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Effects of Gross Motor Functioning and Transition Phase on Health-Related Quality of Life in Norwegian Adolescents With Cerebral Palsy

Graduate thesis in Profesjonsstudiet i Psykologi
Trondheim, December 2015

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Preface

My curiosity into the adolescence and independence development of those diagnosed with cerebral palsy was sparked in the NTNU internal clinic. After some research online, I discovered the Cerebral Palsy Register of Norway (CPRN), and the content in their register. I applied for the relevant data, and was allowed to use them in my paper.

I am very grateful to the register for allowing me to use their data, and to Torstein Vik, Guro L. Andersen and Sandra J. