slightly higher at the TC, as was the case for self-efficacy, adherence to treatment, self-management and health-related quality of life (Table 6). On the other hand, young people in the direct hand-over care setting reported a slightly higher score on independence during consultations. However, none of the differences in healthcare-related and self-management-related outcomes was statistically significant and effect sizes were small.

Table 6

Self-reported healthcare-related and self-management outcomes of young people with IBD

	Transition clinic (*n*=14)	Control setting (*n*=19)	Effect size*	*P*-value†
Healthcare-related				
Transfer experiences (Theoretical range: 18-90)	67.79 (±12.86)	62.95 (±8.44)	0.38	0.201
Satisfaction with transition (Theoretical range: 1-10)	7.43 (±1.34)	6.89 (±1.20)	0.40	0.238
Patient-centeredness (Theoretical range: 5-20)	16.64 (±3.46)	16.26 (±3.31)	0.11	0.751
Self-management				
Self-management (Theoretical range: 0-96)	81.64 (±10.26)	78.79 (±10.81)	0.26	0.450
Independence during consultations (Theoretical range: 1-10)	8.43 (±1.60)	8.53 (±1.02)	-0.06	0.832
Self-efficacy (Theoretical range: 16-64)	55.93 (±6.92)	54.37 (±8.13)	0.19	0.567
Adherence to treatment‡ (Theoretical range: 5-25)	22.33 (±3.45)	21.18 (±3.54)	0.32	0.389
Health-related quality of life§ (Theoretical range: 0-100)	78.34 (±23.87)	77.67 (±15.43)	0.03	0.923

* Cohen's d (based on largest SD).

† Independent samples *t*-test.

‡ TC group: *n*=12; direct hand-over care group: *n*=17.

§ Direct hand-over care group: *n*=18.

IBD, inflammatory bowel disease; TC, transition clinic.

DISCUSSION

Unlike to the direct hand-over care setting, the evaluated outpatient TC for young people with IBD conducted multidisciplinary team meetings of professionals of both pediatric and adult care, as well as consultations between young people and adult care professionals before transfer. Interestingly, we found positive trends in young people's satisfaction and experiences with the transfer when treated at the TC, suggesting that the TC may foster the quality of transitional care. However, the differences found were not statistically significant (likely due to the low response rates in the survey study). Also, literature suggests that young people prefer professionals of both pediatric and adult care be present at the same time in consultations (joint consultations) (Bennett et al., 2016). The evaluated TC provided separate consultations, however, and providing joint consultations may possibly elicit more positive experiences.

In the recent topical review by the Pediatric Committee of the European Crohn's and Colitis Organization (P-ECCO), the importance was emphasized of empowering young people by nurturing their knowledge and skills to manage IBD (Van Rheenen et al., 2017). Participation in a transition program should enable this and specific interventions are useful to do so (Brooks et al., 2018; Carlsen et al., 2017; Van Rheenen et al., 2017). Examples of interventions are seeing young people alone, without parents, during consultations or preparing an individual transition plan (Van Staa et al., 2015). However, the TC we evaluated did not provide structural interventions or transition plans such as Ready Steady Go (Nagra et al., 2015). In both settings, there was no policy for split consultations and young people were not routinely seen on their own. Professionals recognized the need for more structure in content of the process and more attention for transition-specific topics. Mere awareness of the importance of transition among healthcare providers is not enough to foster young people's skills (Fishman et al., 2014). This could help explain why no significant differences were found in self-management-related experiences between young people treated at the TC and those treated at the control setting, although another study on a TC for young people with IBD did find significant positive effects on self-efficacy (Yerushalmy-Feler et al., 2017). Still, the low response rate and possible recall bias of young people who transferred over 2 years ago could also be held responsible for this.

Young people treated at the TC had fewer missed consultations after transfer than those treated at the control setting. This finding is in line with current literature where strong evidence is found for the enhancement of clinic attendance (Brooks et al., 2017) and this topic is also mentioned in the practice points of the topical review of P-ECCO (Van Rheenen et al., 2017). A positive effect of TCs on the continuity and safety of gastroenterology care has been reported previously (Little et al., 2017). Another study of outcomes in adolescents with IBD following transfer also found fewer missed consultations in the group that received transitional care (Cole et al., 2015). In our study, young people treated at the direct hand-over setting more often had a relapse in the year before transfer and were more often transferred while dealing with clinically active disease. At the TC, specific attention was given to disease activity, since it is known that having active disease at transfer can negatively influence the transition process (Van den Brink et al., 2019). The professionals preferred to postpone the transfer until the disease was in clinical remission. This flexibility of timing of transfer is recommended for direct hand-over IBD care too.

Important barriers for the organization of a TC were time restrictions and planning difficulties, lack of financial coverage and a lack of awareness of the importance of transitional care among adult care providers. In the literature, these issues are also described as barriers to successful transition for young people (Clarke & Lusher, 2016). This finding highlights the need to embed transitional care in healthcare policy, so that time and resources can be made available to provide good transitional care. Recent and current development of guidelines and consensus statements suggest that this awareness is growing in the field. However, the next question is how awareness may be translated to actual healthcare policy measures and how these recommendations can be implemented in daily healthcare practice.

CONCLUSION

This evaluation of a TC demonstrated that young people with IBD who had been treated at a TC had fewer missed consultations after transfer than those treated in direct hand-over care. They were less likely to have active disease during transfer, less often experienced a relapse in the year before transfer and showed a positive trend for experiences and satisfaction with transfer. Still, no significant differences were found in self-management-related experiences of young people with IBD treated at the TC compared with those in the control setting, suggesting there is room for improvement in the TC model. This was also suggested by the qualitative results of the study; that is, healthcare providers mentioned several organizational and financial challenges that may have influenced the outcomes. Although there are developments in guidelines and consensus statements about the organization and content of transitional care, the next step is to implement these recommendations in healthcare policy and daily practice.

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REFERENCES

Arah, O. A., ten Asbroek, A. H., Delnoij, D. M., de Koning, J. S., Stam, P. J., Poll, A. H., Vriens, B., Schmidt, P. F., & Klazinga, N. S. (2006). Psychometric properties of the Dutch version of the hospital-level Consumer Assessment of Health Plans Survey instrument. *Health Services Research, 41*(1), 284-301. https://doi.org/10.1111/j.1475-6773.2005.00462.x

Battersby, M. W., Ask, A., M Reece, M., J Markwick, M., & P Collins, J. (2003). The Partners in Health scale: The development and psychometric properties of a generic assessment scale for chronic condition self-management. *Australian Journal of Primary Health, 9*(3), 41-52. https://doi.org/https://doi.org/10.1071/PY03022

Bennett, A. L., Moore, D., Bampton, P. A., Bryant, R. V., & Andrews, J. M. (2016). Outcomes and patients' perspectives of transition from paediatric to adult care in inflammatory bowel disease. *World Journal of Gastroenterology, 22*(8), 2611-2620.

Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook, 61*(5), 311-336. https://doi.org/10.1016/j.outlook.2013.01.008

Bishop, J., Lemberg, D., & Day, A. (2014). Managing inflammatory bowel disease in adolescent patients. *Adolescent Health, Medicine and Therapeutics, 5*, 1-13.

Brooks, A., Rowse, G., Ryder, A., Peach, E., Corfe, B., & Lobo, A. (2016). Systematic review: psychological morbidity in young people with inflammatory bowel disease–risk factors and impacts. *Alimentary Pharmacology & Therapeutics, 44*(1), 3-15.

Brooks, A. J., Smith, P. J., Cohen, R., Collins, P., Douds, A., Forbes, V., Gaya, D. R., Johnston, B. T., McKiernan, P. J., & Murray, C. D. (2017). UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care. *Gut, 66*(6), 988-1000.

Brooks, A. J., Smith, P. J., & Lindsay, J. O. (2018). Monitoring adolescents and young people with inflammatory bowel disease during transition to adult healthcare. *Frontline Gastroenterology, 9*(1), 37-44.

Carlsen, K., Haddad, N., Gordon, J., Phan, B. L., Pittman, N., Benkov, K., Dubinsky, M. C., & Keefer, L. (2017). Self-efficacy and resilience are useful predictors of transition readiness scores in adolescents with inflammatory bowel diseases. *Inflammatory Bowel Diseases, 23*(3), 341-346.

Carrizosa, J., An, I., Appleton, R., Camfield, P., & Von Moers, A. (2014). Models for transition clinics. *Epilepsia, 55*(Suppl. 3), 46-51. https://doi.org/10.1111/epi.12716

Clarke, T., & Lusher, J. (2016). Transitioning patients with inflammatory bowel disease (IBD) from adolescent to adult services: a systematic review. *Frontline Gastroenterology, 7*(4), 264-270.

Cole, R., Ashok, D., Razack, A., Azaz, A., & Sebastian, S. (2015). Evaluation of outcomes in adolescent inflammatory bowel disease patients following transfer from pediatric to adult health care services: Case for transition. *Journal of Adolescent Health, 57*(2), 212-217. https://doi.org/10.1016/j.jadohealth.2015.04.012

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood, 96*(6), 548-553. https://doi.org/10.1136/adc.2010.202473

Elli, L., Maieron, R., Martelossi, S., Guariso, G., Buscarini, E., Conte, D., di Giulio, E., Staiano, A., Barp, J., Bassotti, G., Bianco, M. A., Buri, L., Carrara, M., Ghidini, B., Giannini, O., Knafelz, D., Miele, E., Peralta, S., Riccio, E., Tomba, C., Zilli, M., & Guadagnini, T. (2015). Transition of gastroenterological patients from paediatric to adult care: A position statement by the Italian Societies of Gastroenterology. *Digestive and Liver Disease, 47*(9), 734-740. https://doi.org/10.1016/j.dld.2015.04.002

Fegran, L., Hall, E. O., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. *International Journal of Nursing Studies, 51*(1), 123-135. https://doi.org/10.1016/j.ijnurstu.2013.02.001

Fishman, L. N., Ziniel, S. I., Adrichem, M. E., Fernandes, S. M., & Arnold, J. (2014). Provider awareness alone does not improve transition readiness skills in adolescent patients with inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition, 59*(2), 221-224.

Goodhand, J., Hedin, C. R., Croft, N. M., & Lindsay, J. O. (2011). Adolescents with IBD: The importance of structured transition care. *Journal of Crohn's and Colitis, 5*(6), 509-519. https://doi.org/10.1016/j.crohns.2011.03.015

Gray, W. N., & Maddux, M. H. (2016). Current transition practices in pediatric IBD: Findings from a national survey of pediatric providers. *Inflammatory Bowel Diseases, 22*(2), 372-379. https://doi.org/10.1097/mib.0000000000000642

Hargreaves, D. S. (2011). Revised You're Welcome criteria and future developments in adolescent healthcare. *Journal of Clinical Research in Pediatric Endocrinology, 3*(2), 43-50. https://doi.org/10.4274/jcrpe.v3i2.10

Kemp, K., Griffiths, J., & Lovell, K. (2012). Understanding the health and social care needs of people living with IBD: a meta-synthesis of the evidence. *World Journal of Gastroenterology, 18*(43), 6240-6249.

Limperg, P. F., Haverman, L., van Oers, H. A., van Rossum, M. A., Maurice-Stam, H., & Grootenhuis, M. A. (2014). Health related quality of life in Dutch young adults: psychometric properties of the PedsQL generic core scales young adult version. *Health and Quality of Life Outcomes, 12*, 9. https://doi.org/10.1186/1477-7525-12-9

Lindfred, H., Saalman, R., Nilsson, S., Sparud-Lundin, C., & Lepp, M. (2012). Self-reported health, self-management, and the impact of living with inflammatory bowel disease during adolescence. *Journal of Pediatric Nursing, 27*(3), 256-264. https://doi.org/10.1016/j.pedn.2011.02.005

Little, R., McLoughlin, L., & Szabo, A. (2017). 9 Transforming transition for paediatric IBD patients in Northern Ireland. *Gut, 66*, A4.

Lugasi, T., Achille, M., & Stevenson, M. (2011). Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies. *Journal of Adolescent Health, 48*(5), 429-440. https://doi.org/10.1016/j.jadohealth.2010.10.016

Mahler, C., Hermann, K., Horne, R., Ludt, S., Haefeli, W. E., Szecsenyi, J., & Jank, S. (2010). Assessing reported adherence to pharmacological treatment recommendations. Translation and evaluation of the Medication Adherence Report Scale (MARS) in Germany. *Journal of Evaluation in Clinical Practice, 16*(3), 574-579. https://doi.org/10.1111/j.1365-2753.2009.01169.x

Mazur, A., Dembinski, L., Schrier, L., Hadjipanayis, A., & Michaud, P. A. (2017). European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Paediatrica, 106*(8), 1354-1357. https://doi.org/10.1111/apa.13901

Nagra, A., McGinnity, P. M., Davis, N., & Salmon, A. P. (2015). Implementing transition: Ready Steady Go. *Archives of Disease in Childhood: Education and Practice Edition, 100*(6), 313-320. https://doi.org/10.1136/archdischild-2014-307423

Nehring, W. M., Betz, C. L., & Lobo, M. L. (2015). Uncharted territory: Systematic review of providers' roles, understanding, and views pertaining to health care transition. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 30*(5), 732-747. https://doi.org/10.1016/j.pedn.2015.05.030

Petkov, J., Harvey, P., & Battersby, M. (2010). The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Quality of Life Research, 19*(7), 1079-1085. https://doi.org/10.1007/s11136-010-9661-1

Philpott, J. R., & Kurowski, J. A. (2019). Challenges in transitional care in inflammatory bowel disease: a review of the current literature in transition readiness and outcomes. *Inflammatory Bowel Diseases, 25*(1), 45-55.

Sattoe, J. N. T., Peeters, M. A. C., Hilberink, S. R., Ista, E., & van Staa, A. L. (2016). Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open, 6*(8), e011926. https://doi.org/10.1136/bmjopen-2016-011926

Shaw, K. L., Southwood, T. R., & McDonagh, J. E. (2007). Development and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care among adolescents with juvenile idiopathic arthritis. *Child: Care, Health & Development, 33*(4), 380-388. https://doi.org/10.1111/j.1365-2214.2006.00699.x

Sonneveld, H. M., Strating, M. M., van Staa, A. L., & Nieboer, A. P. (2013). Gaps in transitional care: what are the perceptions of adolescents, parents and providers? *Child: Care, Health & Development, 39*(1), 69-80. https://doi.org/10.1111/j.1365-2214.2011.01354.x

Surís, J. C., & Akré, C. (2015). Key elements for, and indicators of, a successful transition: an international Delphi study. *Journal of Adolescent Health, 56*(6), 612-618. https://doi.org/10.1016/j.jadohealth.2015.02.007

Van den Brink, G., van Gaalen, M. A., Zijlstra, M., de Ridder, L., van der Woude, C. J., & Escher, J. C. (2019). Self-efficacy did not predict the outcome of the transition to adult care in adolescents with inflammatory bowel disease. *Acta Paediatrica, 108*(2), 333-338.

Van Rheenen, P. F., Aloi, M., Biron, I. A., Carlsen, K., Cooney, R., Cucchiara, S., Cullen, G., Escher, J. C., Kierkus, J., & Lindsay, J. O. (2017). European Crohn's and Colitis Organisation topical review on transitional care in inflammatory bowel disease. *Journal of Crohn's and Colitis, 11*(9), 1032-1038.

Van Staa, A. L. (2012). *On Your Own Feet: Adolescents with chronic conditions and their preferences and competencies for care.* Erasmus University Rotterdam.

Van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health & Development, 37*(6), 821-832. https://doi.org/10.1111/j.1365-2214.2011.01261.x

Van Staa, A. L., & Sattoe, J. N. T. (2014). Young adults' experiences and satisfaction with the transfer of care. *Journal of Adolescent Health, 55*(6), 796-803. https://doi.org/10.1016/j.jadohealth.2014.06.008

Van Staa, A. L., Sattoe, J. N. T., & Strating, M. M. (2015). Experiences with and outcomes of two interventions to maximize engagement of chronically ill adolescents during hospital consultations: A mixed methods study. *Journal of Pediatric Nursing, 30*(5), 757-775. https://doi.org/10.1016/j.pedn.2015.05.028

Yerushalmy-Feler, A., Ron, Y., Barnea, E., Nachum, A., Matalon, S., Dali-Levy, M., Dotan, I., & Cohen, S. (2017). Adolescent transition clinic in inflammatory bowel disease: quantitative assessment of self-efficacy skills. *European Journal of Gastroenterology & Hepatology, 29*(7), 831-837.

8

The added value of transition programs in Dutch diabetes care: a controlled evaluation study

Mariëlle A.C. Peeters
Jane N.T. Sattoe
Madelon B. Bronner
Roland A. Bal
AnneLoes van Staa

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ABSTRACT

Purpose

The desirability of evaluating transition programs is widely acknowledged. This study aimed to explore the added value of transitional care investments for young adults with type 1 diabetes mellitus.

Design and methods

Based on qualitative data, two groups of diabetes teams were created through cluster analysis: paying more (HI-ATT) versus less attention (LO-ATT) to transitional care. Retrospective controlled evaluation included chart reviews on healthcare use and clinical outcomes; and a survey on young adults' experiences, satisfaction with care, and self-management skills.

Results

Data from 320 patients in fifteen diabetes teams were collected; 123 young adults (38.4%) completed a questionnaire. Self-reported outcomes showed that young adults treated by a HI-ATT team felt better prepared for transfer ($p < .05$). Self-management outcomes did not differ between groups. HI-ATT teams had more scheduled consultations in the year after transfer ($p < .05$); only 10.6% of all measurements had reached targeted HbA1c scores.

Conclusions

Current transitional care investments in Dutch diabetes care did not lead to notable improvements in experiences and outcomes, except for preparation for transfer. The period after transfer, however, is just as important. Attention is required for parent involvement.

Practice implications

Transitional care investments should extend beyond the transfer. By educating young adults about the importance of regular clinic attendance and introducing additional person-centered consultations in adult care, nurses may help ensure continuity of care. Nurses could also introduce support programs for parents to prepare for the transition and their change in role, taking into account their continuing partnership.

INTRODUCTION

Health prospects of young adults with chronic conditions have improved, especially regarding type 1 diabetes mellitus (T1DM) (Michaud et al., 2018; Zhou et al., 2016). Still, T1DM patients' transition from adolescence to adulthood – referring to the process of moving from being a child to becoming a young adult including the transfer from pediatric to adult healthcare – is characterized by risk and vulnerability (Cameron et al., 2018; White et al., 2018). These young adults have to take up responsibility for self-management of the disease in the context of competing developmental tasks, such as changing social relationships, shifting roles between them and their parents, and academic and career demands (Agarwal et al., 2017). The transition period has been associated with less outpatient hospital clinic attendance and more dropout or disengagement from specialist services (White et al., 2017). Psychosocial issues are common in this phase, and young T1DM patients have significantly higher rates of diabetes-related distress than other age groups (Iyengar et al., 2019). These issues could lead to deterioration of glycosylated hemoglobin (HbA1c) levels with an associated increase in acute and even chronic complications such as ketoacidosis or microvascular problems (Burns et al., 2018; Clements et al., 2016; Farrell et al., 2018; Gray et al., 2018).

Both national (Dutch Diabetes Federation, 2020) and international (National Institute for Health and Care Excellence [NICE], 2016; DiMeglio et al., 2018) healthcare standards and consensus guidelines acknowledge the importance of and the need to improve transitional care. Still, many young patients experience large care gaps when transitioning from pediatric to adult settings, causing discomfort, confusion and high rates of loss to follow-up (Agarwal et al., 2017; Goralski et al., 2017; Van Staa et al., 2011; Zhou et al., 2016). From a professional viewpoint, treatment of patients in the transition phase is also challenging, as pediatric and adult care providers have their own working ways (e.g., with regard to consultation and the use of electronic medical record systems) and clinical guidelines (e.g., about monitoring glycemic control).

Several interventions have been developed and implemented to bridge the gap between pediatric and adult care, and to support young adults and healthcare professionals; from educational programs and skills training to appointing transition coordinators and setting up transition clinics (Crowley et al., 2011). Various interventions have shown promising benefits for young adults with T1DM, but evaluation of multifactorial transition programs remains complex (Le Roux et al., 2017). It is not feasible to implement all interventions at every center, and generalizability is often limited due to differing study designs and outcome measures (Campbell et al., 2016; White et al., 2017). As a result, factors that effectively influence the transition process are still poorly understood (Betz et al., 2018; Chu et al., 2015; Colver et al., 2018; Gray et al., 2018; Schultz & Smaldone, 2017; Sheehan et al., 2015). Consensus on the definition of transition success is lacking and little high-quality evidence on which to base transition practice is available (Campbell et al., 2016; White et al., 2017).

This study, part of a national quality improvement initiative (called 'Better Transition in Type 1 Diabetes') to advance transitional care in diabetes (Van Staa et al., 2020), was designed to explore the added value of transitional care investments for young adults (aged 16-30 years) with T1DM in the Netherlands. In this context, transitional care investments are all efforts made by diabetes care providers aimed at improving the quality of transitional care. The final aim was to provide additional insight into the benefits of transitional care investments with regard to transfer experiences and satisfaction, self-management-related outcomes, healthcare use and clinical outcomes.

METHODS

Study aim and design

We performed a retrospective, controlled evaluation of process, clinical and patient-reported outcomes – based on the original study design of Sattoe et al. (2016). Using a mixed methods approach, this evaluation focuses on the expected added value of transitional care investments containing different elements. Qualitative data were collected through observing healthcare professionals' consultations with young adults with T1DM and semi-structured interviews with healthcare professionals, and served as input for categorizing the participating diabetes teams into two groups for quantitative comparison. The quantitative evaluation included medical chart reviews and an online questionnaire among young adults with T1DM (Table 1).

Setting and participants

All medical centers in the Netherlands providing care to young adults with T1DM were invited for participation in the project, conducted between 2016 and 2018. Representation of the multidisciplinary teams of professionals from both pediatric and adult diabetes care was required, as well as the intention to further improve transitional care arrangements. Fifteen hospitals signed up for participation. A consultant (JH/AvS) and a researcher (MP/JS) visited each team to further explain the project, answer questions and arrange start of the data collection. These intake interviews also served to map the centers' organization of the outpatient care for young adults with T1DM.

One hospital withdrew during the project due to staff shortages; two other hospitals did not participate in the research part because they could not comply with the study protocol, leaving twelve hospitals participating. Three had recently merged and provided care at multiple locations with different teams of healthcare providers and different transitional pathways. In total, fifteen multidisciplinary teams of diabetes care providers from both pediatric and adult care were included, such as diabetes specialist nurses, nurse practitioners, pediatricians, endocrinologists, dieticians, and psychologists. We evaluated data of all patients who had a confirmed diagnosis of T1DM (irrespective of the time elapsed since diagnosis), had made the transfer to adult services in the 2012-2014 period, had no cognitive impairment, and were able to speak and read Dutch.

Data collection

Previously, a general survey among Dutch professionals working in pediatric and young adult diabetes care revealed large differences in the design and execution of transitional care (Van Staa et al., 2020). This was confirmed during the intake interviews in the participating teams. We inventoried the transitional care arrangements in each diabetes team at the start of the program using various methods, following the original study design (Sattoe et al., 2016). Input came from the intake interviews at the start of the program, semi-structured interviews with professionals from both pediatric and adult care (n = 41), and observations of health professionals' consultations with young adults in both settings (n = 57). Themes addressed were organization, structure and working ways, content of transitional care arrangements, and experienced barriers and facilitators. The quality of care of each team was rated on the eight core elements of the *On Your Own Feet* transitional care framework (Figure 1) (Van Staa et al., 2020).

Figure 1. Transitional care framework *'On Your Own Feet'* (Van Staa et al., 2020)

For the quantitative evaluation, we collected a set of background, process and outcome variables. Data from the chart reviews (*n* = 320) included, among other things, no-show (primary process outcome), scheduled consultations, emergency department visits, hospital admissions, and HbA1c levels. These data were collected at four measurement moments: T1, two years before transfer; T2, the year before transfer; T3, the year after transfer; and T4, two years after transfer. For practical and ethical reasons, T3 and T4 data were only available for young adults who had transferred to adult care within the same hospital (*n* = 293). All 320 young adults were invited to fill out an online questionnaire about their transfer experiences (primary patient-reported outcome), containing the following aspects: reception in adult care, alliance between pediatric and adult care, preparation for the transfer, readiness to transfer, and youth involvement (Van Staa & Sattoe, 2014). Trust in care providers and coping with T1DM were also explored in the questionnaire. Reminders were sent after two and four weeks. Table 1 provides an overview of the operationalization and data collection method per variable.

Data analysis

Qualitative part

On the basis of our rich qualitative data set, we established detailed reports on each participating diabetes team, in which we described their setting, composition of the team, and their organization of transitional care. A member check was conducted to assess the accuracy with which these reports represented the team's actuality. The eight core elements of good transitional care were leading in our thick descriptions; the elements were divided into three categories of interventions: 1) interventions to improve the organization of care; 2) interventions to stimulate independence and self-management of young adults; and 3) collaboration with young adults and within the multidisciplinary team of professionals representing both pediatric care and adult care (Van Staa et al., 2020). A detailed description of the eight elements is presented in Appendix A.

Three researchers independently scored each team on the eight elements. Scores ranged from 1 – indicating 'minimal transitional care' – to 4 – indicating 'excellent transitional care'. Teams that used systematic interventions for transitional care – i.e., concrete tools or instruments to arrange transitional care – received higher scores. Examples of interventions are multidisciplinary team consultation meetings, independent consultations with young adults (without parents), transition protocols, transition coordinators, and individual transition plans (Van Staa et al., 2020). Kendall's *W* was calculated to measure concordance of raters' scores on the eight core elements (0 = no agreement among raters; 1 = complete agreement among raters). The mean Kendall's *W* coefficient was 0.579, indicating moderate agreement. Consensus on the scores was established in

Table 1

Operationalization of background characteristics, process and outcome measures[a]

Theme	Variable	Operationalization	Method of data collection	Measurement moment (chart review)[b] or measurement tool used (survey)
Background characteristics				
	Gender	Male/female	Chart review	
	Date of birth	dd/mm/yyyy	Chart review	
	Transferred to	Intern/extern	Chart review	T3
	Age at transfer	In years	Chart review	T3
Process outcomes				
Medical follow-up	Last appointment pediatric care	dd/mm/yyyy	Chart review	T2
	First appointment adult care	dd/mm/yyyy	Chart review	T3
	No-show at first appointment in adult care	Yes/no/unknown	Chart review	T3
	Scheduled physical consultations	Number per year	Chart review	T1; T2; T3; T4
	Missed consultations	Number per year	Chart review	T1; T2; T3; T4
	Hospitalizations related to condition	Number per year	Chart review	T1; T2; T3; T4
	Emergency department visits	Number per year	Chart review	T1; T2; T3; T4
Outcome measures				
Clinical	HbA1c	All observed values per year	Chart review	T1; T2; T3; T4
Healthcare-related	Transfer experiences	Experiences on five subscales: 1) reception in adult care, 2) alliance between pediatric and adult care, 3) preparation for the transfer, 4) readiness to transfer, and 5) youth involvement	Survey	On Your Own Feet – Transfer Experiences Scale (OYOF-TES) (validated 20-item scale with 5-point Likert scales, $\alpha = 0.64\text{-}0.86$) (Van Staa & Sattoe, 2014)
	Satisfaction with transition	Satisfaction with the overall process of transfer to adult care	Survey	Self-reported satisfaction on a 1-10 scale
	Trust in healthcare providers	Trust in pediatric and adult care providers	Survey	Self-reported trust on a 1-10 scale
Self-management-related	Self-management skills	Self-management of chronic condition	Survey	Partners in Health Scale (PIH) (validated 12-item scale with 9-point Likert scales, $\alpha = 0.82$) (Petkov et al., 2010)
Quality of life	Health-related quality of life	Health-related quality of life on four domains: 1) physical, 2) emotional, 3) social, and 4) school/work	Survey	PedsQL 4.0 adult version (validated 23-item scale with 5-point Likert scales, $\alpha = 0.77\text{-}0.94$) (Limperg et al., 2014)

[a] Based on study protocol published elsewhere (Sattoe et al., 2016).

[b] T1: second year before transfer; T2: year before transfer; T3: year after transfer; and T4: second year after transfer.

a research team meeting. The scores for each element were then summed up (minimum = 8; maximum = 32), resulting in a highest score of 26 and a lowest of 10.

Quantitative part

To enable further quantitative analysis, an exploratory hierarchical cluster analysis using the within-groups linkage method was performed to cluster teams (Mooi & Sarstedt, 2011). The summed consensus scores served as input for the cluster analysis. Two distinctive groups were derived from the dendrogram resulting from the hierarchical cluster analysis. Subsequently, K-means clustering with two clusters resulted in a group of five teams with a final cluster center of 13.8, indicating less attention for transitional care (LO-ATT), versus ten teams with a final cluster center of 21.3, indicating more attention for transitional care (HI-ATT) ($p < .01$).

The resulting format was used to compare consensus-based mean scores on the eight core elements and the presence of transition interventions between both groups of diabetes teams. Process, clinical and patient-reported outcomes were also compared between the two groups. Independent samples *t*-tests and Pearson chi-square tests served to compare chart review and survey outcomes. Effect sizes were calculated to measure the magnitude of the differences between both groups (Cohen's $d = 0.2$ small effect, 0.5 medium and 0.8 large). Overall within-group differences over the four years of measurement were tested with paired samples *t*-tests; correlations were examined with Pearson's and Spearman's tests. To investigate differences and interactions on transfer experiences and transition satisfaction, healthcare use, and HbA1c levels, mixed repeated measures analyses of variance (ANOVA) were performed using measurement moment (T1-T4) as within-factor and group of teams (HI-ATT versus LO-ATT) as between-factor. SPSS 26.0 was used to perform the statistical analyses.

Ethics approval and consent to participate

The Ethics Review Board of Erasmus MC approved the original study protocol (Sattoe et al., 2016) as well as the updated protocol in which diabetes specific outcomes were described. Ethical approval was also obtained from all local hospital review boards. Teams and young adults were informed about the goals of the research orally and in writing, and they were ensured complete confidentiality and anonymity. All young adults gave consent; to enhance participation, every third respondent to the online questionnaire received a €20 gift voucher.

RESULTS

Response and background characteristics

Table 2 provides a description of the total study sample of 320 young adults with T1DM who were included in the chart review; 38.4% (*n* = 123) responded to the online questionnaire. The non-responders (*n* = 197) did not differ from the responders in age (23.6 ± 1.38 versus 23.9 ± 1.51; *p* = .106), but they were more often male (62.9% versus 40.7%; *p* = .000). Five teams also invited patients who had made the transfer in 2015 and 2016 to complete the online questionnaire, which resulted in 19 additional responses on the self-reported outcomes.

Table 2

Total study sample of young adults with type 1 diabetes (*n* = 320)

	LO-ATT teams (*n* = 130)	HI-ATT teams (*n* = 190)	*p*-value[a]
Gender (male)	66 (50.8%)	108 (56.8%)	0.284
Age	23.71 (±1.42)	23.71 (±1.44)	0.988
Age at transfer[b]	18.64 (±1.77)	18.62 (±1.11)	0.905
Transfer within the same hospital[c]	118 (92.9%)	175 (92.6%)	0.914
Response to online survey	53 (40.8%)	70 (36.8%)	0.478

[a] Independent Samples *T*-test or Pearson χ^2-test ($p<.05$).

[b] *n*=128 in the LO-ATT group and *n*=184 in the HI-ATT group.

[c] *n*=127 in the LO-ATT group and *n*=189 in the HI-ATT group; the other patients have become lost to follow-up after transfer to adult care.

In both groups of teams, more than 90% of the young adults (118/130 in LO-ATT teams and 175/190 in HI-ATT teams) transferred to adult services within the same hospital. There were no statistically significant differences in the background characteristics of young adults between the two groups. Regarding the core elements of the *On Your Own Feet* framework, HI-ATT teams scored significantly higher on all eight elements except for parent involvement (*p* <. 05) (Table 3). The effect sizes for all eight core elements are large (*d* > .82). Regarding the use of specific transitional care interventions, only one notable difference was found. All HI-ATT teams organized joint consultation sessions (i.e., transition clinics) wherein young people are seen by professionals from both pediatric and adult care at the same time, in contrast to only two of the LO-ATT teams (100% versus 40%; *p* = .022).

Table 3
Overview of transitional care interventions and consensus-based mean scores on the eight core elements[a]

	LO-ATT teams (*n*=5)	HI-ATT teams (*n*=10)	Effect size[b]	*p*-value[c]
Consensus-based mean scores on the eight core elements (1 = minimal transitional care; 4 = excellent transitional care)				
Future-oriented	1.60 (±0.55)	2.50 (±0.58)	1.55	0.029*
Coordination	1.60 (±0.89)	2.90 (±0.88)	1.46	0.028*
Continuity of care	2.20 (±0.84)	3.30 (±0.82)	1.31	0.042*
Parent involvement	1.60 (±0.55)	2.40 (±0.97)	0.82	0.063
Self-management	1.60 (±0.55)	2.60 (±0.52)	1.82	0.010*
Psychosocial care	2.20 (±0.45)	2.80 (±0.42)	1.33	0.038*
Youth participation	1.40 (±0.55)	2.30 (±0.68)	1.32	0.020*
Team collaboration	2.00 (±0.00)	2.50 (±0.53)	0.94	0.015*
Transitional care interventions				
Transition coordinator	2 (40%)	6 (60%)	NA	0.608
Transition protocol (in use)	0 (0%)	2 (20%)	NA	0.524
Multidisciplinary team consultation meetings with pediatric and adult care providers	1 (20%)	4 (40%)	NA	0.600
Joint consultation	2 (40%)	10 (100%)	NA	0.022*
Structural support for parents	1 (20%)	2 (20%)	NA	1.000
Structural use of a quality of life questionnaire	1 (20%)	7 (70%)	NA	0.119
Structural use of an individual transition plan	0 (0%)	3 (30%)	NA	0.505
Independent consultations with young adults (without parents)	1 (20%)	4 (40%)	NA	0.600

[a] Based on the transitional care framework 'On Your Own Feet' (Van Staa et al., 2020).
[b] Cohen's *d* (based on largest *SD*).
[c] Independent Samples *T*-test or Fisher's Exact Test.
* Significant at *p*<.05.

Transfer experiences, satisfaction, self-management and quality of life outcomes

Regarding young adults' transfer experiences, no significant differences were found between HI-ATT and LO-ATT teams, except for the subscale 'Preparation for the transfer' (Table 4). Those treated by a HI-ATT team felt better prepared for transfer to adult care than those treated by a LO-ATT team (3.16 ± 0.86 versus 2.83 ± 0.99, $p = .042$). Moreover, Spearman's test showed a moderate positive correlation of preparation for transfer with overall satisfaction with transition ($r_S = 0.517$; $p = .000$). Individual item analysis of the Transfer Experiences Scale revealed that the young adults in the HI-ATT group had more often met their new healthcare providers before the transfer ($p = .044$), and more often felt having received enough information about the transfer ($p = .016$). Additionally, they more often judged the timing of the transfer to be just about right ($p = .012$). Those treated by a LO-ATT team more often reported that the new care providers were well informed about them and their condition (*p* = .040).

Overall satisfaction with transition was scored with a mean of 7.01 (± 1.53, *n* = 167), and was strongly correlated with the transfer experiences sum score (r_s = 0.737; *p* = .000). In this regard, there was no significant difference between the groups of teams (*p* = .856). The young adults, on average, showed significantly more trust in their pediatric healthcare providers than in their adult healthcare providers (8.24 ± 1.73 versus 7.54 ± 1.77, *p* = .001; *n* = 168). Trust in healthcare providers was not significantly different between the HI-ATT and LO-ATT groups, and neither were health-related self-management and quality of life outcomes (Table 4). Spearman's test showed a weak correlation between the transfer experiences sum score and trust in pediatric healthcare providers (r_s = 0.170; *p* = .028) and a moderate correlation between the transfer experiences sum score and trust in adult healthcare providers (r_s = 0.492; *p* = .000).

Table 4

Differences in transfer experiences, satisfaction with transition and self-management skills

	LO-ATT teams (*n*=56)	HI-ATT teams (*n*=85)	Effect size[a]	*p*-value[b]
Mean scores on OYOF-TES subscales (1 = strongly disagree; 5 = strongly agree)				
Reception in adult care (*α*=.861)	4.03 (±0.72)	3.88 (±0.89)[c]	0.17	0.295
Alliance between pediatric and adult care (*α*=.832)	3.18 (±0.96)	3.16 (±0.83)	0.02	0.909
Preparation for the transfer (*α*=.637)	2.83 (±0.99)	3.16 (±0.86)	-0.33	0.042*
Readiness to transfer (*α*=.796)	3.93 (±0.71)	4.11 (±0.63)	-0.25	0.102
Youth involvement (*α*=.671)	3.32 (±0.98)	3.26 (±1.00)	0.06	0.740
Total score	70.68 (±13.30)	72.01 (±12.15)	-0.10	0.540
Overall satisfaction and trust (0-10 scale)				
Overall satisfaction with transition	7.11 (±1.57)	7.15 (±1.49)[d]	-0.03	0.856
Trust in pediatric healthcare providers	8.05 (±1.74)	8.48 (±1.51)	-0.25	0.123
Trust in adult healthcare providers	7.82 (±1.42)	7.38 (±2.04)	0.22	0.129
Self-management and quality of life outcomes				
Self-management skills (PIH)	80.84 (±7.98)	79.60 (±9.25)[d]	0.13	0.412
Health-related quality of life (PedsQL-YA)	79.55 (±13.29)[e]	78.23 (±16.02)[d]	0.08	0.613

[a] Cohen's *d* (based on largest *SD*).
[b] Independent Samples *T*-test.
[c] *n*=86.
[d] *n*=84.
[e] *n*=55.
* Significant at *p*<.05.

Healthcare use

Overall, young adults had significantly more scheduled consultations in pediatric care than in adult care (14.77 ± 11.35 versus 11.67 ± 7.51, *p* = .000). The number of missed consultations had significantly increased after transfer (0.66 ± 1.44 versus 1.14 ± 1.98, *p* = .000). In the two years before transfer, 30.1% (*n* = 94) of the young adults had missed at least one scheduled consultation, compared to 42.0% (*n* = 123) in the two years after transfer.

Looking at the differences between HI-ATT and LO-ATT teams (Table 5), we found that the HI-ATT teams had more scheduled consultations in the year after transfer (7.38 ±

Table 5

Differences in healthcare use and clinical outcomes

	LO-ATT teams		HI-ATT teams		Effect size[a]	*p*-value[b]
No. of scheduled consultations (mean; SD)						
T1	*n*=130	8.56 (±5.58)	*n*=185	7.85 (±6.47)	0.11	0.309
T2	*n*=130	6.31 (±5.11)	*n*=185	6.91 (±7.69)	-0.08	0.437
T3	*n*=128	5.97 (±4.24)	*n*=177	7.38 (±4.49)	-0.31	0.006*
T4[c]	*n*=124	4.55 (±3.29)	*n*=172	5.01 (±4.70)	-0.10	0.353
No-show at first appointment in adult care (N; %)						
	n=119	17 (14.3%)	*n*=174	19 (10.9%)	NA	0.389
No. of missed consultations (mean; SD)						
T1	*n*=129	0.33 (±0.90)	*n*=185	0.38 (±0.95)	-0.05	0.637
T2	*n*=129	0.33 (±0.75)	*n*=185	0.35 (±0.81)	-0.02	0.889
T3	*n*=126	.071 (±1.49)	*n*=177	0.67 (±1.42)	0.03	0.778
T4	*n*=122	0.48 (±0.84)	*n*=172	0.45 (±0.94)	0.03	0.794
No. of hospital admissions (mean; SD)						
T1	*n*=130	0.21 (±0.46)	*n*=188	0.22 (±0.64)	-0.02	0.810
T2	*n*=130	0.16 (±0.50)	*n*=189	0.19 (±0.67)	-0.04	0.676
T3	*n*=128	0.20 (±0.77)	*n*=176	0.25 (±0.87)	-0.06	0.570
T4	*n*=124	0.22 (±0.69)	*n*=170	0.11 (±0.48)	0.16	0.144
No. of emergency department visits (mean; SD)						
T1	*n*=130	0.18 (±0.40)	*n*=187	0.18 (±0.42)	0.00	0.992
T2	*n*=130	0.10 (±0.39)	*n*=187	0.16 (±0.49)	-0.12	0.267
T3	*n*=128	0.21 (±0.57)	*n*=176	0.25 (±0.71)	-0.06	0.609
T4	*n*=124	0.27 (±0.71)	*n*=169	0.19 (±0.65)	0.11	0.340
HbA1c (mean NGSP, IFCC; SD)						
T1	*n*=121	8.6% (71; ±14.10)	*n*=171	8.7% (72; ±16.49)	-0.04	0.750
T2	*n*=120	8.6% (71; ±13.69)	*n*=179	8.6% (71; ±15.88)	-0.02	0.893
T3	*n*=95	8.6% (70; ±13.42)	*n*=153	8.6% (71; ±15.83)	-0.05	0.667
T4	*n*=91	8.6% (71; ±13.57)	*n*=141	8.6% (70; ±15.34)	0.10	0.436

[a] Cohen's *d* (based on largest *SD*).

[b] Independent Samples *T*-test or Pearson χ^2-test.

[c] T1: second year before transfer; T2: year before transfer; T3: year after transfer; T4: second year after transfer.

* Significant at *p*<.05.

4.49 versus 5.97 ± 4.24, *p* = .006). Mixed repeated measures analyses showed a significant interaction effect between the measurement moment (T) and the group of teams on the number of scheduled consultations (*p* = .014). In the LO-ATT teams, the decrease in the number of scheduled consultations in the years before transfer, from T1 to T2, was significantly bigger than in the HI-ATT teams (*F*(1, 288) = 5.38, *p* = .021).

Clinical outcomes

Mean HbA1c scores did not change over time (*p* = .836); they were elevated across the whole study period with no significant differences between pediatric and adult care (71.04 ± 14.52 versus 70.72 ± 14.48, *p* = .683; *n* = 261). The mean HbA1c scores also did not differ between the LO-ATT and HI-ATT teams, and the development of glycemic control over time was not significantly different between both groups (*p* = .358).

Considering the International Society of Pediatric and Adolescent Diabetes (ISPAD) Clinical Practice Consensus Guidelines (DiMeglio et al., 2018), only 10.6% of our T1-T4 measurements (*n* = 114) met targeted HbA1c scores of ≤ 53 mmol/mol (for children, adolescents and young adults until the age of 25 years); 14.6% of the measurements (*n* = 157) scored very high (≥ 86 mmol/mol). HbA1c measurements were carried out more often in pediatric than in adult care (5.64 ± 2.44 versus 4.40 ± 2.10, *p* = .000; *n* = 261). Moreover, those with higher HbA1c scores were seen more often in pediatric care than in adult care (*r* = 0.187, *p* = .001).

DISCUSSION

This study compared two groups of healthcare teams that differed in their investments in transitional care for young adults with T1DM, i.e., teams with more attention for transitional care (HI-ATT) versus teams with less attention in this regard (LO-ATT). Only a few gradual results in favor of the HI-ATT teams were found.

Young adults treated by the HI-ATT teams felt better prepared for transfer to adult care than those treated by the LO-ATT teams; they especially valued the possibility to meet their new healthcare providers before the transfer. This is one of the three key features of transitional care associated with improved outcomes identified in the five-year transition research program by Colver et al. (2020). Furthermore, the young adults in our study found receiving enough information about the transfer important. Feeling well prepared for transfer was positively correlated with one's overall satisfaction with the transition process. However, being offered transitional care interventions did not prove to be decisive factor for this satisfaction. Our results suggest that interventions were still not systematically used; even not in the HI-ATT teams, although those teams had offered more joint consultations. Accordingly, the presence or absence of specific transitional care interventions did not appear to be a good indicator for the outcomes of transitional care. This is unexpected, but confirms the complexity of evaluating transitional care, which is still characterized by large differences and inconsistencies in implementation of interventions (Campbell et al., 2016; Le Roux et al., 2017). An example is the structural use of quality of life questionnaires. Regularly addressing psychosocial issues is highly recommended for young adults with T1DM, many of whom experience psychosocial problems and diabetes-related distress (Bronner et al., 2020; Iyengar et al., 2019; Van Staa et al., 2020). However, we do not know if and how the teams that use quality of life questionnaires bring up quality of life issues during consultations.

A general point of attention appearing from our results is the overall lack of structured support for parents. Colver et al. (2020) identified appropriate parental involvement with the child with a chronic health condition as the second key feature of transitional care associated with improved outcomes, as it would help achieve maximal service uptake. The pediatric-to-adult care transition phase necessitates a role shift away from a child's dependence on parents to manage a disease such as T1DM towards independently manage the disease. However, during this phase young adults' lives are still characterized by interdependencies, which facilitate their diabetes management (Allen et al., 2011). These interdependencies are not always reflected in healthcare policy and practice. Therefore, it would be worthwhile to develop a service structure that recognizes the continuing role of parents in a young adult's diabetes care and that support parents in adjusting to a new existence (Allen et al., 2011; Betz et al., 2015; Coyne & Hallowell, 2020). A systematic review of studies of parents' perceptions of their role in transition made clear that parents could be key facilitators of the child's healthcare transition by supporting him or her to become an expert in self-management (Heath et al., 2017).

From a clinical perspective, adolescents and young adults generally have the worst HbA1c scores among T1DM patients (Iyengar et al., 2019). In a previous study, only 17% of young adults with T1DM (18-25 years) met the ISPAD goal of less than 7.0% (≤ 53 mmol/mol) (Beck et al., 2012), which is even better than the 10.6% proportion of the HbA1c measurements in our study. Although recent registry data of the American Diabetes Association indicate that glycemic control is still not improving, despite advances in technology and newer insulins (Beck et al., 2019), research suggests that transition interventions may be effective in maintaining glycemic control after transfer to adult care (Farrell et al., 2018; Schultz & Smaldone, 2017). Our study showed a decreasing trend in the number of HbA1c measurements and scheduled consultations after transfer, while poor glycemic control persisted in adult care. This observation emphasizes the need for more attention for young adults in the adult care setting.

Clinic attendance is crucial to promote self-care (i.e., self-monitoring and taking care of one's own health) and – from the broader perspective – self-management (i.e., the ability to integrate the chronic condition in daily life), and consequently diabetes control

(Farrell et al., 2018). Strengthening young adults' confidence in self-management is the third key feature of transitional care associated with improved outcomes, mentioned by Colver et al. (2020). Ideally, self-management support is provided all the way from pediatric into adult care, since competency building and evaluation of self-management skills continues after rapport with the new care providers has been established (Iyengar et al., 2019; Van Staa et al., 2020). Therefore, in our *Better Transition in Type 1 Diabetes* innovation program, Dutch versions of the Ready Steady Go instruments (Nagra et al., 2015) have been implemented to help young adults gain knowledge and skills to manage T1DM. In the present study, we found that the HI-ATT teams had more scheduled consultations than the LO-ATT teams in the year after transfer. This might indicate that HI-ATT teams were better able to remain in touch with the young adults after transfer. Nevertheless, the number of scheduled consultations decreased in both groups in the second year after transfer, and there were fewer HbA1c measurements after transfer.

The focus of healthcare providers often is on preparing and organizing a smooth transfer to adult care, while attention for the period afterwards remains underexposed, but is highly needed. The positive correlation we established between the young adults' overall satisfaction with transition and trust in adult healthcare providers emphasizes the importance of building a confidential relationship with young adults after entering adult diabetes services; a study of Klostermann et al. (2005) underlined this. Designating a transition coordinator may help ensure continuity of care and support (Iyengar et al., 2019; Van Staa et al., 2020), especially when the coordinator role is executed on both sides of the transfer – thereby 'bridging the gap' between the settings. Nurses seem excellently positioned to fulfill this role given the relationships they establish with young adults and their parents (Betz & Redcay, 2005; Coyne & Hallowell, 2020; Van Staa et al., 2015).

Practice implications

Additional consultations in the first year after transfer will likely ensure continuity of care, build relationships with the new healthcare team, and promote young adults' confidence in managing their diabetes. Nurses can also help by creating awareness about the importance of regular clinic attendance among the young adults. Furthermore, nurses can support parents to prepare for the transition and to adjust to their new role, taking into account their continuing partnership. Finally, more consistent use of interventions could perhaps make a difference in transition experiences and outcomes. Future evaluation research of transitional care should also consider the actual implementation and adaptation of interventions used.

Strengths and limitations

This study was unique in its design by evaluating transitional care for young adults with T1DM among fifteen different transition programs in the Netherlands. At the start of the program, we carefully researched each team's arrangements and investigated whether the scope of transitional care investments was related to outcomes in terms of transfer experiences and satisfaction, self-management, healthcare use and clinical results.

Due to the complexity of the various transitional care interventions included in our study, the evolving nature of transitional care, and its multidisciplinary character, a randomized controlled trial was not considered possible (Campbell et al., 2016). We therefore performed a retrospective, controlled pre-post design over a four-year period (of young adults transferred between 2012-2014). The time elapsed between this period and our qualitative evaluation of the transitional care (2016) might have been a source of some recall bias. To minimize the risk of bias, we have asked the teams to provide information about changes in approaches and interventions during the past years. Furthermore, limited data were available for the retrospective study. For instance, HbA1c scores alone do not fully capture diabetes control. Additional information on daily diabetes self-care and significant changes in self-care behavior during the transition period would enable to create a more complete picture (Farrell et al., 2018). Finally, the suboptimal response rate to the questionnaire (38.4%; $n = 123$) might be a limitation of this study, although this is comparable with that in other post-transition diabetes studies (Garvey et al., 2013).

CONCLUSION

The attention and effort being paid to transition in Dutch diabetes care for young adults does not seem enough to enhance their experiences and outcomes, except for preparation for transfer. Still, investments in transitional care should not only focus on preparing the young adults for and organizing a smooth transfer. The period after transfer – when confidentiality needs to be rebuilt – is as important. Furthermore, the continuing role of parents in light of the shifting responsibilities between parents and young adults should be considered. In our study, almost none of the participating diabetes teams paid special attention to parental involvement.

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REFERENCES

Agarwal, S., Raymond, J. K., Schutta, M. H., Cardillo, S., Miller, V. A., & Long, J. A. (2017). An adult health care-based pediatric to adult transition program for emerging adults with type 1 diabetes. *Diabetes Educator, 43*(1), 87-96. https://doi.org/10.1177/0145721716677098

Allen, D., Channon, S., Lowes, L., Atwell, C., & Lane, C. (2011). Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service. *Diabetic Medicine, 28*(8), 994-1000. https://doi.org/10.1111/j.1464-5491.2011.03310.x

Beck, R. W., Miller, K. M., & Foster, N. C. (2019). The T1D Exchange Clinic Network and Registry: 10 years of enlightenment on the state of type 1 diabetes in the United States. *Diabetes Technology & Therapeutics, 21*(6), 310-312. https://doi.org/10.1089/dia.2019.0129

Beck, R. W., Tamborlane, W. V., Bergenstal, R. M., Miller, K. M., DuBose, S. N., Hall, C. A., & T1D Exchange Clinic Network. (2012). The T1D Exchange clinic registry. *Journal of Clinical Endocrinology & Metabolism, 97*(12), 4383-4389. https://doi.org/10.1210/jc.2012-1561

Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. *Journal of Family Nursing, 21*(3), 362-412. https://doi.org/10.1177/1074840715595024

Betz, C. L., & Redcay, G. (2005). Dimensions of the transition service coordinator role. *Journal for Specialists in Pediatric Nursing, 10*(2), 49-59. https://doi.org/10.1111/j.1744-6155.2005.00010.x

Betz, C. L., Smith, K., Van Speybroeck, A., Jacobs, R. A., Rivera, N., Lee, J., Saghhafi, S., Nguyen, B., & Tu, H. (2018). Descriptive analysis and profile of health care transition services provided to adolescents and emerging adults in the Movin' On Up health care transition program. *Journal of Pediatric Health Care, 32*(3), 273-284. https://doi.org/10.1016/j.pedhc.2017.11.006

Bronner, M. B., Peeters, M. A. C., Sattoe, J. N. T., & van Staa, A. L. (2020). The impact of type 1 diabetes on young adults' health-related quality of life. *Health and Quality of Life Outcomes, 18*(1), 137. https://doi.org/10.1186/s12955-020-01370-8

Burns, K., Farrell, K., Myszka, R., Park, K., & Holmes-Walker, D. J. (2018). Access to a youth-specific service for young adults with type 1 diabetes mellitus is associated with decreased hospital length of stay for diabetic ketoacidosis. *Internal Medicine Journal, 48*(4), 396-402. https://doi.org/10.1111/imj.13649

Cameron, F. J., Garvey, K., Hood, K. K., Acerini, C. L., & Codner, E. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Diabetes in adolescence. *Pediatric Diabetes, 19*(Suppl. 27), 250-261. https://doi.org/10.1111/pedi.12702

Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., While, A., & Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews, 4*, CD009794. https://doi.org/10.1002/14651858.CD009794.pub2

Chu, P. Y., Maslow, G. R., von Isenburg, M., & Chung, R. J. (2015). Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *Journal of Pediatric Nursing, 30*(5), e19-27. https://doi.org/10.1016/j.pedn.2015.05.022

Clements, M. A., Foster, N. C., Maahs, D. M., Schatz, D. A., Olson, B. A., Tsalikian, E., Lee, J. M., Burt-Solorzano, C. M., Tamborlane, W. V., Chen, V., Miller, K. M., Beck, R. W., & T1D Exchange Clinic Network. (2016). Hemoglobin A1c (HbA1c) changes over time among adolescent and young adult participants in the T1D exchange clinic registry. *Pediatric Diabetes, 17*(5), 327-336. https://doi.org/10.1111/pedi.12295

Colver, A., McConachie, H., Le Couteur, A., Dovey-Pearce, G., Mann, K. D., McDonagh, J. E., Pearce, M. S., Vale, L., Merrick, H., Parr, J. R., & Transition Collaborative Group. (2018). A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Medicine, 16*(1), 111. https://doi.org/10.1186/s12916-018-1102-y

Colver, A., Rapley, T., Parr, J. R., McConachie, H., Dovey-Pearce, G., Le Couteur, A., McDonagh, J. E., Bennett, C., Maniatopoulos, G., Pearce, M. S., Reape, D., Chater, N., Gleeson, H., & Vale, L. (2020). Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services - implications of a 5-year research programme. *Clinical Medicine Journal, 20*(1), 74-80. https://doi.org/10.7861/clinmed.2019-0077

Coyne, B., & Hallowell, S. C. (2020). Measurable outcomes for transition: The nurses' role. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An international perspective on nurses' roles and interventions* (pp. 111-126). Springer Nature.

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood, 96*(6), 548-553. https://doi.org/10.1136/adc.2010.202473

DiMeglio, L. A., Acerini, C. L., Codner, E., Craig, M. E., Hofer, S. E., Pillay, K., & Maahs, D. M. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Glycemic control targets and glucose monitoring for children, adolescents, and young adults with diabetes. *Pediatric Diabetes, 19*(Suppl. 27), 105-114. https://doi.org/10.1111/pedi.12737

Dutch Diabetes Federation (2020, October 12). *Zorgstandaard Diabetes [Healthcare Standard Diabetes]*. https://www.zorgstandaarddiabetes.nl/type-1/kind/inhoud/behandeling/transitiefase/

Farrell, K., Fernandez, R., Salamonson, Y., Griffiths, R., & Holmes-Walker, D. J. (2018). Health outcomes for youth with type 1 diabetes at 18months and 30months post transition from pediatric to adult care. *Diabetes Research and Clinical Practice, 139*, 163-169. https://doi.org/10.1016/j.diabres.2018.03.013

Garvey, K. C., Finkelstein, J. A., Laffel, L. M., Ochoa, V., Wolfsdorf, J. I., & Rhodes, E. T. (2013). Transition experiences and health care utilization among young adults with type 1 diabetes. *Patient Preference and Adherence, 7*, 761-769. https://doi.org/10.2147/PPA.S45823

Goralski, J. L., Nasr, S. Z., & Uluer, A. (2017). Overcoming barriers to a successful transition from pediatric to adult care. *Pediatric Pulmonology, 52*(S48), S52-S60. https://doi.org/10.1002/ppul.23778

Gray, S., Cheetham, T., McConachie, H., Mann, K. D., Parr, J. R., Pearce, M. S., Colver, A., & Transition Collaborative Group. (2018). A longitudinal, observational study examining the relationships of patient satisfaction with services and mental well-being to their clinical course in young people with type 1 diabetes mellitus during transition from child to adult health services. *Diabetic Medicine, 35*(9), 1216-1222. https://doi.org/10.1111/dme.13698

Heath, G., Farre, A., & Shaw, K. (2017). Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling, 100*(1), 76-92. https://doi.org/10.1016/j.pec.2016.08.011

Iyengar, J., Thomas, I. H., & Soleimanpour, S. A. (2019). Transition from pediatric to adult care in emerging adults with type 1 diabetes: a blueprint for effective receivership. *Clinical Diabetes and Endocrinology, 5*, 3. https://doi.org/10.1186/s40842-019-0078-7

Klostermann, B. K., Slap, G. B., Nebrig, D. M., Tivorsak, T. L., & Britto, M. T. (2005). Earning trust and losing it: adolescents' views on trusting physicians. *Journal of Family Practice, 54*(8), 679-687.

Le Roux, E., Mellerio, H., Guilmin-Crepon, S., Gottot, S., Jacquin, P., Boulkedid, R., & Alberti, C. (2017). Methodology used in comparative studies assessing programmes of transition from paediatrics to adult care programmes: a systematic review. *BMJ Open, 7*(1), e012338. https://doi.org/10.1136/bmjopen-2016-012338

Limperg, P. F., Haverman, L., van Oers, H. A., van Rossum, M. A., Maurice-Stam, H., & Grootenhuis, M. A. (2014). Health related quality of life in Dutch young adults: psychometric properties of the PedsQL generic core scales young adult version. *Health and Quality of Life Outcomes, 12*, 9. https://doi.org/10.1186/1477-7525-12-9

Michaud, P. A., Schrier, L., Ross-Russel, R., van der Heijden, L., Dossche, L., Copley, S., Alterio, T., Mazur, A., Dembinski, L., Hadjipanayis, A., Del Torso, S., Fonseca, H., & Ambresin, A. E. (2018). Paediatric departments need to improve residents' training in adolescent medicine and health: a position paper of the European Academy of Paediatrics. *European Journal of Pediatrics, 177*(4), 479-487. https://doi.org/10.1007/s00431-017-3061-2

Mooi, E., & Sarstedt, M. (2011). *A concise guide to market research*. Springer-Verlag.

Nagra, A., McGinnity, P. M., Davis, N., & Salmon, A. P. (2015). Implementing transition: Ready Steady Go. *Archives of Disease in Childhood: Education and Practice Edition, 100*(6), 313-320. https://doi.org/10.1136/archdischild-2014-307423

National Institute for Health and Care Excellence (2016*). Transition from children's to adults' services for young people using health or social care services, Guideline 43*. NICE.

Petkov, J., Harvey, P., & Battersby, M. (2010). The internal consistency and construct validity of the partners in health scale: validation of a patient rated chronic condition self-management measure. *Quality of Life Research, 19*(7), 1079-1085. https://doi.org/10.1007/s11136-010-9661-1

Sattoe, J. N. T., Peeters, M. A. C., Hilberink, S. R., Ista, E., & van Staa, A. L. (2016). Evaluating outpatient transition clinics: a mixed-methods study protocol. *BMJ Open, 6*(8), e011926. https://doi.org/10.1136/bmjopen-2016-011926

Schultz, A. T., & Smaldone, A. (2017). Components of interventions that improve transitions to adult care for adolescents with type 1 diabetes. *Journal of Adolescent Health, 60*(2), 133-146. https://doi.org/10.1016/j.jadohealth.2016.10.002

Sheehan, A. M., While, A. E., & Coyne, I. (2015). The experiences and impact of transition from child to adult healthcare services for young people with type 1 diabetes: a systematic review. *Diabetic Medicine, 32*(4), 440-458. https://doi.org/10.1111/dme.12639

Van Staa, A. L., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development, 37*(6), 821-832. https://doi.org/10.1111/j.1365-2214.2011.01261.x

Van Staa, A. L., Peeters, M. A. C., & Sattoe, J. N. T. (2020). On Your Own Feet: A practical framework for improving transitional care and young people's self-management. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An international perspective on nurses' roles and interventions* (pp. 191-228). Springer Nature.

Van Staa, A. L., & Sattoe, J. N. T. (2014). Young adults' experiences and satisfaction with the transfer of care. *Journal of Adolescent Health, 55*(6), 796-803. https://doi.org/10.1016/j.jadohealth.2014.06.008

Van Staa, A. L., Sattoe, J. N. T., & Strating, M. M. (2015). Experiences with and outcomes of two interventions to maximize engagement of chronically ill adolescents during hospital consultations: A mixed methods study. *Journal of Pediatric Nursing, 30*(5), 757-775. https://doi.org/10.1016/j.pedn.2015.05.028

White, M., O'Connell, M. A., & Cameron, F. J. (2017). Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *The Lancet: Child & Adolescent Health, 1*(4), 274-283. https://doi.org/10.1016/S2352-4642(17)30089-5

White, P. H., Cooley, W. C., Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 142*(5), e20182587. https://doi.org/10.1542/peds.2018-2587

Zhou, H., Roberts, P., Dhaliwal, S., & Della, P. (2016). Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services - an integrative review. *Journal of Clinical Nursing, 25*(21-22), 3113-3130. https://doi.org/10.1111/jocn.13326

Appendix A

The eight core elements of the *On Your Own Feet* framework explained (Van Staa et al., 2020)

ORGANIZATION OF TRANSITIONAL CARE	
Future-oriented	Written protocols and policies are useful to organize planned, developmentally appropriate and holistic transitional care. Early preparation and gradual movement towards more responsibilities and independence for the young person are important elements in this, as well as meeting the new health care professionals prior to the transfer.
Coordination	It is recommended to appoint a transition coordinator to monitor the transition process, e.g., the collaboration and communication between pediatric and adult health care professionals and the logistics around the transition and transfer. This coordinator should be easy to contact for young persons (and their families) in case of problems or misunderstandings.
Continuity of care	A shared vision on transition, adequate transfer of information (both orally and written) knowing to whom the young person is being transferred, and monitoring and evaluation of follow-up are factors that contribute to continuity of care.
INDEPENDENCE AND SELF-MANAGEMENT	
Parent involvement	Parents should be involved in their child's transition process and must be supported in gradually giving their child more control and responsibilities.
Self-management	A person-oriented and holistic approach is important to support young people in their transition. Attention should not only be paid to medical aspects, but also to psychosocial developments and challenges faced by the young people in this phase of life. Young people should be prepared for independence and self-management in adulthood and adult care. Developmentally appropriate care to work on self-efficacy and to achieve transfer readiness is of great importance here.
Psychosocial care	Attention for psychosocial issues is a critical part of transitional care. Timely referral of young people to psychosocial care (e.g., a psychologist, social worker, or dietician) is important to prevent psychosocial problems from escalating. Routine measurement of psychosocial patient-reported outcome measures is helpful in monitoring.
COLLABORATION AND YOUTH INVOLVEMENT	
Young person	Transition should be tailored and developmentally appropriate. In addition, young people should be actively involved in their own care. Their wants, needs and preferences must be identified and taken seriously.
Team	Interdisciplinary coordination and alignment between pediatric and adult care professionals, alignment of working methods and procedures (where possible and relevant), and meeting new care professionals prior to the transfer are essential elements for adequate transitional care.

9

General discussion and conclusion

OUTLINE

The central aim of this thesis was to clarify the essence of good transitional care, based on research among young people with diabetes mellitus type 1 (T1DM), and to explore how the provision of transitional care can be evaluated. Part I provided insights into how T1DM impacts the lives of young people, and how they are currently supported in their transition towards adulthood and adult care. Deeper understanding of young people's needs, values and preferences was required to get a better view on what good transitional care entails. Subsequently, knowledge on these aspects served as significant input for part II. In this second part, a framework to evaluate the functioning and outcomes of outpatient transition clinics across health care settings – considered as best practice in providing good transitional care – was developed and tested. This final chapter reflects on the main findings of the research in the light of current literature. New insights are described with respect to available knowledge, and implications for practice and future research are presented and discussed.

MAIN FINDINGS

There is still much work to do in the field of health care services for young people with chronic conditions. Part I of this thesis addressed the question of what good transitional care actually entails. The three studies among young people with T1DM all highlighted that transition in care involves more than just the physical transfer from pediatric to adult care services. It can be concluded that the *On Your Own Feet* transitional care framework – as presented in the Introduction – fits the overarching themes extracted from these studies, underlining the importance of a holistic perspective on transition in care. First of all, the impact of T1DM on young people's health-related quality of life (HRQOL) proved to be significant (chapter 2). They struggled to maintain a balance between the demands of managing their diabetes and the multiple other life transitions inherent to becoming an adult. More than one-third of the young people with T1DM who participated in our research experienced diabetes distress after transfer to adult care (chapter 3). This was associated with less favorable transition experiences, self-management and HRQOL. Therefore, structural attention is needed for young people's attitudes, motivation and worries regarding self-management of T1DM in the light of their 'normal' daily life. Building positive relationships and adopting motivating interaction styles may help clinicians to empower young people to become actively involved in their own diabetes management and treatment, to prevent diabetes distress, and to foster HRQOL.

The concept of developmentally appropriate care is the guiding principle here, requiring health care professionals to go beyond the medical aspects of the chronic condition and address developmental and psychosocial challenges in the young person's life (Farre et al., 2016). By focusing on biopsychosocial development rather than chronological age, this concept meets the requirements of a holistic and person-centered approach as presented by the *On Your Own Feet* framework. In this way, young people are empowered to make choices in care that best fit their individual circumstances. Observations of outpatient consultations (chapter 4) made clear that current transitional care practices do not meet up to these requirements. Health care professionals in both pediatric and adult care had difficulty in getting young people actively involved in their care, and a holistic perspective in the provision of care was often lacking. Attention for the betterment of patient-professional interactions in the consultation room is therefore needed. Moreover, providing holistic and developmentally appropriate care should be facilitated by the multidisciplinary team and the wider organizational level or health care system.

By covering all elements of the *On Your Own Feet* framework, the 'transition clinic' is often recommended as best practice and is expected to contribute to the provision of holistic and developmentally appropriate care. At the same time, the transition clinic can be considered a complex intervention. It requires cultural and behavioral changes from professionals and young people, and involves several levels of organizations (i.e., the pediatric and adult care settings) and a multidisciplinary team of professionals. Moreover, it aims at affecting various health-related and psychosocial outcomes, and requires flexibility and tailoring in its execution (Craig et al., 2008). Due to this complexity, there is still no clearly defined format of a transition clinic available, which complicates the evaluation of transitional care.

Part II elaborated upon this issue and started with presenting a comprehensive evaluation framework, including both process measures and (patient-reported) outcome measures, to compare the transition clinic with direct hand-over care (chapter 5). This framework was tested in several settings. The controlled studies of transition clinics for young people with cystic fibrosis (CF) (chapter 6) and inflammatory bowel disease (IBD) (chapter 7) – which were part of the *Self-management and Participation Innovation Lab* (SPIL) program (2012–2016) – showed variety in set-up of the transition clinics, working ways and protocols used; but differences in outcomes with control clinics could hardly be established. The protocol was also used for exploring different aspects and effects of transition and transitional care – either or not transition clinics – among the participating diabetes teams of the *Better Transition in Type 1 Diabetes* project (2016–2018) (chapter 8). This overall evaluation study was guided by the *On Your Own Feet* framework and confirmed large differences in the organization and execution of transitional care for young people with T1DM in the Netherlands. Hence, part II revealed that one-to-one comparisons of transitional care between studies and disease groups, and also within disease groups, are unrealistic. Although we had developed a comprehensive framework, the evaluation of complex interventions – such as the transition clinic – still proved to be challenging. Therefore, the question remains how good transitional care can be best evaluated.

BEYOND TRANSITION: THE NEED FOR DEVELOPMENTALLY APPROPRIATE CARE

The call for developmentally appropriate health care as emphasized in part I of this thesis, is not new. The World Health Organization highlighted the need to move towards adolescent-responsive health care services for young people some years ago (World Health Organization [WHO], 2014), and developmentally appropriate health care was considered an appropriate concept to underpin this move (Farre et al., 2016; Farre et al., 2015; Sawyer, 2003). It acknowledges that every young person makes the transition to adulthood and adult care in their own way, with individual challenges based on the biopsychosocial developmental stage rather than chronological age. Developmentally appropriate health care requires, according to the literature, a lifespan perspective incorporated in both pediatric and adult care services for people with childhood-onset conditions (such as T1DM) to fill the existing gaps (Coyne et al., 2019; Rapley et al., 2019; Roebroeck et al., 2009; Sawyer, 2003; Van Staa, 2012). Health care services – including providers, organizations, and policies – need to respond to and align with the changing developmental needs of young people in a consistent and universal manner, and provide care across settings (Rapley et al., 2019). Creating a context for this prerequisite requires a certain degree of flexibility and should focus on a broad range of aspects of health care provision; ranging from the micro level (e.g., how health care professionals interact with young people), to the meso level (e.g., how health care professionals collaborate with each other), and the macro level (e.g., how services are organized and funded) (Leijten et al., 2018; Rapley et al., 2019).

Below, the five dimensions of developmentally appropriate health care (see Table 1) are explained (Farre et al., 2016), and divided into micro-, meso- and macro level. Bridging the gaps between pediatric and adult care poses unique challenges on each level. Developmentally appropriate health care can possibly contribute to overcoming barriers and create a context that makes it possible to provide good transitional care.

Table 1

The five dimensions of developmentally appropriate health care for young people (adapted from Farre et al. (2016)), classified by micro-, meso- and macro level

MICRO LEVEL
Biopsychosocial development and holistic care: a focus on biopsychosocial development rather than chronological age, with routine biopsychosocial developmental assessment and approach to the young person adjusted accordingly.
Adjustment of care as the young person develops: the need for flexibility to acknowledge the biopsychosocial developmental changes over time and the potential for regression in relapsing health conditions.
Empowerment of the young person by embedding health education and health promotion: that knowledge and skills training for young people is embedded into routine clinical practice to enable them to gradually become more autonomous with respect to the care of their own health as they grow up. Services need to be designed so as to nurture and support such skill development.
MESO LEVEL
Acknowledgement of young people as a distinct group: the recognition that their specific needs—in terms of informational resources, services, spaces, pathways and required competencies of staff—are distinctly different to those of younger children and older adults as a result of their developmental status.
MACRO LEVEL
Interdisciplinary and interorganizational work: a focus on continuity of care, coordination, consistency and communication across agencies. Connecting health, education, employment, social, voluntary agencies at a clinical and system level.

MICRO LEVEL

Part I of this thesis concerned the micro level, where interactions between young people and health care professionals are at the core of transitional care. The vulnerability of young people with T1DM – who are at risk of having psychological problems (e.g., diabetes distress) and a lower HRQOL – shows how important it is to adopt a person-centered and holistic approach that looks beyond the young person's physical condition. Our observations of outpatient hospital consultations with young people with T1DM demonstrated that health care professionals generally had difficulty in finding effective ways for interacting with these young people. Conversations about daily life and the challenges faced during transition to adulthood and adult care often remained shallow, and young people's cues were not always taken up. Health care professionals' lack of understanding of young people's needs, priorities, values and concerns prevents these young people from becoming active partners in their own care and diabetes management. Therefore, in accordance with the dimensions as described in Table 1, the main findings of part I underscore the need to adopt a person-centered and holistic perspective, to adjust care as the young person develops, and to empower the young person to take an active role in care.

Adopting a person-centered and holistic perspective

Young people's needs and preferences should be explored at the crossroads of medical, role, and emotion management, while acknowledging their normal developmental tasks alongside the challenge of taking up medical management of the chronic condition (Lorig & Holman, 2003). The studies among young people with T1DM in this thesis showed, however, that psychosocial problems are common in the transitional phase and that structural attention for the whole person is often lacking. Although person-centeredness has been the official focus of health policy developments and research for about twenty years now – it is included in the Institute of Medicine report (Wolfe, 2001) as one of the improvement goals to enhance quality of care – transitional care practices still show a different pattern.

In light of this, routine measurement of Patient-Reported Outcome Measures (PROMs) in both pediatric and adult care – across the transition period – is highly recommended, provided that the results are discussed with the young person during consultations (Haverman et al., 2019). Preferably, these discussions are driven by shared decisions on personalized health goals, thereby facilitating patient empowerment and self-management (Castro et al., 2016). If deemed necessary, the health care professional can act accordingly, for instance through referring the young person to psychosocial care (e.g., to a psychologist or social worker) (Haverman et al., 2013). Although there is little evidence about the usefulness of PROMs in the care for young people with chronic conditions yet, experiences are generally positive, also for young people with T1DM (De Wit et al., 2020; Mosor et al., 2021). An example of an effective web-based portal is KLIK (www.hetklikt.nu), which allows for systematic monitoring of HRQOL in children and young people with chronic conditions in the Netherlands (Haverman et al., 2011; Haverman et al., 2019; Haverman et al., 2013). KLIK contributed significantly to more communication about psychosocial issues related to having a chronic condition, without lengthening the duration of the consultation (Engelen et al., 2012; Haverman et al., 2013). There are also other conversation models that could contribute to more person-centered care, such as the diabetes consultation model of Rutten et al. (2018) combined with the use of the Self-Management Web (Beck et al., 2019) as suggested in chapter 4, the Skills for Growing Up tool (Hilberink et al., 2020; Maathuis et al., 2012; Sattoe et al., 2014), and Ready Steady Go (Nagra et al., 2015; Van der Slikke et al., 2018). Nevertheless, structural attention for young people's psychosocial needs is currently far from standard practice, as confirmed by the studies in this thesis (in both part I and II).

Appropriate parent involvement

A person-centered and holistic approach in transitional care for young people with chronic conditions also implies that health care services should be able to adapt to the dynamic nature of young people's development, which is not necessarily defined by chronological age (Farre & McDonagh, 2017; Saxby et al., 2020). Young people with chronic conditions can, and do, develop self-management skills at varying rates and intervals, influenced by individual experiences (Modi et al., 2012; Saxby et al., 2020). The observational study of outpatient consultations with young people with T1DM (chapter 4) clearly illustrated that every young person has his or her own needs, priorities, values and concerns regarding disease management, and shows different attitudes and levels of involvement in care. In the end, young people cannot be expected to assume full responsibility for their disease management at a fixed point in time. However, over time, they can be encouraged to become cooperative self-managers, with the support of their parents (or other informal caregivers) and health care professionals (Saxby et al., 2020). Eventually, they have to take up full responsibility in living with the chronic condition. A highly recommended means to support this development is the use of independent consultations, for instance by means of the 'split-visit model' in which young people start the consultation alone with the health care professional, while parents join later. A study of Van Staa et al. (2015) reported mainly positive experiences with this intervention, such as increased independent behaviors and involvement of the young people. They also experienced more room to talk about subjects they did not want their parents to know about, implying that the intervention enhanced confidentiality (Daley et al., 2020; Klostermann et al., 2005; Van Staa et al., 2015). According to the prospective study of Colver et al. (2020), promotion of young people's confidence in managing their condition is one of the key features of transitional care that are associated with improved outcomes; independent consultations could possibly contribute to this.

At the same time, it should be mentioned that working towards gradual self-management of a chronic condition is not a concern of young people and health care professionals alone. Parents' or other informal caregivers' roles[1] in the transition process must be taken into serious consideration; they should certainly not be excluded (Van Staa et al., 2015; Yi-Frazier et al., 2021). The parents' role is an integral component of the transition, as they affect the process and are reciprocally affected by it too (Heath et al., 2017). A possible limitation of the work presented in this thesis is, therefore, that the parent's role during transition was not systematically studied. Still, the nationwide evaluation study among young people with T1DM (chapter 8) showed an overall lack of structured support by Dutch diabetes teams for parents. Parents are often perceived as a barrier on young people's road to independence. Studies in the past often focused on clashing perceptions on health and non-health-related life domains between parents and their children, as in my own previous research (Peeters et al., 2014).

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[1] From here, the term 'parent(s)' is used as an umbrella term to include all informal caregivers responsible for parenting during transition.

More recently, parents' continuing influential role in young people's health, development and wellbeing is increasingly recognized. Young people's lives are still characterized by interdependencies during the transition phase, which feature facilitates the uptake of their condition's management (Allen et al., 2011; Betz et al., 2015; Colver et al., 2020). In accordance with the principles of developmentally appropriate health care, appropriate parent involvement should definitely be incorporated in the transitional care for young people with chronic conditions (Farre et al., 2016). Moreover, there is evidence that these young people's outcomes are likely to improve if transitional care incorporates appropriate parent involvement (Colver et al., 2020; Shaw et al., 2021). For instance, parent involvement in care was found to exert positive effects on glycemic control in young people with T1DM (Cunningham et al., 2011; Eilander et al., 2017; Maas-van Schaaijk et al., 2013; Mackey et al., 2014; Rumburg et al., 2017). Be that as it may, another study showed that parents of adolescents with T1DM can experience increased levels of stress and depression that are related to the burden of diabetes management (Yi-Frazier et al., 2021), which in turn could have a negative impact on their children's health outcomes.

The transfer of responsibilities between young people and their parents is a very complicated process, particularly in case of T1DM, given the complexity and scope of the diabetes care tasks (Aalders, 2021). If responsibilities are transferred too early, young people may feel overwhelmed by the treatment demands, which may lead to suboptimal self-care and clinical outcomes, and may also have a negative impact upon their quality of life. On the other hand, if parents keep control while their child is ready to take over responsibilities, the child is deprived of learning and practicing self-care skills, which may sometimes even cause family conflicts (Aalders, 2021). Health care professionals in diabetes care – but also in transitional care in general – should therefore regularly address the division of tasks and responsibilities between young people and their parents, thereby supporting parents to find a balance between being involved and encouraging autonomy (Aalders, 2021; Allen et al., 2011; Betz et al., 2015; Colver et al., 2020; Coyne et al., 2019; Yi-Frazier et al., 2021). The question remains, however, why this is not yet reflected in health care policy and practice. Even though "appropriate parent involvement" is also a key feature of transitional care according to Colver et al. (2020), it remains unclear what "appropriate" exactly means in this regard. Some cases require a higher level of parent involvement than others, dependent on young person, parent, and context factors. Anyway, appropriate parent support from health care professionals should be tailored taking into account all these factors.

Self-management and empowerment

The same question can be posed for self-management interventions in transitional care practices. Effective self-management is considered essential for everyone living with a chronic condition, especially for young people (Modi et al., 2012). During emerging adulthood, they are expected to take over from their parents or caregivers the self-management tasks and responsibilities. Since this is not easy, appropriate self-management support is needed to empower these young people to manage the physical, mental and social consequences of their condition in daily life (Harvey et al., 2008; Sattoe, 2015; Sattoe et al., 2021; Trappenburg et al., 2013). This is also evident from the studies among young people with T1DM in this thesis.

Self-management is key in successful transition to adult health care (Nguyen et al., 2016; Sattoe et al., 2021; Surís & Akré, 2015) and mastery of self-management skills is therefore often one of the outcomes of transitional care evaluations, also in the study protocol presented in part II of this thesis. Moreover, there is a great body of knowledge on how to support young people with chronic conditions and their families in self-management. For instance, we know that self-management interventions that provide education aimed solely at behavior change are not successful (Bal et al., 2016; Van Hooft et al., 2017). Successful interventions are those that focus on patients' intrinsic processes, i.e. motivation or self-efficacy (Van Hooft et al., 2017). Thus, self-management interventions should facilitate conversations between young people, parents and health care professionals, ensuring a holistic view and focusing on youth involvement, instead of merely measuring their skills or performance. Young people should be given the opportunity to address and discuss the burden of care tasks and responsibilities related to their chronic condition, which form a critical part of their transition process as demonstrated in part I of this thesis.

Despite an increasingly strong emphasis on the importance of self-management and self-management support in transitional care and the insights into how to provide this, there is still a need to look for strategies that actually foster self-management and empowerment of young people with chronic conditions. This is something that cannot be achieved solely at the micro level of the health care system, where it is highly dependent on individual characteristics of care providers; it should be facilitated at the meso- and macro level as well.

MESO LEVEL

At the meso level, which refers to the multidisciplinary team level, young people in general should be recognized as a group with specific views, needs and approaches, because of the unique challenges they face in their transition towards adulthood and adult care. This thesis confirms this for young people with T1DM, and it is also evident from the literature (Farre et al., 2016; Rapley et al., 2019; Zaidi, 2021). Health care professionals need skills to properly involve both the young people and their parents in care

(Heath et al., 2017). However, the observational study in chapter 4 demonstrated that adequate interaction with young people is challenging, while the evaluation of diabetes transitional care in chapter 8 shows that parental involvement requires attention.

Knowledge and skills in adolescent health

Wright et al. (2017) mentioned that the lack of education and training to deal with adolescent issues and the specific care needs of young people going through the transition to adulthood and adult care, is a significant barrier to delivering good transitional care. Despite the availability of various practical tools to facilitate person-centered communication between health care professionals, young people and parents – such as the Skills for Growing Up tool (Hilberink et al., 2020; Maathuis et al., 2012; Sattoe et al., 2014), Ready Steady Go (Nagra et al., 2015; Van der Slikke et al., 2018), the Self-Management Web (Beck et al., 2019; Been-Dahmen et al., 2019), and a structured diabetes conversation model (Rutten et al., 2018) – the actual use of such instruments in daily practice often lags behind. As a consequence, their intended purpose – i.e., gaining more insight into the specific needs and preferences of young people – has often not been achieved. The observational study among young people with T1DM in chapter 4 presented this as a main barrier to the provision of person-centered care around transition and transfer.

To give health care professionals more insight into needed knowledge and skills improvements based on young people's and parents' transition and transfer experiences, mirror meetings are highly recommended (De Wit et al., 2008). Such group discussions with health care professionals were held in the context of the *Better Transition in Type 1 Diabetes* program (chapter 8) and served as an eye-opener for diabetes teams on young people's experiences with current care practices, unmet needs and preferences. Furthermore, reinforcement and positive feedback at the team level could help professionals to improve their skills. This feature is considered one of the perceived benefits of a transition clinic, where professionals were encouraged to work and learn together (chapters 6 & 7).

According to Wright et al. (2017), increased experiential learning is also paramount to improve knowledge and skills. This will be discussed in more detail later on in this chapter, in the macro level section. Attention will be paid to the need for more profound and structural embedded education and training on adolescent health care in both pre-service and in-service programs.

Creating awareness

Young people's specific care needs, too, require greater awareness among health care professionals from both pediatric and adult care. More specifically, a network should be established of team-based and young person-oriented health care professionals who acknowledge the value and worth of developmentally appropriate health care services (Rapley et al., 2019; Zaidi, 2021). Still, this turns out to be difficult, as professionals from different departments (i.e. pediatric and adult care departments) are used to act independently, in isolation, with cultural and structural barriers that inhibit working together and communicating effectively (Li et al., 2018). A young person's moment of transfer to adult care is often determined by chronological age rather than biopsychosocial development and transition readiness. As a consequence, the so-called third phase of transition that continues in adult care – after the initial preparation phase in pediatric care and the shorter phase around transfer to adult services – often remains unaddressed. This is also apparent from the various evaluation studies in part II of this thesis (i.e., among young people with CF, IBD and T1DM) that underscore the importance of adult care professionals' involvement in transitional care. This involvement starts with the young person meeting the adult care team before transfer, which Colver et al. (2020) mentioned as the third key feature of transitional care that is associated with improved outcomes and, therefore, requires priority. Furthermore, enhanced follow-up in adult care is of high importance to ensure young people's engagement in care, especially in the first years after transfer (Crowley et al., 2011). Now, the question remains how to create such awareness among professionals from both pediatric and adult care, who have to work side-by-side to define, analyze, and create a context for developmentally appropriate health care across settings.

The evaluation studies in part II of this thesis all highlight the importance of coordination in transitional care. Former studies underpinned that designating a transition coordinator could be a useful intervention to achieve stability during the transitional phase (Annunziato et al., 2013; Betz et al., 2018; Colver et al., 2018; Hilliard et al., 2014; National Institute of Health and Care Excellence [NICE], 2016; Spaic et al., 2019). The transition coordinator serves as a spokesperson for young adults and their families, ensures confidentiality, and manages the logistics around transition and transfer. Also, a transition coordinator can aid to facilitate a good working relationship between pediatric and adult care professionals, thereby smoothening the transition process and ensuring continuity of care and support in a developmentally appropriate context (Iyengar et al., 2019; Van Staa et al., 2020). The coordinator role is probably most effective when executed on both sides of the transfer, thereby 'bridging the gap' between the settings and fostering the involvement of adult care professionals. More specifically, professionals who participated in the CF study (chapter 6) pointed out that such a coordinating role can be best taken up by a member of the care team, preferably a dedicated nurse specialist. Literature also shows that nurses seem excellently positioned to fulfill this role, given the relationships they establish with young people and their parents (Betz & Coyne, 2020; Betz & Redcay, 2005; Coyne & Hallowell, 2020). Furthermore, nurses often play a pivotal role in the design, actual development and implementation of transition programs, and as connectors of pediatric and adult services (Van Staa et al., 2015). For example, in the Dutch *Better Transition in Type 1 Diabetes* program (chapter 8), most team leaders were nurses or nurse specialists. Particularly advanced practice nurses are seen as having the experience and capacities to act as program developers and leaders in transitional care (Betz & Redcay, 2005; Joly, 2016). This is confirmed from the perspective of young patients and their families who – according to a review of Hyde et al. (2020) – received good care and clear explanations from advanced practice nurses. Moreover, these young patients and their families felt empowered and were more than before knowledgeable about the condition, and sometimes they were more satisfied with dealing with nurses than dealing with physicians (Hyde et al., 2020). Therefore, it seems worthwhile to consider the role of advanced practice nurses more in future transitional care.

MACRO LEVEL

The micro level and meso level have now been elaborated upon, but today, perhaps the biggest challenges in providing developmentally appropriate care are at the macro level. The wider organizational and system level – i.e., the macro level – should be supportive too and create a context for the provision of appropriate transitional care for young people with chronic conditions up to the age of about 25 years (Van Staa et al., 2020). For instance, joint delivery of transitional care between pediatric and adult health care professionals is highly recommended, but requires time investment from both sides and appropriate financial coverage. Currently, the Dutch health care system seems insufficiently equipped to realize this, which is a problem in more European countries (Ercan et al., 2009; Mazur et al., 2017). Some necessary preconditions in the wider organizational context will be explained one by one below. The *On Your Own Feet* transitional care framework does as of yet not address these issues.

Laws and regulations

The field of pediatrics in the Dutch health care system covers individuals aged 0 to 18 years and prepares children for the transfer to adult care. Still, health care services for young people with chronic conditions too often pay little attention to the future, and are mostly embedded in separated teams (i.e., a pediatric and an adult care team) with sometimes even different locations. The evaluation studies in part II of this thesis (chapters 6 to 8) confirm this general lack of alignment and collaboration between pediatric and adult care providers, with teams having their own structures and working ways (e.g., with regard to outpatient consultations, follow-up, and the use of electronic medical record systems) and clinical guidelines (e.g., about treatment and monitoring signs and symptoms). No notable differences were found between teams paying more attention versus teams paying less attention to transitional care, which finding emphasizes the overall need to provide transitional care in a more consistent and universal way, and across settings. Moreover, in their study on young adults' experiences and satisfaction with the transfer of care, Van Staa and Sattoe (2014) reported that good alignment and collaboration between pediatric and adult services are crucial for a positive experience. Also, receiving a warm welcome in adult care was considered to be of high importance (Colver et al., 2020; Van Staa & Sattoe, 2014). The case of Emma in the Introduction chapter illustrated this: "*It felt like I had to start all over again,*" she said, while health care professionals are expected to respond to her changing developmental needs in maybe the most turbulent period in her life.

Another relevant topic here is the Dutch Act on the Medical Treatment Agreement (WGBO), which provides the legal basis for focusing on young people alone from the age of 16, who are expected to make medical decisions on their own from this age on. The focus of the WGBO on the individual patient – with autonomy (i.e., the right to make informed decisions about one's own care and treatment) as a central value – is essential in health law to create equality in the relationship between patient and health care professional. At the same time, particularly in chronic care, the patient's social environment is also of great importance (Dwarswaard et al., 2016). As discussed above, especially parental involvement is important in supporting young people in their self-management tasks (Allen et al., 2011; Betz et al., 2015; Colver et al., 2020; Coyne et al., 2019; Heath et al., 2017; Yi-Frazier et al., 2021), although support from other family members or friends could be needed to manage the chronic condition as well. However, the emphasis on autonomy in health care decisions (from the age of 16 years according to the WGBO) might persuade professionals that relatives should have limited involvement in care and treatment. After a young person has transferred to adult services, parents are often no longer involved to the same extent as in pediatric services; sometimes they are even completely excluded from discussions about their child's condition, which is absolutely not desirable, as discussed in the micro level section above (Allen et al., 2011; Betz et al., 2015; Coyne et al., 2019).

While from a legalistic perspective a decision may be considered autonomous only when it is reached completely independently, it is unrealistic and developmentally inappropriate to expect young people (but also patients at other ages) to act completely independent, ignoring their social context – i.e. their parents, peers, and other important people in their lives – when making medical decisions (Dove et al., 2017; Sawyer & Rosenberg, 2020). Rather, young people will commonly consider their relatives' perspectives as well as how their decisions will impact others, calling for recognition of the principle of "relational autonomy". Sawyer and Rosenberg (2020) proposed that health care professionals should seek to understand the extent to which a young person is weighing others' opinions in making a decision and whether this promotes the young person's health and condition management.

Quality standards and clinical guidelines

Quality standards and clinical guidelines crucially provide norms for good quality transitional care or developmentally appropriate care for young people with chronic conditions. However, young people – and especially those in transitional care – are generally underrepresented in quality standards and clinical guidelines. This results in various negative health outcomes (e.g., loss to follow-up, medication adherence problems, lower HRQOL), as shown by previous studies (Garvey et al., 2017; Hanghoj & Boisen, 2014; Heery et al., 2015; Sheehan et al., 2015) and insights from the studies among young people with T1DM in part I of this thesis (chapters 2 to 4). A systematic review of Samarasinghe et al. (2020) investigated how effectively transition has been incorporated into existing disease-specific clinical practice guidelines, taking into consideration seven key principles of transitional care: (1) a systematic and formal transition process; (2) early preparation, (3) identification of a transition coordinator, (4) good communication strategy and collaboration between health professionals, (5) individualized transition plan, (6) enhancing self-management and (7) active follow-up after transition. These principles embody the recommendations on transitional care proposed in the NICE guideline (2016) and are in accordance with the core elements of the *On Your Own Feet* transitional care framework as presented in the Introduction chapter of this thesis (Van Staa et al., 2020). According to Samarasinghe et al. (2020), clinical practice guidelines that address transition from pediatric to adult care have been issued for a limited number of physical chronic conditions; especially follow-up and evaluation were rarely mentioned. The greatest number of guidelines addressing transitional care concerns diabetes, but follow-up and evaluation were neither discussed here (Samarasinghe et al., 2020). Notably, this shortage seems to be reflected in the evaluation studies in this thesis too (chapters 6 to 8), as these found fewer scheduled consultations and more missed consultations in adult care, and sometimes even missing data in patient's charts in adult care. Moreover, the study among young people with T1DM (chapter 8) showed a decreasing trend in HbA1c measurements after transfer, despite the persisting poor glycemic control. This confirms the call for attention for follow-up and evaluation in quality standards and clinical guidelines. Currently, the Knowledge Institute of the Federation of Medical Specialists in the Netherlands is developing – together with partners from professional organizations, patient representatives and health insurers – the first Quality Standard on Transition in Care in the Netherlands. This standard should provide Dutch health care providers of young people with chronic conditions with concrete recommendations, tools and action plans for the organization of transitional care; the NICE guideline (2016) serves as a starting point in this process. With special attention being paid to embedding the quality standard into transitional care practices (i.e. dissemination and implementation), this is a significant step towards structural improvement of Dutch transitional care.

Information and communication technology

When reviewing patient charts as part of the evaluation studies in this thesis, we encountered many different electronic health record systems, which complicated the process of data collection. A joint electronic health record that facilitates transition continuity of care by enabling patient data sharing is still exceptional. Even within hospital settings, different departments (i.e., pediatric or adult care) or locations were using different systems. This diversification also impedes research into long-term outcomes in transitional care, which is highly needed, and makes loss to follow-up difficult to detect.

Furthermore, the implementation of web-based applications in transitional care – i.e., for systematic monitoring of HRQOL and psychosocial problems – still faces several practical barriers. Institutional arrangements are not always cooperative; for instance, Haverman et al. (2019) had noticed that incompatibility with the hospital's electronic health record forced health care professionals to log in into multiple systems simultaneously. Also, aspects with regard to data encryption and information security should be handled carefully. Capable technical support is highly needed to facilitate appropriate use of IT systems in transitional care. Moreover, implementing and monitoring PROMs in transitional care encompasses additional challenges. In addition to a generic approach on living with a chronic condition, different versions of PROMs might be needed with specific elements for different diagnoses and age groups, as well as parent- and self-report versions (Sattoe, 2015). The Skills for Growing Up tool (Hilberink et al., 2020; Maathuis et al., 2012; Sattoe et al., 2014) already allows for disease-specific customizations; different versions are available for use in rehabilitation care, renal disease, cystic fibrosis, epilepsy, mild intellectual disability, and virus infections. The Ready Steady Go program (Nagra et al., 2015; Van der Slikke et al., 2018) is a generic tool. Both tools include also parent versions. Moreover, the Ready Steady Go tool has an adult version, which poses the challenge of securing continuity in follow-up and evaluation in adult care.

Adolescent health in education and training programs

The problem of insufficient knowledge and skills on adolescent health and development has already been identified at the multidisciplinary team level, but support from both the organizational and the health care system level is required to fill the gaps (Wright et al., 2017). This is not only an issue in the Netherlands, but also internationally (WHO, 2019). The need to improve health care services for young people should be recognized in national curricula for physicians, nurses and allied health care professionals, and must be highlighted and addressed as a matter of urgency (WHO, 2019; Wright et al., 2017).

Bearing in mind the holistic perspective as suggested in part I of this thesis, adolescent health care issues should be incorporated into both pre-service and in-service programs. This would as well foster lifelong learning of health care professionals. A position paper of the European Academy of Pediatrics proposed a set of competency-based training goals and objectives as well as pedagogic approaches for pediatricians (Michaud et al., 2018), which are of course at least as important for professionals from adult care. Providing professionals with in-service state-of-the-art training is considered essential for experiential learning and building understanding on up-to-date adolescent health care issues (WHO, 2019). Recent research results, such as the observations of outpatient consultations in transitional care that highlight the need to enhance communication and interaction skills (chapter 4), could provide input for such a training. Ideally, health care professionals are offered examples of both preferable and non-preferable practices – as classified in chapter 4 – so that comparisons can be made and differences can be identified to assist in feedback. Training programs should also pay attention to monitoring and discussing PROMs, and to the use of tools to stimulate self-management and empowerment. For instance, nurses who had been trained in performing the Self-Management Web interventions experienced this as very helpful, particularly the role playing and discussing filmed consultations (Been-Dahmen et al., 2019). Reinforcement and positive feedback helped them to improve their skills.

Management

Both evaluation studies of transition clinics in this thesis (chapters 6 & 7) revealed that high engagement and motivation of health care professionals are essential for a successful transition clinic. In addition, dedicated health care professionals are likely to contribute to better transition experiences and satisfaction with transfer. The need for enthusiastic people in transitional care – who are willing to work together through establishment of long-term collaborative relationships in multidisciplinary teams with the shared goal of providing the best care to young people – has already been mentioned as a facilitator at the meso level. However, establishing such a culture requires a positive and stimulating environment for transition innovation from policy makers and managers. Joint consultations between pediatric and adult care providers could possibly contribute to creating a sense of teamwork. Yet, despite the significance of a supportive context at team level, several organizational constraints are still standing in the way. Contact times are often too short, and health care professionals have to deal with heavy patient loads. More and more they feel the pressure to see as many patients as possible, which hinders them from giving their young patients the special attention they need during their transition process. This is a common problem reported by health care professionals who participated in the research described in this thesis, and is confirmed by other studies (Kim & White, 2018; Levinson, 2011). Unfortunately, management actions to enable structural improvement of transitional care for young people with chronic conditions lag behind, because evidence is lacking on factors that effectively influence the transition process (Betz et al., 2018; Chu et al., 2015; Colver et al., 2018; Gray et al., 2018; Schultz & Smaldone, 2017; Sheehan et al., 2015). This lack makes it very difficult to extract financial resources. Moreover, in addition to more profound research on working elements in transitional care, evidence on the kinds and amount of resources required for recommended transitional care practices to become feasible should be obtained too. This argument will be elaborated in the next paragraph.

The need for evidence and financial coverage

A number of interventions to support young people with chronic conditions in their transition to adulthood and transfer to adult care have been developed since attention for this topic has arisen in health care policy and research about 25 years ago. One key intervention is the transition clinic, which can ideally be considered 'complete' as this intervention responds to all eight core elements of the *On Your Own Feet* transitional care framework (Van Staa et al., 2020). At the same time, its multifactorial character complicates evaluation of its effectiveness (Le Roux et al., 2017). However, high-quality evidence is required to inform policy makers and managers, and to convince health insurers of the need for appropriate financial coverage of transitional care programs. In light of this, part II of this thesis concentrated on the evaluation of transitional care, and therefore started with the development of a relevant evaluation framework based on criteria for successful transition (Surís & Akré, 2015) that allows for comparisons between disease groups (chapter 5). Three evaluation studies followed and provided insight into different models of a transition clinic; these studies revealed large differences in the design and execution of transitional care (either or not by means of a transition clinic). Apart from trends toward better health care-related results (i.e., transfer experiences, satisfaction with transition, and trust in health care providers) and few gradual results regarding medical follow-up (i.e., scheduled and missed consultations), very few statistically significant effects could be established. Thus, factors that effectively influence the transition process remain poorly understood. Apparently, the evaluation framework presented in chapter 5 is not sufficiently appropriate for providing high-quality evidence after all. Despite the framework's unique retrospective, controlled pre-post design over a four-year period (two years prior to transfer and two years after transfer), more longitudinal research with a prolonged follow-up period after exit from pediatric care is needed. In line with the definition of adolescence as presented in the Introduction chapter, evaluating outcomes of transitional care up to the age of 25 years might be recommended for those who transfer around 18 years (and even longer for those who transfer to adult care at a later age). Up till now, such long-term cohort studies in transitional care are not available. Also, the small number of eligible patients in the field of transition evaluation research is still challenging and always will be, due to the relatively low numbers of young people in transition in each medical specialty (Le Roux et al., 2017) and the known challenge of recruitment of young people to intervention studies (Saarijärvi et al., 2020).

GENERAL DISCUSSION

Part I of this thesis underlined the importance of providing holistic and developmentally appropriate care for young people with chronic conditions, with special attention for the case of T1DM. The *On Your Own Feet* transitional care framework provided the core elements with concrete tools and (self-management) interventions that should lead further implementation of recommended transitional care practices. However, these are mainly concentrated on the level of individual patients (micro) and – to some extent – the multidisciplinary team (meso).

The studies in part II of this thesis revealed that structural improvement of transitional care requires changes at the overarching health care system level (macro) and that, up till now, support from this level is lacking. The results from part II also made clear that the question about which outcomes are suitable for evaluating good transitional care remains unanswered. Maybe the question is rather whether it is realistic to expect high-quality evidence for investments in transitional care. Is high-quality evidence really needed to provide good transitional care to young people with chronic conditions or should we accept that this will not work for complex interventions and therefore be satisfied with maybe ‘weaker’ results? Does lack of evidence mean that we should not invest in care for this group? If its probative value is substantially outweighed by young people’s transfer experiences and satisfaction, should we focus on this aspect in future research then? Of course, the indicator of ‘patient not lost to follow-up’ after transfer to adult care should not be ignored, as this was considered almost unanimously an essential indicator of a successful transition, according to an international panel of experts in a study of Surís and Akré (2015). At the same time, however, it should be noted that this is a somewhat ambiguous concept, therefore difficult to measure and to use in evaluations among study groups in transitional care. When do we actually speak about lost to follow-up?

Self-management and clinical outcomes did not prove relevant in the evaluation studies in this thesis, which raises the question whether it is actually justified to expect significant results on these outcomes within the established timeframe of two years before and two years after transfer to adult care (which is actually quite long in current transitional care research). For instance, the evaluation study among young people with T1DM (chapter 8) revealed that glycemic control did not change over time and that this was not different between teams paying more versus teams paying less attention to transitional care. Young people's medical condition depends on so much more than how transitional care is provided, such as self-care skills and intrinsic motivation to adhere to treatment recommendations, and the presence (or absence) of a supportive environment in this turbulent period of major social changes. With regard to self-management outcomes, acquiring self-management skills is highly important for young people with chronic conditions in the transition period, as this could help them control the medical condition. To actually stimulate self-management in daily practice and to incorporate it in health care policy, conditions at the meso- and macro level should be developed. In the end, more consistent use of interventions could perhaps make a difference for transition experiences, requiring evaluation research to consider the actual implementation and use of interventions. Moreover, patient empowerment has been suggested as a relevant concept to help young people to develop the necessary self-management skills (Acuña Mora, 2021). Patient empowerment leads to improved communication skills of young people and is, therefore, relevant for them in becoming an active partner in the care process (Acuña Mora, 2021; Saarijärvi et al., 2021). This is exactly what often seems to be missing during outpatient consultations in transitional care, as the observational study among young people with T1DM (chapter 4) made clear. Hence, it is recommended to include the level of patient empowerment in transitional care evaluations; the Gothenburg Young Persons Empowerment Scale (GYPES) can be used to assess young people's empowerment (Acuña Mora et al., 2018).

Evidence on cost-effectiveness

Having said this, one aspect is left that should be addressed in relation to the need for appropriate financial coverage of transitional care; that is, evidence on cost-effectiveness. Little is known about this and the costs of transitional care (or more specifically setting up a transition clinic) were not included in the evaluation framework presented in this thesis. This can be considered a limitation, because from the viewpoint of managers, policy makers and health insurers more insight into the costs of transitional care seems highly needed to support the implementation of recommended practices at macro level (Colver et al., 2020; López-Bastida et al., 2017; Rocks et al., 2020). To illustrate this, professionals who participated in the evaluation study of transitional care for young people with IBD (chapter 7) reported that organizing joint consultations requires them to do 'voluntary work', since only one department is getting paid for this. It is evident that significant investment is required, both financially and professionally, which potentially places a burden on health expenditures on the short term (Tsiachristas et al., 2011; Tsiachristas et al., 2015). Managers of health care settings and funders should adopt an organization-wide approach to ensure that good transitional care is implemented in pediatric and adult care services, not just adopted by enthusiasts in specific (mostly pediatric) multidisciplinary teams (Colver et al., 2020), as was also often the case in our studies. This way, wider long-term socioeconomic benefits of investing in transitional care – for instance through improvements in young people's empowerment and self-management of conditions, and more favorable health outcomes or even less chronic complications – may outweigh the investments (Rocks et al., 2020).

CONCLUSION

In conclusion, the research in this thesis revealed that good transitional care adopts a holistic perspective, and is provided in a person-centered and developmentally appropriate way. To make this possible, several practical recommendations have been formulated, but actual implementation into clinical practice lags behind due to the lack of a supportive context at the wider organizational and health care system level, uncertainty about suitable outcome measures for evaluating appropriate transitional care, and lack of evidence on long-term socioeconomic benefits. The time has come to look beyond the outpatient setting and create a sense of urgency among health care managers, policy makers and health insurers. This requires more evidence on working elements in transitional care, combined with additional insights into the amount of financial and organizational resources that are needed for recommendations to become implemented. Although this will remain a complex matter, outcomes in transitional care research, for which significant results can be expected, should be critically reconsidered based on current knowledge. Attention should also be paid to the sample sizes and follow-up periods.

FUTURE DIRECTIONS

Implications for clinical practice

- Good transitional care requires a holistic, person-centered and developmentally appropriate approach. Stimulating active involvement of young people in the consultation room is key to achieve this, with a central position for the young person in agenda-setting and shared decision-making.
- Health care professionals should pay more attention to parents' continuing role in their children's transition to adulthood and adult care, supporting them to find a balance between their involvement and encouraging the young person's autonomy.

- Professionals from both pediatric and adult care should establish strong collaborative relationships to work together in creating a context for the provision of good transitional care. Assigning a dedicated professional to take up a coordinating role, preferably an advanced practice nurse who works on both sides of the transfer, is recommended to create a sense of urgency and to organize logistical processes. Such a coordinator can also facilitate multidisciplinary team meetings to work and learn together, and could organize in-service trainings to stay up-to-date in adolescent health issues.
- More attention for dissemination and implementation of research insights is required. Perhaps, regular national conferences on transitional care that bring together all actors involved (i.e., young people, parents, health care professionals, researchers, managers, policy makers, and health insurers) could contribute to this. Also, mirror meetings should be organized at the macro level, so that young people's voices can be heard by those who have to create the preconditions for appropriate transitional care.
- Health care issues of young people with chronic conditions should be structurally embedded into educational programs for health care professionals in both pediatric and adult care, in order to create awareness about the special health care needs of this group and to enhance skills for providing transitional care. Research, for example observation narratives or video recordings, can serve as input for educational purposes.

Recommendations for future research

- Future evaluations of transitional care could focus on transfer experiences and satisfaction, on healthcare use after transfer to adult care, and on patient empowerment, instead of general self-management skills and clinical outcomes. It seems unrealistic to expect significant results on these outcomes after transfer to adult care. Moreover, more insight is needed into the actual implementation and use of self-management interventions.
- More insight into long-term socioeconomic benefits of investing in transitional care is needed to support the implementation of recommended transitional care practices at macro level. This requires incorporation of cost-effectiveness analysis into future evaluations of transitional care and, thus, clarity about suitable outcome measures of transitional care.
- More longitudinal research with a prolonged follow-up period (preferably at least five years) after exit from pediatric care is needed.
- Future research on transitional care could adopt a generic approach to enable inclusion of larger study samples of young patients, thereby increasing the reliability of the evaluation results.

REFERENCES

Aalders, J. (2021). *Whose diabetes is it anyway: The division and transfer of diabetes care responsibilities between children with type 1 diabetes and their parents*. Tilburg University.

Acuña Mora, M. (2021). *Patient empowerment during the transition to adulthood in young persons with chronic conditions*. University of Gothenburg.

Acuña Mora, M., Luyckx, K., Sparud-Lundin, C., Peeters, M., van Staa, A., Sattoe, J., Bratt, E. L., & Moons, P. (2018). Patient empowerment in young persons with chronic conditions: Psychometric properties of the Gothenburg Young Persons Empowerment Scale (GYPES). *PLoS One, 13*(7), e0201007. https://doi.org/10.1371/journal.pone.0201007

Allen, D., Channon, S., Lowes, L., Atwell, C., & Lane, C. (2011). Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service. *Diabetic Medicine, 28*(8), 994-1000. https://doi.org/10.1111/j.1464-5491.2011.03310.x

Annunziato, R. A., Baisley, M. C., Arrato, N., Barton, C., Henderling, F., Arnon, R., & Kerkar, N. (2013). Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. *Journal of Pediatrics, 163*(6), 1628-1633. https://doi.org/10.1016/j.jpeds.2013.07.031

Bal, M. I., Sattoe, J. N., Roelofs, P. D., Bal, R., van Staa, A., & Miedema, H. S. (2016). Exploring effectiveness and effective components of self-management interventions for young people with chronic physical conditions: A systematic review. *Patient Educaction and Counseling, 99*(8), 1293-1309. https://doi.org/10.1016/j.pec.2016.02.012

Beck, D., Been-Dahmen, J., Peeters, M., Grijpma, J. W., van der Stege, H., Tielen, M., van Buren, M., Weimar, W., Ista, E., Massey, E., & van Staa, A. (2019). A nurse-led self-management support intervention (ZENN) for kidney transplant recipients using intervention mapping: Protocol for a mixed-methods feasibility study. *JMIR Research Protocols, 8*(3), e11856. https://doi.org/10.2196/11856

Been-Dahmen, J. M. J., Beck, D. K., Peeters, M. A. C., van der Stege, H., Tielen, M., van Buren, M. C., Ista, E., van Staa, A., & Massey, E. K. (2019). Evaluating the feasibility of a nurse-led self-management support intervention for kidney transplant recipients: a pilot study. *BMC Nephrology, 20*(1), 143. https://doi.org/10.1186/s12882-019-1300-7

Betz, C. L., & Coyne, I. T. (2020). *transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An international perspective on nurses' roles and interventions*. Springer Nature. https://doi.org/10.1007/978-3-030-23384-6

Betz, C. L., Nehring, W. M., & Lobo, M. L. (2015). Transition needs of parents of adolescents and emerging adults with special health care needs and disabilities. *Journal of Family Nursing, 21*(3), 362-412. https://doi.org/10.1177/1074840715595024

Betz, C. L., & Redcay, G. (2005). Dimensions of the transition service coordinator role. *Journal of Specialists in Pediatric Nursing, 10*(2), 49-59. https://doi.org/10.1111/j.1744-6155.2005.00010.x

Betz, C. L., Smith, K., Van Speybroeck, A., Jacobs, R. A., Rivera, N., Lee, J., Saghhafi, S., Nguyen, B., & Tu, H. (2018). Descriptive analysis and profile of health care transition services provided to adolescents and emerging adults in the Movin' On Up health care transition program. *Journal of Pediatric Health Care, 32*(3), 273-284. https://doi.org/10.1016/j.pedhc.2017.11.006

Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling, 99*(12), 1923-1939. https://doi.org/10.1016/j.pec.2016.07.026

Chu, P. Y., Maslow, G. R., von Isenburg, M., & Chung, R. J. (2015). Systematic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *Journal of Pediatric Nursing, 30*(5), e19-27. https://doi.org/10.1016/j.pedn.2015.05.022

Colver, A., Pearse, R., Watson, R. M., Fay, M., Rapley, T., Mann, K. D., Le Couteur, A., Parr, J. R., McConachie, H., & Transition Collaborative, G. (2018). How well do services for young people with long term conditions deliver features proposed to improve transition? *BMC Health Services Research, 18*(1), 337. https://doi.org/10.1186/s12913-018-3168-9

Colver, A., Rapley, T., Parr, J. R., McConachie, H., Dovey-Pearce, G., Couteur, A. L., McDonagh, J. E., Bennett, C., Maniatopoulos, G., Pearce, M. S., Reape, D., Chater, N., Gleeson, H., & Vale, L. (2020). Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services - implications of a 5-year research programme. *Clinical Medicine Journal, 20*(1), 74-80. https://doi.org/10.7861/clinmed.2019-0077

Coyne, B., & Hallowell, S. C. (2020). Measurable outcomes for transition: The nurses' role. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An international perspective on nurses' roles and interventions* (pp. 111-126). Springer Nature. https://doi.org/10.1007/978-3-030-23384-6

Coyne, I., Sheehan, A., Heery, E., & While, A. E. (2019). Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences. *Journal of Clinical Nursing, 28*(21-22), 4062-4076. https://doi.org/10.1111/jocn.15006

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., & Medical Research Council Guidance. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ, 337*, a1655. https://doi.org/10.1136/bmj.a1655

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of Disease in Childhood, 96*(6), 548-553. https://doi.org/10.1136/adc.2010.202473

Cunningham, N. R., Vesco, A. T., Dolan, L. M., & Hood, K. K. (2011). From caregiver psychological distress to adolescent glycemic control: the mediating role of perceived burden around diabetes management. *Journal of Pediatric Psychology, 36*(2), 196-205. https://doi.org/10.1093/jpepsy/jsq071

Daley, A. M., Lestishock, L., & White, P. H. (2020). Pediatric nurse practitioners' perspectives on engaging adolescents to shift from pediatric to adolescent-focused health care services. *Journal of Pediatric Health Care, 34*(6), 550-559. https://doi.org/10.1016/j.pedhc.2020.06.007

De Wit, F., Mul, M., & Bal, R. A. (2008). Leren van patiënten: Spiegelbijeenkomsten leveren zorgverleners nuttige feedback [Learning from patients: Mirror meeting provide useful feedback to healthcare professionals]. *Medisch Contact, 63*(23), 990-993.

De Wit, M., Versloot, J., Zenlea, I., & Goethals, E. R. (2020). Using Person-Reported Outcomes (PROs) to motivate young people with diabetes. *Current Diabetes Reports, 20*(7), 23. https://doi.org/10.1007/s11892-020-01305-z

Dove, E. S., Kelly, S. E., Lucivero, F., Machirori, M., Dheensa, S., & Prainsack, B. (2017). Beyond individualism: Is there a place for relational autonomy in clinical practice and research? *Clinical Ethics, 12*(3), 150-165. https://doi.org/10.1177/1477750917704156

Dwarswaard, J., Bakker, E. J., van Staa, A., & Boeije, H. R. (2016). Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. *Health Expectations, 19*(2), 194-208. https://doi.org/10.1111/hex.12346

Eilander, M. M. A., Snoek, F. J., Rotteveel, J., Aanstoot, H. J., Bakker-van Waarde, W. M., Houdijk, E., Nuboer, R., Winterdijk, P., & de Wit, M. (2017). Parental diabetes behaviors and distress are related to glycemic control in youth with type 1 diabetes: longitudinal data from the DINO study. *Journal of Diabetes Research, 2017*, 1462064. https://doi.org/10.1155/2017/1462064

Engelen, V., Detmar, S., Koopman, H., Maurice-Stam, H., Caron, H., Hoogerbrugge, P., Egeler, R. M., Kaspers, G., & Grootenhuis, M. (2012). Reporting health-related quality of life scores to physicians during routine follow-up visits of pediatric oncology patients: is it effective? *Pediatric Blood & Cancer, 58*(5), 766-774. https://doi.org/10.1002/pbc.23158

Ercan, O., Alikasifoglu, M., Erginoz, E., Janda, J., Kabicek, P., Rubino, A., Constantopoulos, A., Ilter, O., & Vural, M. (2009^). Demography of adolescent health care delivery and training in Europe. *European Journal of Pediatrics, 168*(4), 417-426. https://doi.org/10.1007/s00431-008-0759-1

Farre, A., & McDonagh, J. E. (2017). Helping health services to meet the needs of young people with chronic conditions: towards a developmental model for transition. *Healthcare (Basel), 5*(4). https://doi.org/10.3390/healthcare5040077

Farre, A., Wood, V., McDonagh, J. E., Parr, J. R., Reape, D., Rapley, T., & Transition Collaborative Group. (2016). Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. *Archives of Disease in Childhood, 101*(7), 628-633. https://doi.org/10.1136/archdischild-2015-309473

Farre, A., Wood, V., Rapley, T., Parr, J. R., Reape, D., & McDonagh, J. E. (2015). Developmentally appropriate healthcare for young people: a scoping study. *Archives of Disease in Childhood, 100*(2), 144-151. https://doi.org/10.1136/archdischild-2014-306749

Garvey, K. C., Foster, N. C., Agarwal, S., DiMeglio, L. A., Anderson, B. J., Corathers, S. D., Desimone, M. E., Libman, I. M., Lyons, S. K., Peters, A. L., Raymond, J. K., & Laffel, L. M. (2017). Health care transition preparation and experiences in a U.S. national sample of young adults with type 1 diabetes. *Diabetes Care, 40*(3), 317-324. https://doi.org/10.2337/dc16-1729

Gray, S., Cheetham, T., McConachie, H., Mann, K. D., Parr, J. R., Pearce, M. S., Colver, A., & Transition Collaborative Group. (2018). A longitudinal, observational study examining the relationships of patient satisfaction with services and mental well-being to their clinical course in young people with type 1 diabetes mellitus during transition from child to adult health services. *Diabetic Medicine*. https://doi.org/10.1111/dme.13698

Hanghoj, S., & Boisen, K. A. (2014). Self-reported barriers to medication adherence among chronically ill adolescents: a systematic review. *Journal of Adolescent Health, 54*(2), 121-138. https://doi.org/10.1016/j.jadohealth.2013.08.009

Harvey, P. W., Petkov, J. N., Misan, G., Fuller, J., Battersby, M. W., Cayetano, T. N., Warren, K., & Holmes, P. (2008). Self-management support and training for patients with chronic and complex conditions improves health-related behaviour and health outcomes. *Australian Health Review, 32*(2), 330-338. https://doi.org/10.1071/ah080330

Haverman, L., Engelen, V., van Rossum, M. A., Heymans, H. S., & Grootenhuis, M. A. (2011). Monitoring health-related quality of life in paediatric practice: development of an innovative web-based application. *BMC Pediatrics, 11*, 3. https://doi.org/10.1186/1471-2431-11-3

Haverman, L., van Oers, H. A., van Muilekom, M. M., & Grootenhuis, M. A. (2019). Options for the interpretation of and recommendations for acting on different PROMs in daily clinical practice using KLIK. *Medical Care, 57 Suppl 5 Suppl 1*, S52-S58. https://doi.org/10.1097/MLR.0000000000001061

Haverman, L., van Rossum, M. A., van Veenendaal, M., van den Berg, J. M., Dolman, K. M., Swart, J., Kuijpers, T. W., & Grootenhuis, M. A. (2013). Effectiveness of a web-based application to monitor health-related quality of life. *Pediatrics, 131*(2), e533-543. https://doi.org/10.1542/peds.2012-0958

Heath, G., Farre, A., & Shaw, K. (2017). Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling, 100*(1), 76-92. https://doi.org/10.1016/j.pec.2016.08.011

Heery, E., Sheehan, A. M., While, A. E., & Coyne, I. (2015). Experiences and outcomes of transition from pediatric to adult health care services for young people with congenital heart disease: a systematic review. *Congenital Heart Disease, 10*(5), 413-427. https://doi.org/10.1111/chd.12251

Hilberink, S. R., Grootoonk, A., Ketelaar, M., Vos, I., Cornet, L., & Roebroeck, M. E. (2020). Focus on autonomy: Using 'Skills for Growing Up' in pediatric rehabilitation care. *Journal of Pediatric Rehabilitation Medicine, 13*(2), 161-167. https://doi.org/10.3233/PRM-190618

Hilliard, M. E., Perlus, J. G., Clark, L. M., Haynie, D. L., Plotnick, L. P., Guttmann-Bauman, I., & Iannotti, R. J. (2014). Perspectives from before and after the pediatric to adult care transition: a mixed-methods study in type 1 diabetes. *Diabetes Care, 37*(2), 346-354. https://doi.org/10.2337/dc13-1346

Hyde, R., MacVicar, S., & Humphrey, T. (2020). Advanced practice for children and young people: A systematic review with narrative summary. *Journal of Advanced Nursing, 76*(1), 135-146. https://doi.org/10.1111/jan.14243

Iyengar, J., Thomas, I. H., & Soleimanpour, S. A. (2019). Transition from pediatric to adult care in emerging adults with type 1 diabetes: a blueprint for effective receivership. *Clinical Diabetes and Endocrinology, 5*, 3. https://doi.org/10.1186/s40842-019-0078-7

Joly, E. (2016). Integrating transition theory and bioecological theory: a theoretical perspective for nurses supporting the transition to adulthood for young people with medical complexity. *Journal of Advanced Nursing, 72*(6), 1251-1262. https://doi.org/10.1111/jan.12939

Kim, B., & White, K. (2018). How can health professionals enhance interpersonal communication with adolescents and young adults to improve health care outcomes? Systematic literature review. *International Journal of Adolescence and Youth, 23*(2), 198-218. https://doi.org/10.1080/02673843.2017.1330696

Klostermann, B. K., Slap, G. B., Nebrig, D. M., Tivorsak, T. L., & Britto, M. T. (2005). Earning trust and losing it: adolescents' views on trusting physicians. *Journal of Family Practice, 54*(8), 679-687.

Le Roux, E., Mellerio, H., Guilmin-Crepon, S., Gottot, S., Jacquin, P., Boulkedid, R., & Alberti, C. (2017). Methodology used in comparative studies assessing programmes of transition from paediatrics to adult care programmes: a systematic review. *BMJ Open, 7*(1), e012338. https://doi.org/10.1136/bmjopen-2016-012338

Leijten, F. R. M., Struckmann, V., van Ginneken, E., Czypionka, T., Kraus, M., Reiss, M., Tsiachristas, A., Boland, M., de Bont, A., Bal, R., Busse, R., Rutten-van Molken, M., & consortium, S. (2018). The SELFIE framework for integrated care for multi-morbidity: Development and description. *Health Policy, 122*(1), 12-22. https://doi.org/10.1016/j.healthpol.2017.06.002

Levinson, W. (2011). Patient-centred communication: a sophisticated procedure. *BMJ Quality & Safety, 20*(10), 823-825. https://doi.org/10.1136/bmjqs-2011-000323

Li, J., Talari, P., Kelly, A., Latham, B., Dotson, S., Manning, K., Thornsberry, L., Swartz, C., & Williams, M. V. (2018). Interprofessional Teamwork Innovation Model (ITIM) to promote communication and patient-centred, coordinated care. *BMJ Quality & Safety, 27*(9), 700-709. https://doi.org/10.1136/bmjqs-2017-007369

López-Bastida, J., López-Siguero, J. P., Oliva-Moreno, J., Perez-Nieves, M., Villoro, R., Dilla, T., Merino, M., Jiang, D., Aranda-Reneo, I., Reviriego, J., & Vazquez, L. A. (2017). Social economic costs of type 1 diabetes mellitus in pediatric patients in Spain: CHRYSTAL observational study. *Diabetes Research and Clinical Practice, 127*, 59-69. https://doi.org/10.1016/j.diabres.2017.02.033

Lorig, K. R., & Holman, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. https://doi.org/10.1207/S15324796ABM2601_01

Maas-van Schaaijk, N. M., Roeleveld-Versteegh, A. B. C., & van Baar, A. L. (2013). The interrelationships among paternal and maternal parenting stress, metabolic control, and depressive symptoms in adolescents with type 1 diabetes mellitus. *Journal of Pediatric Psychology, 38*(1), 30-40. https://doi.org/10.1093/jpepsy/jss096

Maathuis, C. G. B., Vos, I., Roebroeck, M. E., & Hilberink, S. R. (2012). Een instrument om vaardigheden voor zelfstandigheid te vergroten: De Groei-wijzer [An instrument to improve skills for independence: The Skills for Growing Up]. *Nederlands Tijdschrift voor Revalidatiegeneeskunde, 3*, 115-119.

Mackey, E. R., Struemph, K., Powell, P. W., Chen, R., Streisand, R., & Holmes, C. S. (2014). Maternal depressive symptoms and disease care status in youth with type 1 diabetes. *Health Psychology, 33*(8), 783-791. https://doi.org/10.1037/hea0000066

Mazur, A., Dembinski, L., Schrier, L., Hadjipanayis, A., & Michaud, P. A. (2017). European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Paediatrica, 106*(8), 1354-1357. https://doi.org/10.1111/apa.13901

Michaud, P. A., Schrier, L., Ross-Russel, R., van der Heijden, L., Dossche, L., Copley, S., Alterio, T., Mazur, A., Dembinski, L., Hadjipanayis, A., Del Torso, S., Fonseca, H., & Ambresin, A. E. (2018). Paediatric departments need to improve residents' training in adolescent medicine and health: a position paper of the European Academy of Paediatrics. *European Journal of Pediatrics, 177*(4), 479-487. https://doi.org/10.1007/s00431-017-3061-2

Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., Guilfoyle, S. M., Gray, W. N., & Drotar, D. (2012). Pediatric self-management: a framework for research, practice, and policy. *Pediatrics, 129*(2), e473-485. https://doi.org/10.1542/peds.2011-1635

Mosor, E., Studenic, P., Alunno, A., Padjen, I., Olsder, W., Ramiro, S., Bini, I., Caeyers, N., Gossec, L., Kouloumas, M., Nikiphorou, E., Stones, S., Wilhelmer, T. C., & Stamm, T. A. (2021). Young people's perspectives on patient-reported outcome measures in inflammatory arthritis: results of a multicentre European qualitative study from a EULAR task force. *RMD Open, 7*(1). https://doi.org/10.1136/rmdopen-2020-001517

Nagra, A., McGinnity, P. M., Davis, N., & Salmon, A. P. (2015). Implementing transition: Ready Steady Go. *Archives of Disease in Childhood – Education and Practice, 100*(6), 313-320. https://doi.org/10.1136/archdischild-2014-307423

Nguyen, T., Henderson, D., Stewart, D., Hlyva, O., Punthakee, Z., & Gorter, J. W. (2016). You never transition alone! Exploring the experiences of youth with chronic health conditions, parents and healthcare providers on self-management. *Child: Care, Health and Development, 42*(4), 464-472. https://doi.org/10.1111/cch.12334

National Insitute for Health and Care Excellence. (2016). *Transition from children's to adults' services for young people using health or social care services, Guideline 43*. NICE.

Peeters, M. A. C., Hilberink, S. R., & van Staa, A. L. (2014). The road to independence: lived experiences of youth with chronic conditions and their parents compared. *Journal of Pediatric Rehabilitation Medicine, 7*(1), 33-42. https://doi.org/10.3233/PRM-140272

Rapley, T., Farre, A., Parr, J. R., Wood, V. J., Reape, D., Dovey-Pearce, G., McDonagh, J., & Transition Collaborative Group. (2019). Can we normalise developmentally appropriate health care for young people in UK hospital settings? An ethnographic study. *BMJ Open, 9*(9), e029107. https://doi.org/10.1136/bmjopen-2019-029107

Rocks, S., Berntson, D., Gil-Salmeron, A., Kadu, M., Ehrenberg, N., Stein, V., & Tsiachristas, A. (2020). Cost and effects of integrated care: a systematic literature review and meta-analysis. *European Journal of Health Economics, 21*(8), 1211-1221. https://doi.org/10.1007/s10198-020-01217-5

Roebroeck, M. E., Jahnsen, R., Carona, C., Kent, R. M., & Chamberlain, M. A. (2009). Adult outcomes and lifespan issues for people with childhood-onset physical disability. *Developmental Medicine & Child Neurology, 51*(8), 670-678. https://doi.org/10.1111/j.1469-8749.2009.03322.x

Rumburg, T. M., Lord, J. H., Savin, K. L., & Jaser, S. S. (2017). Maternal diabetes distress is linked to maternal depressive symptoms and adolescents' glycemic control. *Pediatric Diabetes, 18*(1), 67-70. https://doi.org/10.1111/pedi.12350

Rutten, G., van Vugt, H. A., de Weerdt, I., & de Koning, E. (2018). Implementation of a structured diabetes consultation model to facilitate a person-centered approach: Results from a nationwide Dutch study. *Diabetes Care, 41*(4), 688-695. https://doi.org/10.2337/dc17-1194

Saarijärvi, M., Wallin, L., Moons, P., Gyllensten, H., & Bratt, E. L. (2020). Factors affecting adolescents' participation in randomized controlled trials evaluating the effectiveness of healthcare interventions: the case of the STEPSTONES project. *BMC Medical Research Methodology, 20*(1), 205. https://doi.org/10.1186/s12874-020-01088-7

Saarijärvi, M., Wallin, L., Moons, P., Gyllensten, H., & Bratt, E. L. (2021). Mechanisms of impact and experiences of a person-centred transition programme for adolescents with CHD: the Stepstones project. *BMC Health Services Research, 21*(1), 573. https://doi.org/10.1186/s12913-021-06567-1

Samarasinghe, S. C., Medlow, S., Ho, J., & Steinbeck, K. (2020). Chronic illness and transition from paediatric to adult care: a systematic review of illness specific clinical guidelines for transition in chronic illnesses that require specialist to specialist transfer. *Journal of Transition Medicine, 2*(1). https://doi.org/doi:10.1515/jtm-2020-0001

Sattoe, J. N. T., Hilberink, S. R., Peeters, M. A. C., & van Staa, A. L. (2014). 'Skills for growing up': supporting autonomy in young people with kidney disease. *Journal of Renal Care, 40*(2), 131-139. https://doi.org/10.1002/jorc.12046

Sattoe, J. N. T. (2015). *Growing up with a Chronic Condition: Challenges for Self-management and Self-management Support*. Erasmus University Rotterdam.

Sattoe, J. N. T., Van Staa, A. L., & Hilberink, S. R. (2021). *Self-management of young people with chronic conditions: a strength-based approach for empowerment and support*. Springer Nature. https://doi.org/10.1007/978-3-030-64293-8

Sawyer, K., & Rosenberg, A. R. (2020). How should adolescent health decision-making authority be shared? *AMA Journal of Ethics, 22*(5), E372-379. https://doi.org/10.1001/amajethics.2020.372

Sawyer, S. M. (2003). Developmentally appropriate healthcare for young people with chronic illness: questions of philosophy, policy, and practice. *Pediatric Pulmonology, 36*(5), 363-365. https://doi.org/10.1002/ppul.10369

Saxby, N., Beggs, S., Kariyawasam, N., Battersby, M., & Lawn, S. (2020). Do guidelines provide evidence-based guidance to health professionals on promoting developmentally appropriate chronic condition self-management in children? A systematic review. *Chronic Illness, 16*(4), 239-252. https://doi.org/10.1177/1742395318799844

Schultz, A. T., & Smaldone, A. (2017). Components of interventions that improve transitions to adult care for adolescents with type 1 diabetes. *Journal of Adolescent Health, 60*(2), 133-146. https://doi.org/10.1016/j.jadohealth.2016.10.002

Shaw, K. L., Heath, G., & Farre, A. (2021). Transition to adulthood: shifting roles between young people with chronic conditions and their parents. In J. N. T. Sattoe, A. L. Van Staa, & S. R. Hilberink (Eds.), *Self-management of young people with chronic conditions: a strength-based approach for empowerment and support* (pp. 107-134). Springer Nature. https://doi.org/10.1007/978-3-030-64293-8_6

Sheehan, A. M., While, A. E., & Coyne, I. (2015). The experiences and impact of transition from child to adult healthcare services for young people with type 1 diabetes: a systematic review. *Diabetic Medicine, 32*(4), 440-458. https://doi.org/10.1111/dme.12639

Spaic, T., Robinson, T., Goldbloom, E., Gallego, P., Hramiak, I., Lawson, M. L., Malcolm, J., Mahon, J., Morrison, D., Parikh, A., Simone, A., Stein, R., Uvarov, A., Clarson, C., for the JDRF Canadian Clinical Trial CCTN1102 Study Group. (2019). Closing the gap: Results of the multicenter Canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. *Diabetes Care, 42*(6), 1018-1026. https://doi.org/10.2337/dc18-2187

Surís, J. C., & Akré, C. (2015). Key elements for, and indicators of, a successful transition: an international Delphi study. *Journal of Adolescent Health, 56*(6), 612-618. https://doi.org/10.1016/j.jadohealth.2015.02.007

Trappenburg, J., Jonkman, N., Jaarsma, T., van Os-Medendorp, H., Kort, H., de Wit, N., Hoes, A., & Schuurmans, M. (2013). Self-management: one size does not fit all. *Patient Education and Counseling, 92*(1), 134-137. https://doi.org/10.1016/j.pec.2013.02.009

Tsiachristas, A., Hipple-Walters, B., Lemmens, K. M. M., Nieboer, A. P., & Rutten-van Mölken, M. P. M. H. (2011). Towards integrated care for chronic conditions: Dutch policy developments to overcome the (financial) barriers. *Health Policy, 101*(2), 122-132. https://doi.org/10.1016/j.healthpol.2010.10.013

Tsiachristas, A., Wallenburg, I., Bond, C. M., Elliot, R. F., Busse, R., van Exel, J., Rutten-van Molken, M. P., de Bont, A., & team, M. (2015). Costs and effects of new professional roles: Evidence from a literature review. *Health Policy, 119*(9), 1176-1187. https://doi.org/10.1016/j.healthpol.2015.04.001

Van der Slikke, C. M. M., Bronner, M. B., & Van Staa, A. L. (2018). Klaar voor de overstap met Ready Steady Go [Ready to transfer with ready steady go]. *Magazine Kinderverpleegkunde, 24*(1), 16-18.

Van Hooft, S. M., Been-Dahmen, J. M. J., Ista, E., van Staa, A. L., & Boeije, H. R. (2017). A realist review: what do nurse-led self-management interventions achieve for outpatients with a chronic condition? *Journal of Advanced Nursing, 73*(6), 1255-1271. https://doi.org/10.1111/jan.13189

Van Staa, A. L. (2012). *On Your Own Feet: Adolescents with chronic conditions and their preferences and competencies for care.* Erasmus University Rotterdam.

Van Staa, A. L., Peeters, M. A. C., & Sattoe, J. N. T. (2020). On Your Own Feet: A practical framework for improving transitional care and young people's self-management. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: an international perspective on nurses' roles and interventions* (pp. 191-228). Springer Nature. https://doi.org/10.1007/978-3-030-23384-6

Van Staa, A. L., & Sattoe, J. N. T. (2014). Young adults' experiences and satisfaction with the transfer of care. *Journal of Adolescent Health, 55*(6), 796-803. https://doi.org/10.1016/j.jadohealth.2014.06.008

Van Staa, A. L., Sattoe, J. N. T., & Strating, M. M. (2015). Experiences with and outcomes of two interventions to maximize engagement of chronically ill adolescents during hospital consultations: a mixed methods study. *Journal of Pediatric Nursing, 30*(5), 757-775. https://doi.org/10.1016/j.pedn.2015.05.028

World Health Organization. (2014). *Towards adolescent responsive health systems: Steering the transition from adolescent-friendly projects to adolescent responsive health systems.* https://apps.who.int/adolescent/second-decade/section6/page8/sdolescent-responsiveness.html

World Health Organization. (2019). *Adolescent Health and Development in the WHO European Region: Can we do better?* WHO.

Wolfe, A. (2001). Institute of Medicine report: Crossing the Quality Chasm: A new health care system for the 21st century. *Policy, Politics, & Nursing Practice, 2*(3), 233-235. https://doi.org/10.1177/152715440100200312

Wright, R. J., Howard, E. J., Newbery, N., & Gleeson, H. (2017). 'Training gap' - the present state of higher specialty training in adolescent and young adult health in medical specialties in the UK. *Future Healthcare Journal, 4*(2), 80-95. https://doi.org/10.7861/futurehosp.4-2-80

Yi-Frazier, J. P., Senturia, K., Wright, D. R., Lind, C., & Malik, F. S. (2021). The clock is ticking: Parental stress around emerging adulthood for adolescents with type 1 diabetes. *Journal of Pediatric Nursing*. Advance online publication. https://doi.org/10.1016/j.pedn.2021.07.012

Zaidi, R. (2021). Transitional care in diabetes: a quest for the Holy Grail. *Practical Diabetes, 38*(3), 31-35a. https://doi.org/10.1002/pdi.2339

10

Summary

Samenvatting

SUMMARY

Adolescence is a complex and challenging period for people with chronic conditions as they are facing multiple life-course transitions while managing a demanding disease. At the same time, they are expected to transfer from pediatric to adult care services. This transfer or actual move between care systems is merely one event in the total of '*transition in care*' process, including preparation, planning, tracking, and follow-up. Attention for access to and good quality of care during the transition period (i.e., the years around the transfer to adult care) is highly needed.

Much has been learned in recent years about the core elements of transitional care and the risks of a poorly organized transfer, but it remains unclear what good transitional care actually entails, especially from the viewpoint of the young people themselves. A prerequisite to further embed and improve transitional care in clinical practice is obtaining more evidence on how to compare and evaluate various transitional care arrangements. These were reasons to undertake the research described in this thesis, which elaborates on the current situation of transitional care for young people with chronic conditions in the Netherlands. Special attention is paid to the case of diabetes mellitus type 1 (T1DM) as one of the most common somatic chronic conditions among Dutch children and young people. The two-year *Better Transition in Type 1 Diabetes* (BTD) program (2016-2018) – a nationwide mixed-methods research and quality improvement program aimed to advance diabetes transitional care in the Netherlands – formed the basis of the research.

The thesis consists of two parts, of which the first part (chapters 2 to 4) addresses the question of what good transitional care actually entails. The studies presented in part I provide insight into how T1DM impacts on the lives of young people, what this means for their needs and preferences in care, and how they are currently supported in their transition towards adulthood and adult care. The second part (chapters 5 to 8) concentrates on the *'transition clinic'*, a key intervention where professionals from pediatric and adult care collaborate in the delivery of outpatient transitional care. This intervention is highlighted as it responds to the core elements of the *On Your Own Feet* transitional care framework and is often advocated as best practice. Part II starts with the development of an evaluation framework for the functioning and outcomes of outpatient transition clinics compared with direct hand-over care, followed by three studies that aimed to test this framework in different patient groups.

PART I – A HOLISTIC PERSPECTIVE ON TRANSITION IN CARE FOR T1DM

The unique challenges that young people with T1DM face when growing up into adulthood and entering adult care, pose a risk for impaired health-related quality of life (HRQOL). In the context of the BTD program, **chapter 2** assesses the impact of T1DM on HRQOL in a national cohort of young adults (19-28 years) from twelve participating hospitals in the Netherlands. Data were obtained through online questionnaires completed by the young adults with T1DM after they had transferred to adult care. HRQOL was self-reported with the Pediatric Quality of Life Inventory for young adults, assessing four domains: physical health, emotional functioning, social functioning, and school or work functioning. The outcomes were compared with those of Dutch norm groups of healthy young adults and young adults with different chronic health conditions. Analyses revealed that the young adults with T1DM scored significantly worse than did the healthy peers on all domains of HRQOL, except social functioning. Particularly their functioning at school or work was perceived worse than that of the norm group. The study group's overall HRQOL-scores were comparable to norm scores of young adults with different chronic conditions, although the physical and social functioning of the young people with T1DM was better. About one quarter of the young adults with T1DM reported fatigue. Based on these insights, it can be concluded that young adults with T1DM struggle to maintain a balance between the demands of managing diabetes and their personal and professional life. Although they may be socially active, as a downside many of them encounter problems at work or school and suffer from fatigue. These findings underscore the need to regularly assess HRQOL in outpatient clinics, and to detect and discuss health-related topics such as work- and education-related issues during transition in care. This is of great importance for successful transition.

Chapter 3 focuses on diabetes distress, a serious problem in people with diabetes which is associated with unfavorable clinical and psychosocial outcomes. Up till now, little is known about the prevalence and impact of diabetes distress among young people with T1DM who transferred to adult care. However, since transition is an important phase to support the development of self-management skills and to prepare for adult life while maintaining good quality of life, it is useful to further explore the differences between young people with and without diabetes distress. The insights gained could help to tailor self-management support to the needs of young people. The study presented in this chapter therefore aimed to explore these differences regarding transfer experiences, self-management outcomes, and HRQOL. As in chapter 2, data were collected through an online questionnaire completed by young adults with T1DM after transfer to adult care. Diabetes distress was measured with the short-form Problem Areas in Diabetes (PAID) scale, on which higher scores indicate more stress. A score of eight points or higher on the sum score of the PAID (range 0-20) was classified as having diabetes distress. In this study, more than one-third of the young adults with T1DM experienced diabetes distress after transfer to adult care. Those young adults had less positive transfer experiences, suggesting that the transfer in care could contribute to diabetes distress. The results showed that specific attention is required for reception in adult care, alliance between pediatric and adult care, and readiness to transfer. Having diabetes distress was also associated with less favorable self-management and HRQOL outcomes in all domains of functioning. So, systematic screening of diabetes distress and attention for and addressing young adults' worries is recommended in clinical practice as well.

Though the importance of adopting a holistic approach in transitional care is evident, there is little insight into how patient-provider interactions in the consultation room actually proceed. For instance, do professionals engage in open, in-depth conversations; use motivational interviewing techniques; involve young people in shared decision-making; and address non-medical topics? **Chapter 4** addresses these questions by describing the results of semi-structured observations of outpatient consultations with young people with T1DM (15-25 years) in twelve hospitals in the Netherlands which participated in the BTD program. The consultations concerned pediatric care, adult care, and joint consultations. The results show that, apart from some good examples, health care professionals generally had difficulty in interacting adequately with young people. They paid little attention to the young people's individual attitudes and priorities regarding disease management, and non-medical topics remained generally underexposed. Conversations about daily life often remained shallow, as young people's cues were not always taken up. Furthermore, decisions about personal and health-related goals were often not made together with the young people. Deeper understanding of the interactions in the consultation room has emphasized the need for a more holistic and person-centered approach in transitional care for young people with T1DM. By adopting such an approach, professionals could empower the young people to take an active role in their diabetes management.

PART II – EVALUATING TRANSITIONAL CARE: A COMPLEX MATTER

A number of interventions have been developed to support young people with chronic conditions in their transition to adulthood and transfer to adult care, such as the transition clinic (TC). Though TCs are often advocated as best practices in transitional care, additional insight into the models and added value of a TC compared with usual care (without a TC) was required. **Chapter 5** proposes an evaluation framework in the form of a mixed-methods study protocol with a retrospective controlled design. The framework involves semi-structured interviews with health care professionals, observations of consultations with young people, chart reviews of young people transferred two to four years prior to data collection, and questionnaires among the young people included in the chart reviews. According to the protocol, qualitative data should be analyzed through thematic analysis, and results will provide insights into structures and daily routines of TCs as well as the experienced barriers and facilitators in transitional care. Quantitatively, within-group differences on clinical outcomes and healthcare use must be studied over four measurement moments (two years before and two years after transfer). Subsequently, comparisons can be made between intervention and control groups on all outcomes at all measurement moments. Since 'no-show after transfer' is seen as an important process measure for transitional care, this is the primary process outcome in the study protocol. Young people's 'experiences and satisfaction with the transfer' is considered a primary patient-reported outcome. Secondary outcomes consider clinical outcomes, healthcare usage, self-management outcomes, and perceived quality of care.

Chapter 6 presents the first study that used the proposed evaluation framework, which was conducted among young people with cystic fibrosis (CF). In this study, the most notable feature distinguishing the TC and direct hand-over care comprised joint consultations between pediatric and adult care professionals in the former. Furthermore, a transition coordinator and an early started and structured process of preparation of young people were considered facilitating factors for the success of the TC. Perceived benefits of the TC were, among other things, obtaining a holistic view of the patient and fine-tuning of care between the settings. Reported main barriers were lack of time, planning difficulties, and reimbursement issues. Young people treated at the TC tended to have better transfer experiences and were more satisfied with the process of transition. They reported significantly more trust in their adult care professionals than those receiving direct hand-over care. However, their self-management-related outcomes were less favorable, which could be due to the actual integration of self-management interventions in routine clinical practice. Regarding health care use and clinical outcomes, no notable differences were found. In conclusion, the evaluation study among young people with CF revealed that solutions for organizational and financial barriers are required for further improvement of transitional CF care. Also, self-management interventions should be better embedded in clinical practice.

Chapter 7 presents a similar type of study performed in a different patient group, namely young people with inflammatory bowel disease (IBD). Two outpatient IBD clinics in the Netherlands participated, one providing transitional care at a TC and the other providing direct hand-over transitional care. At the TC, multidisciplinary team meetings and alignment of care between pediatric and adult care providers were standard practice. Also, non-medical topics received more attention during consultations with young people at the TC. Similar to the CF setting, main barriers reported by health care professionals were time restrictions, planning difficulties, and insufficient financial coverage. In addition, limited involvement of adult care providers was considered a barrier for setting up a TC for young people with IBD. Facilitators experienced were high professional motivation and a high case load. The latter means that the number of patients seen at the TC was large enough for clinics to be structurally scheduled over the year. Regarding health care use, the young people at the TC had significantly more planned consultations over the year before transfer. Furthermore, they tended to have better transfer experiences and to be more satisfied with the transition process. In contrast to the CF study, this study showed some relevant clinical outcomes too. Those in direct hand-over care more often experienced a relapse before transfer and had more missed consultations after transfer. No notable differences were found in self-management outcomes. Thus, also in IBD care, the TC offers opportunities to improve transitional care, but organizational and financial barriers need to be addressed before guidelines and consensus statements in health care policy and clinical practice can be effectively implemented.

Chapter 8 focuses on the evaluation of transitional care efforts for young people with T1DM in the Netherlands, which revealed that it is actually impossible to compare a TC and usual care, because of large differences in the design and execution of transitional care. The study presented in this chapter aimed to provide insight into the added value of transitional care investments for young adults with T1DM from a broader perspective. Detailed reports were established on each of the fifteen participating diabetes teams from twelve hospitals in the Netherlands, in which their setting, composition of the team, and their organization of transitional care were described. Based on these qualitative data, two groups of diabetes teams were created through cluster analysis: teams paying more (HI-ATT) versus teams paying less attention (LO-ATT) to transitional care. Self-reported outcomes showed that the young adults treated by a HI-ATT team felt better prepared for transfer, but self-management outcomes did not differ between the groups. Regarding health care use, HI-ATT teams had more scheduled consultations in the year after transfer. From a clinical viewpoint, no promising results could be established. For example, mean HbA1c scores were elevated across the whole study period with no significant differences between pediatric and adult care, or between LO-ATT and HI-ATT teams. Considering the International Society of Pediatric and Adolescent Diabetes (ISPAD) Clinical Practice Consensus Guidelines, only 10.6% of the measurements within the four-year study period met targeted HbA1c scores (≤ 53 mmol/mol).

Concluding from this study, current transitional care investments in Dutch diabetes care did not lead to notable improvements in experiences and outcomes, except for preparation for transfer. The period after transfer, however, is just as important. Transitional care investments should therefore extend beyond the transfer. Moreover, the results suggested that interventions were still not systematically used in daily practice. Since the presence or absence of specific interventions did not appear to be a good indicator for the outcomes of transitional care, core interventions for the provision of good transitional care could not be established. Another general point of attention appearing from this study is the overall lack of structured support for parents. Nurses would do well to implement parental support programs to prepare for the transition and their change in role, taking into account their continuing partnership.

CONCLUSION

The research in this thesis emphasized that good transitional care adopts a holistic perspective, and is person-centered and developmentally appropriate. To make this possible, several practical recommendations have been formulated, but actual implementation into clinical practice lags behind due to the lack of a supportive context at the wider organizational and health care system levels. The time has come to look beyond the outpatient clinic and create a sense of urgency among health care managers, policy makers and health insurers. This requires consensus on the essential elements of transitional care and on the need for nationwide implementation. More evidence on working elements in transitional care is therefore needed, combined with insights into the financial and organizational resources that are needed to implement recommendations. This thesis has developed a comprehensive evaluation framework and showed some improved outcomes of transitional care efforts. However, results also confirmed that evaluating good transitional care is a complex matter, as it remains unclear what suitable outcome measures for transitional care are. The results obtained in combination with existing knowledge have taught us that we should critically reconsider whether it is realistic to expect significant outcomes on certain outcome measures, and shift our focus in transitional care evaluations. Moreover, attention should go out to longer follow-up periods, larger sample sizes, and long-term socioeconomic benefits of transitional care investments.

SAMENVATTING

Voor mensen met chronische aandoeningen vormt de adolescentie een buitengewoon complexe en uitdagende levensfase. Naast de hoge eisen die de ziekte aan hen stelt, krijgen zij te maken met verschillende veranderingen in hun leven, zoals veranderende sociale relaties en rollen en nieuwe uitdagingen in studie en werk. Tegelijkertijd moeten zij de overstap maken van de kinderzorg naar de volwassenzorg. Deze overstap tussen zorgsystemen is slechts één gebeurtenis binnen het totale proces van 'transitie in zorg', waartoe ook de voorbereiding op de overstap, planning van de transfer, en opvolging in de volwassenenzorg behoren. Daarbij spelen tevens het achterlaten van vertrouwde zorgverleners en het aangaan van relaties met nieuwe zorgverleners een rol. Aandacht voor de toegankelijkheid en goede kwaliteit van de zorg tijdens de transitiefase is dan ook hard nodig.

Er is de afgelopen jaren al veel geleerd over de kernelementen van goede transitiezorg op het gebied van organisatie, samenwerking en zelfmanagementondersteuning, zoals beschreven in het 'Op Eigen Benen' raamwerk. Ook de risico's van een slecht georganiseerde overdracht, namelijk slechte klinische en psychosociale uitkomsten en uitval uit zorg, zijn bekend. Het blijft echter onduidelijk wat goede transitiezorg nu eigenlijk inhoudt, vooral vanuit het oogpunt van de jongeren zelf. Om transitiezorg verder te kunnen verbeteren en te verankeren in de praktijk, is meer inzicht nodig in hoe verschillende vormen van transitiezorg kunnen worden geëvalueerd en met elkaar kunnen worden vergeleken. Dit vormde de aanleiding tot een onderzoek naar de huidige situatie rondom transitiezorg voor jongeren met chronische aandoeningen in Nederland, zoals in dit proefschrift is beschreven. Speciale aandacht gaat daarbij uit naar diabetes mellitus type 1 (DM1) als één van de meest voorkomende somatische chronische aandoeningen onder Nederlandse kinderen en jongeren. Het tweejarige programma 'Betere Transitie bij Diabetes' (BTD) (2016-2018) – een landelijk *'mixed-methods'* onderzoeks- en kwaliteitsverbeteringsprogramma ter verbetering van de Nederlandse diabetestransitiezorg – vormde de basis van dit proefschrift.

Het proefschrift bestaat uit twee delen, waarvan het eerste deel (hoofdstukken 2 t/m 4) ingaat op de vraag wat goede transitiezorg eigenlijk inhoudt. De onderzoeken die in deel I worden beschreven, bieden inzicht in hoe DM1 het leven van jongeren beïnvloedt, wat dit betekent voor hun behoeften en preferenties ten aanzien van de zorg, en hoe ze momenteel worden ondersteund in hun transitie naar volwassenheid en de volwassenenzorg. Het tweede deel (hoofdstukken 5 t/m 8) richt zich op de 'transitiepoli', een belangrijke interventie waar zorgprofessionals uit zowel de kinder- als de volwassenenzorg samenwerken in het verlenen van poliklinische transitiezorg. De 'transitiepoli' wordt uitgelicht omdat deze interventie idealiter alle kernelementen van transitiezorg, zoals beschreven in het 'Op Eigen Benen' raamwerk, omvat. Daarnaast wordt de transitiepoli vaak als optimale werkwijze aanbevolen. Deel II begint met de ontwikkeling van een uitgebreid evaluatiekader om het functioneren en de uitkomsten van transitiepoli's te kunnen vergelijken met de standaard overdracht van zorg (zonder transitiepoli). Vervolgens worden drie onderzoeken beschreven die gebruik hebben gemaakt van dit evaluatiekader, elk bij een andere patiëntengroep (cystic fibrosis, inflammatoire darmziekten en DM1).

DEEL I – EEN HOLISTISCH PERSPECTIEF OP TRANSITIE IN ZORG VOOR DM1

De unieke uitdagingen waarmee jongeren met DM1 worden geconfronteerd wanneer ze opgroeien naar volwassenheid en overgaan naar de zorg voor volwassenen, verhogen het risico op een verminderde gezondheidsgerelateerde kwaliteit van leven (HRQOL) binnen deze groep. **Hoofdstuk 2** bespreekt de impact van DM1 op HRQOL in een landelijk cohort van jongvolwassenen (19-28 jaar) in twaalf deelnemende ziekenhuizen in Nederland. Gegevens over de fysieke gezondheid, het emotioneel functioneren, het sociaal functioneren en het functioneren op school of op het werk van de jongvolwassenen met DM1 werden verzameld via online vragenlijsten. Deze werden afgenomen aan de hand van de *'Pediatric Quality of Life Inventory'* voor jongvolwassenen, nadat jongvolwassenen waren overgestapt naar de volwassenenzorg. Vervolgens zijn de uitkomsten vergeleken met die van Nederlandse normgroepen van gezonde jongvolwassenen en jongvolwassenen met andere chronische aandoeningen. De analyses laten zien dat jongvolwassenen met DM1 op alle domeinen significant slechter scoorden dan gezonde leeftijdsgenoten, behalve op het domein 'sociaal functioneren'. Vooral het functioneren op school of op het werk was slechter dan dat van de normgroep. De algehele HRQOL-scores van de onderzoeksgroep waren vergelijkbaar met de normscores van jongvolwassenen met andere chronische aandoeningen, hoewel het fysieke en sociale functioneren van jongeren met DM1 beter was. Ongeveer een kwart van alle jongvolwassenen met DM1 rapporteerde vermoeidheid. Op basis van deze inzichten kan worden geconcludeerd dat jongvolwassenen met DM1 moeite hebben om een balans te creëren tussen de eisen van het omgaan met diabetes enerzijds en hun persoonlijke en professionele leven anderzijds. Hoewel ze sociaal actief kunnen zijn, ondervinden velen van hen nadelen in de vorm van problemen op school of op het werk (zoals concentratieproblemen en vergeetachtigheid) en hebben ze last van vermoeidheid. Deze bevindingen onderstrepen de noodzaak om de HRQOL regelmatig te monitoren tijdens poliklinische consulten. Voor een succesvolle transitie is het van essentieel belang dat onderwerpen als werk- en onderwijsgerelateerde problemen, worden opgespoord en besproken door behandelaars.

Hoofdstuk 3 richt zich op diabetes-specifieke stress (*'diabetes distress'*), ofwel de psychische druk en mentale last die wordt ervaren als gevolg van diabetes. Dit vormt een serieus probleem onder mensen met diabetes dat gepaard gaat met ongunstige klinische en psychosociale uitkomsten. Tot nu toe is er weinig bekend over diabetes-specifieke stress bij jongeren met DM1 die zijn overgestapt naar de volwassenenzorg. Aangezien de transitie een belangrijke fase is om de ontwikkeling van zelfmanagementvaardigheden te ondersteunen en om jongeren voor te bereiden op het volwassen leven met een goede kwaliteit van leven, is het nuttig om de verschillen tussen jongeren mét en zonder diabetes-specifieke stress verder te onderzoeken. Dergelijke inzichten kunnen helpen om zelfmanagementondersteuning af te stemmen op de behoeften van jongeren. De studie die in dit hoofdstuk wordt beschreven, had daarom als doel om de verschillen tussen jongeren mét en zonder diabetes-specifieke stress betreffende transitie-ervaringen, zelfmanagement en HRQOL te onderzoeken. Net als in hoofdstuk 2, werden data verzameld door middel van een online vragenlijst die werd ingevuld door jongvolwassenen met DM1 nadat zij waren overgestapt naar de volwassenenzorg. Er werd gebruik gemaakt van de korte versie van de *'Problem Areas in Diabetes'* (PAID) schaal, waarbij hogere scores meer stress aangeven. Meer dan een derde van de jongvolwassenen met DM1 in deze studie ervaarde diabetes-specifieke stress (score ≥ 8, range 0-20) na hun overstap naar de volwassenenzorg. Die jongvolwassenen hadden minder positieve ervaringen met de transitie, wat suggereert dat transitie in zorg zou kunnen bijdragen aan diabetes-specifieke stress. De resultaten laten verder zien dat specifieke aandacht nodig is voor de ontvangst in de volwassenenzorg, de samenwerking tussen de kinder- en de volwassenenzorg, en de voorbereiding op de overstap. Het hebben van diabetes-specifieke stress werd ook geassocieerd met minder gunstige zelfmanagement- en HRQOL-uitkomsten in alle domeinen van het functioneren. Op basis van deze resultaten wordt systematische screening van diabetes-specifieke stress in de praktijk dan ook aanbevolen, evenals het bespreken en aanpakken van de zorgen van jongvolwassenen door zorgprofessionals.

Hoewel het belang van een holistische benadering in transitiezorg duidelijk is, is er weinig inzicht in het daadwerkelijke verloop van de interacties tussen patiënt en zorgverlener in de spreekkamer. Worden er open en diepgaande gesprekken gevoerd door professionals? Wordt er gebruik gemaakt van motiverende gespreksvoeringstechnieken? Betrekken professionals de jongeren in de besluitvorming? Wordt er aandacht besteed aan niet-medische onderwerpen? **Hoofdstuk 4** gaat dieper in op deze vragen aan de hand van semigestructureerde observaties van poliklinische consulten met jongeren met DM1 (15-25 jaar) in dezelfde twaalf ziekenhuizen in Nederland die deelnamen aan het BTD-programma. De consulten betroffen kinderzorg, volwassenenzorg en gezamenlijke consulten. De resultaten laten zien dat, afgezien van enkele goede praktijkvoorbeelden, zorgprofessionals over het algemeen moeite hebben om adequaat met jongeren om te gaan in de spreekkamer. Er werd weinig aandacht besteed aan de houding van de jongeren en aan prioriteiten met betrekking tot het zelfmanagement van diabetes. Daarnaast bleven niet-medische onderwerpen over het algemeen onderbelicht. Gesprekken over het dagelijks leven bleven vaak oppervlakkig omdat de signalen van jongeren niet altijd werden opgepakt. Bovendien werden beslissingen over persoonlijke en gezondheidsgerelateerde doelen vaak niet samen met de jongeren genomen. De resultaten van deze observatiestudie hebben meer inzicht opgeleverd in de interacties in de spreekkamer en benadrukken daarmee de noodzaak van een meer holistische en persoonsgerichte benadering in de transitiezorg voor jongeren met DM1. Zorgprofessionals zouden de jongeren hiermee in staat kunnen stellen om een actievere rol aan te nemen in de zorg en behandeling van hun diabetes.

DEEL II – HET EVALUEREN VAN TRANSITIEZORG: EEN COMPLEXE ZAAK

Om jongeren met chronische aandoeningen te ondersteunen in de transitie naar volwassenheid en de overstap naar de volwassenenzorg, zijn verschillende interventies ontwikkeld. Een voorbeeld is de transitiepoli. Hoewel de transitiepoli vaak wordt aanbevolen als optimale werkwijze in de transitiezorg, is aanvullend inzicht nodig in de modellen en meerwaarde van een transitiepoli ten opzichte van de gebruikelijke zorg (zonder transitiepoli). **Hoofdstuk 5** biedt een evaluatiekader in de vorm van een *'mixed-methods'* studieprotocol met een retrospectief, gecontroleerd ontwerp. Het evaluatiekader omvat semigestructureerde interviews met zorgverleners, observaties van consulten met jongeren, dossieronderzoek bij jongeren die twee tot vier jaar voorafgaand aan de dataverzameling zijn overgestapt naar de volwassenenzorg en vragenlijsten onder de jongvolwassenen die in dit dossieronderzoek zijn opgenomen. Het protocol stelt een thematische analyse van de kwalitatieve gegevens voor, waarbij de resultaten inzicht geven in de structuur en dagelijkse routines van transitiepoli's, en de ervaren belemmerende en bevorderende factoren in de organisatie van transitiezorg. De kwantitatieve analyses zijn gericht op het in kaart brengen van de verschillen in de tijd op klinische uitkomsten en zorggebruik binnen de interventiegroep. Hierbij worden vier meetmomenten gehanteerd (vanaf twee jaar vóór tot twee jaar na de transfer). Vervolgens kunnen op alle uitkomsten en op alle meetmomenten vergelijkingen worden gemaakt tussen de interventie- en controlegroepen. Het 'niet verschijnen na de transfer' wordt gezien als de primaire procesuitkomst in het onderzoeksprotocol; de ervaringen en tevredenheid van jongeren met de transitie vormen de primaire, door de patiënt zelf gerapporteerde, uitkomst. Secundaire uitkomsten omvatten klinische uitkomsten, zorggebruik, zelfmanagementuitkomsten en de ervaren kwaliteit van zorg.

Hoofdstuk 6 beschrijft een studie onder jongeren met cystic fibrosis (CF), die gebruik heeft gemaakt van het ontwikkelde evaluatiekader. Volgens deze studie is het gezamenlijke overleg tussen zorgprofessionals uit de kinder- en volwassenzorg op de transitiepoli, het meest opvallende, onderscheidende kenmerk ten opzichte van de gebruikelijke zorg rondom de transitie naar de volwassenenzorg. Verder werden een transitiecoördinator, een tijdige start van de voorbereiding van de jongere en een gestructureerd voorbereidingstraject beschouwd als belangrijke, bevorderende factoren voor het succes van de transitiepoli. Als voordelen van de transitiepoli werden onder meer het verkrijgen van een holistisch beeld van de jongere en het afstemmen van de zorg tussen de instellingen genoemd. Gebrek aan tijd en financiële middelen en logistieke problemen werden als belangrijkste belemmeringen ervaren. Jongeren die op de transitiepoli werden behandeld, hadden over het algemeen betere transitie-ervaringen en waren meer tevreden met het transitieproces. Ze rapporteerden significant meer vertrouwen in hun professionals in de volwassenenzorg dan degenen die de gebruikelijke zorg ontvingen. De uitkomsten op het gebied van zelfmanagement waren minder gunstig. Dit zou te maken kunnen hebben met de daadwerkelijke toepassing van zelfmanagementinterventies in de dagelijkse praktijk, ofwel in hoeverre ze worden ingezet en gebruikt in de zorg zoals beoogd. Met betrekking tot zorggebruik en klinische uitkomsten werden geen noemenswaardige verschillen gevonden. Concluderend blijkt uit het evaluatieonderzoek onder jongeren met CF dat oplossingen voor organisatorische en financiële barrières nodig zijn om de transitiezorg voor CF verder te verbeteren. Daarnaast moet kritisch worden gekeken naar de implementatie van zelfmanagementinterventies in de dagelijkse praktijk.

Hoofdstuk 7 gaat over een vergelijkbare studie uitgevoerd in een andere patiëntengroep, namelijk bij jongeren met inflammatoire darmziekten (IBD). Twee IBD-poliklinieken in Nederland namen deel, waarvan de ene een transitiepoli betrof en de andere transitiezorg verleende in de vorm van een directe overdracht (gebruikelijke zorg). Binnen de transitiepoli vonden multidisciplinaire teambijeenkomsten en afstemming van de zorg tussen zorgverleners uit de kinder- en volwassenenzorg standaard plaats. Ook was er meer aandacht voor niet-medische onderwerpen tijdens consulten met jongeren op de transitiepoli. Net als in de CF-studie waren tijdsbeperkingen, planningsproblemen en onvoldoende financiële middelen de belangrijkste belemmeringen die door zorgprofessionals werden gemeld. Daarnaast werd de beperkte betrokkenheid van zorgverleners uit de volwassenenzorg ervaren als een drempel voor het opzetten van een transitiepoli voor jongeren met IBD. Bevorderende factoren waren een hoge motivatie onder de zorgprofessionals en een hoge caseload. Dit laatste betekent dat het aantal patiënten dat op de transitiepoli werd gezien groot genoeg was om de poli structureel in te kunnen plannen. Wat zorggebruik betreft, blijkt uit de resultaten dat jongeren die werden behandeld op de transitiepoli significant meer geplande consulten hadden in het jaar vóór de transfer. Verder lieten deze jongeren een positieve trend zien op het gebied van ervaringen met de transfer en tevredenheid over het transitieproces. In tegenstelling tot de CF-studie toont de IBD-studie ook enkele relevante klinische uitkomsten. De jongeren in de controlegroep hadden vaker een terugval vóór de transfer en misten meer consulten na de transfer. Er werden geen noemenswaardige verschillen gevonden in zelfmanagementuitkomsten. Kortom, ook in de IBD-zorg biedt de transitiepoli kansen om de transitiezorg te verbeteren. Organisatorische en financiële barrières moeten echter worden weggenomen voordat richtlijnen en consensusverklaringen effectief kunnen worden geïmplementeerd in het beleid en in de dagelijkse praktijk.

Hoofdstuk 8 richt zich op de evaluatie van de investeringen in transitiezorg voor jongeren met DM1 in Nederland. Deze studie laat zien dat het onmogelijk is om een vergelijking te maken tussen een transitiepoli en een directe overdracht (gebruikelijke zorg) vanwege de grote verschillen die er zijn in de opzet en uitvoering van transitiezorg in de Nederlandse diabeteszorg. Het doel van dit onderzoek was daarom om vanuit een breder perspectief inzicht te geven in de toegevoegde waarde van investeringen in de transitiezorg voor jongvolwassenen met DM1. Vijftien diabetesteams uit twaalf ziekenhuizen in Nederland namen deel. Van elk team werd een gedetailleerde rapportage opgesteld waarin de setting, samenstelling van het team en de organisatie van transitiezorg werden beschreven. Op basis van deze kwalitatieve data werden door middel van clusteranalyse twee groepen van diabetesteams gevormd: teams die meer aandacht besteedden aan transitiezorg (HI-ATT) versus teams die minder aandacht besteedden aan transitiezorg (LO-ATT). De resultaten laten zien dat jongvolwassenen die werden behandeld door een HI-ATT-team, zich beter voorbereid voelden op de transfer. Op zelfmanagementuitkomsten werden geen verschillen gevonden tussen beide groepen. Wat het zorggebruik betreft hadden HI-ATT-teams meer geplande consulten in het eerste jaar na de transfer. Vanuit klinisch oogpunt konden geen veelbelovende resultaten worden vastgesteld. Zo waren de gemiddelde HbA1c-scores gedurende de hele onderzoeksperiode verhoogd zonder significante verschillen tussen de kinderzorg en de volwassenenzorg, noch tussen de LO-ATT- en de HI-ATT-teams. Volgens de consensusrichtlijnen van de *International Society of Pediatric and Adolescent Diabetes* (ISPAD), voldeed slechts 10,6% van alle metingen binnen de onderzoeksperiode van vier jaar aan de beoogde HbA1c-scores (≤ 53 mmol/mol).

De conclusie van deze studie naar transitiezorg voor jongeren met DM1 is dat de huidige investeringen in de Nederlandse diabetestransitiezorg nog niet hebben geleid tot noemenswaardige verbeteringen in ervaringen en uitkomsten, met uitzondering van de voorbereiding op de transfer. De periode na de transfer is echter net zo belangrijk. Investeringen in transitiezorg moeten daarom verder reiken dan het moment van de transfer. Bovendien laten de resultaten zien dat interventies in de dagelijkse praktijk nog steeds niet systematisch worden toegepast. Het al dan niet aanwezig zijn van specifieke interventies bleek geen goede indicator te zijn voor de uitkomsten van transitiezorg, hierdoor konden kerninterventies voor goede transitiezorg in deze studie niet worden vastgesteld. Een ander aandachtspunt dat uit dit onderzoek naar voren kwam, is het algehele gebrek aan ondersteuning van ouders in de transitiefase. Verpleegkundigen zouden ouders kunnen ondersteunen in hun voorbereiding op de overgang van hun kind naar volwassenheid en de volwassenenzorg en de daarmee gepaard gaande veranderingen in hun rol. Belangrijk is dat daarbij rekening wordt gehouden met de wederzijdse band tussen ouders en kind.

CONCLUSIE

Het onderzoek in dit proefschrift benadrukt dat goede transitiezorg een holistisch perspectief hanteert en daarnaast persoons- en ontwikkelingsgericht is. Om dit mogelijk te maken zijn er verschillende praktische aanbevelingen geformuleerd – zoals het bieden van gezamenlijke zorg door professionals uit de kinder- en volwassenenzorg, regelmatig multidisciplinair overleg, het aanstellen van een transitiecoördinator en het structureel monitoren van kwaliteit van leven – maar de daadwerkelijke implementatie in de dagelijkse praktijk blijft achter. Dit komt met name door het ontbreken van ondersteuning vanuit hoger niveau, ofwel vanuit de organisatie en het zorgsysteem. Het wordt tijd om verder te kijken dan het niveau van uitvoering van de zorg en om een gevoel van urgentie te creëren bij zorgmanagers, beleidsmakers en zorgverzekeraars. Hiervoor is consensus nodig over wat nu eigenlijk de essentiële onderdelen van transitiezorg zijn en over de noodzaak van landelijke implementatie. Er is daarom meer bewijs nodig over werkende elementen in de transitiezorg, gecombineerd met aanvullend inzicht in de hoeveelheid financiële en organisatorische middelen die nodig zijn om aanbevelingen te kunnen implementeren. Dit proefschrift heeft een uitgebreid evaluatiekader ontwikkeld en heeft een aantal positieve uitkomsten laten zien als gevolg van investeringen in de transitiezorg. De resultaten bevestigen echter ook dat het evalueren van goede transitiezorg complex is, omdat het onduidelijk blijft wat geschikte uitkomstmaten zijn voor transitiezorg. De verkregen resultaten, in combinatie met de bestaande kennis, hebben ons geleerd dat we kritisch moeten heroverwegen of het realistisch is om op bepaalde uitkomstmaten (zoals zelfmanagementuitkomsten) significante uitkomsten te verwachten. We moeten onze focus in evaluaties van transitiezorg wellicht verleggen naar ervaringen en tevredenheid met transitie, zorggebruik na de transfer en empowerment. Er moet ook aandacht worden besteed aan langere onderzoekstermijnen, grotere steekproeven, en het in kaart brengen van de sociaaleconomische voordelen van investeringen in transitiezorg op de lange termijn.

11

Appendices

Dankwoord
PhD portfolio
List of publications
Curriculum vitae

DANKWOORD

"It's not about perfect, it's about effort. When you bring that effort every single day, that's where transformation happens, that's how change occurs."
(Jillian Michaels)

Dit citaat typeert voor mij het onderzoek en de weg naar kwaliteitsverbetering in de dagelijkse praktijk van de gezondheidszorg. Mijn promotietraject is een vervolg op eerdere onderzoeksprogramma's rondom de zorg voor jongeren met chronische aandoeningen, maar zelfs na al die jaren zijn we nog steeds niet waar we willen zijn. De behoefte aan meer én andere inzichten blijft bestaan; het onderzoek is nooit klaar. Datzelfde gaat op voor kwaliteitsverbetering in de zorg. De studies in mijn proefschrift laten zien dat iedere organisatie en elk team de zorg op een andere manier vormgeeft. Die manieren zijn niet aan te wijzen als goed of slecht, maar het gaat om de inspanningen die worden gedaan om langzaam steeds een beetje beter te kunnen aansluiten op de wensen en behoeften van de individuele patiënt, in mijn onderzoek de jongere met een chronische aandoening. De route naar een betere kwaliteit van zorg is oneindig.

Op persoonlijk vlak refereert het citaat aan alle inspanningen van de afgelopen jaren die ervoor hebben gezorgd dat ik nu met trots mijn proefschrift mag presenteren. Mijn promotietraject kende ups en downs, maar ik heb het bovenal als zeer leerzaam ervaren en ik ben dankbaar voor de enorme bijdrage die het heeft geleverd aan zowel mijn professionele als persoonlijke ontwikkeling. Ik had dit traject nooit kunnen volbrengen zonder de hulp en steun van vele mensen om mij heen, waarvoor hartelijk dank.

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Jane, hoe bijzonder is het dat jij bent begonnen als mijn stagebegeleider en nu, zo'n 10 jaar later, als co-promotor een belangrijk onderdeel van mijn promotiecommissie vormt. We hebben veel samengewerkt en meegemaakt. Natuurlijk jouw eigen promotie, dat was volgens mij de eerste die ik van dichtbij meemaakte, maar ook verschillende congressen en conferenties, waaronder een tripje naar Zwitserland. We gingen vaak samen op pad om data te verzamelen en we hebben samen veel ideeën bedacht en uitgevoerd. Ik heb in de afgelopen jaren veel van je kunnen leren en ik keek op tegen het gemak waarmee jij artikelen schrijft. Ik waardeer het enorm dat je tijdens mijn promotietraject altijd beschikbaar was om even te sparren. Daarnaast bewonder ik de rust die jij hebt en die je uitstraalt, daar ben ik stiekem ook wel een beetje jaloers op…

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Mariëlle

PHD PORTFOLIO

Name PhD student	:	Mariëlle Peeters
Department	:	Erasmus University Rotterdam, Erasmus School of Health Policy and Management
PhD period	:	2016 – 2022
Promotor	:	Prof. dr. R.A. Bal
Supervisors	:	Dr. A.L. van Staa & Dr. J.N.T. Sattoe

PHD TRAINING	**YEAR**
Research skills	
• Univariate/bivariate statistical analysis, Rotterdam University of Applied Sciences	2014
• Multivariate statistical analysis, Rotterdam University of Applied Sciences	2014
• CPO course 'Patient Oriented Research', Erasmus University Medical Center Rotterdam	2015
• International summer course on children and adolescents with chronic illness (including a focus on transition in care), University of Lausanne, Switzerland	2016
• Summer course 'Applied Multivariate Analysis', Utrecht University	2018
• Professionalism and Integrity in Research, Erasmus University Medical Center Rotterdam	2021
Research groups	
• Research meetings 'Self-management & Participation Innovation Lab'	2012 – 2016
• Research meetings 'Better Transition in Type 1 Diabetes'	2016 – 2018
• Research meetings PhD-students Center of Innovations in Care	2018 – now
Presentations at (inter)national conferences	
• 'Young people with diabetes: better transition in care urgently needed'; Symposium Diabetes Society South Netherlands, oral presentation; Eindhoven, The Netherlands	2018
• 'Experiences with transitional care for young people with Diabetes Type 1: A quick scan among young people and healthcare professionals'; STTI 4th Biennial European Conference, oral presentation; Cambridge, United Kingdom	2018
• 'Transition in care for young people with chronic conditions'; Symposium '15 year Transitions in Care', pitch; Rotterdam, The Netherlands	2019
• 'Controlled evaluation of a transition clinic for Dutch young people with cystic fibrosis'; Second European Symposium on Transition, oral presentation; Lausanne, Switzerland	2019
• 'Active involvement of young people with T1DM during outpatient hospital consultations in the transitional phase: between expectations and reality'; 8th Congress of the European Academy of Paediatric Societies, oral presentation; virtual congress	2020
• 'The added value of transition programmes in Dutch diabetes care: A controlled evaluation study'; 8th Congress of the European Academy of Paediatric Societies, poster presentation; virtual congress	2020
Other	
• Participation in research program 'NUrsing Research into Self-management and Empowerment in Chronic Care' (NURSE-CC)	2014 – 2017

TEACHING QUALIFICATIONS AND ACTIVITIES

Training	
• Didactics, Vrije Universiteit Amsterdam	2016
Lecturing	
• Bachelor Occupational Therapy, Rotterdam University of Applied Sciences	2015 – now
Study career coaching	
Education and project supervision in Minor 'Work, health & well-being'	
Education in adolescence and transition	
Education in health law	
Education in evidence-based practice (research skills)	
• Bachelor Nursing, Rotterdam University of Applied Sciences	2017 – now
Education in minor 'Child and youth with special health care needs' (focus on adolescence and transition)	
Education in writing an essay	
Education in health law	
Education in research skills	
• Master Advanced Nursing Practice, Rotterdam University of Applied Sciences	2020 – now
Training 'Qualitative analysis with ATLAS.ti'	
Education in research skills	
Supervising and appraising theses	
• Bachelor Nursing, Rotterdam University of Applied sciences	2018 – now
• Master Health Care Management, Erasmus University Rotterdam	2016 – 2017
Coordinating and developing	
• Elective course 'Health law'	2017
• Education module semester 'Health law'	2017 – now
• Minor 'Work, health & well-being'	2017 – now

LIST OF PUBLICATIONS (NOT INCLUDED IN THIS THESIS)

Acuña Mora, M., Luyckx, K., Sparud-Lundin, C., **Peeters, M. A. C.**, van Staa, A. L., Sattoe, J. N. T., Bratt, E. L., & Moons, P. (2018). Patient empowerment in young persons with chronic conditions: Psychometric properties of the Gothenburg Young Persons Empowerment Scale (GYPES). *PLoS One, 13*(7), e0201007. https://doi.org/10.1371/journal.pone.0201007

Beck, D. K., Been-Dahmen, J. M. J., **Peeters, M. A. C.**, Grijpma, J. W., van der Stege, H. A., Tielen, M., van Buren, M. C., Weimar, W., Ista, E., Massey, E. K., & van Staa, A. L. (2019). A nurse-led self-management support intervention (ZENN) for kidney transplant recipients using intervention mapping: Protocol for a mixed-methods feasibility study. *JMIR Research Protocols, 8*(3), e11856. https://doi.org/10.2196/11856

Been-Dahmen, J. M. J., Beck, D. K., **Peeters, M. A. C.**, van der Stege, H. A., Tielen, M., van Buren, M. C., Ista, E., van Staa, A. L., & Massey, E. K. (2019). Evaluating the feasibility of a nurse-led self-management support intervention for kidney transplant recipients: a pilot study. *BMC Nephrology, 20*(1), 143. https://doi.org/10.1186/s12882-019-1300-7

Braat, C. **Peeters, M. A. C.**, van Staa, A. L., Verduijn, G. M., Oldenmenger, W. H. (2018). Zelfmanagementondersteuning in de spreekkamer. Een uitdaging voor patiënt en verpleegkundige. *Oncologica, 35*(2), 8-12.

Braat, C., Verduijn, G. M., van der Stege, H. A., Offerman, M. P. J., **Peeters, M. A. C.**, van Staa, A. L., & Oldenmenger, W. H. (2021). Evaluation of a nurse-led aftercare intervention for patients with head and neck cancer treated with radiotherapy and cisplatin or cetuximab. *Accepted for publication in Cancer Nursing*.

Peeters, M. A. C., Hilberink, S. R., & van Staa, A. L. (2014). The road to independence: lived experiences of youth with chronic conditions and their parents compared. *Journal of Pediatric Rehabilitation Medicine, 7*(1), 33-42. https://doi.org/10.3233/PRM-140272

Peeters, M. A. C., Braat, C., Been-Dahmen, J. M. J., Verduijn, G. M., Oldenmenger, W. H., & van Staa, A. L. (2018). Support needs of people with head and neck cancer regarding the disease and its treatment. *Oncology Nursing Forum, 45*(5), 587-96. https://doi.org/10.1188/18.ONF.587-596

Sattoe, J. N. T., Hilberink, S. R., **Peeters, M. A. C.**, van Staa, A. L. (2014). 'Skills for growing up': supporting autonomy in young people with kidney disease. *Journal of Renal Care, 40*(2), 131-9. https://doi.org/10.1002/jorc.12046

Van Staa, A. L., **Peeters, M. A. C.**, Bronner, M. B., van der Slikke, C. M. M., de Kruif, E., Havers, J. H. (2018). Betere transitiezorg voor jongeren met diabetes type 1: hard noodzakelijk. Resultaten van het onderzoek- en verbeterprogramma Betere Transitie bij Diabetes. *Diabetes Pro, 2018-4*, 20-25.

Van Staa A. L., **Peeters M. A. C.**, & Sattoe, J. N. T. (2020). On Your Own Feet: A practical framework for improving transitional care and young people's self-management. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for young adults with long-term conditions: an international perspective on nurses' roles and interventions* (pp. 191-228). Springer Nature. https://doi.org/10.1007/978-3-030-23384-6

CURRICULUM VITAE

Mariëlle Peeters was born on the 17th of December 1991. After she finished secondary education at Katholieke Scholengemeenschap Etten-Leur in 2009, she started studying Health Sciences at Erasmus University Rotterdam. Mariëlle graduated in 2012 and transferred to Maastricht University for her master's degree Healthcare Policy, Innovation and Management. She combined her study with working as a research assistant at Rotterdam University of Applied Sciences, Research Center Innovations in Care. After obtaining her master's degree, Mariëlle continued to work there as a junior researcher and participated in several research programs of which one was the *Better Transition in Type 1 Diabetes* program, which formed the basis for the start of her PhD in 2018. Mariëlle's research focused on the provision and evaluation of transitional care for young people with chronic conditions, with special attention to young people with type 1 diabetes mellitus. Besides doing research, Mariëlle teaches health care students at Rotterdam University of Applied Sciences.

*"It's not about perfect, it's about effort. When you bring that effort every single day,
that's where transformation happens, that's how change occurs."*

(Jillian Michaels)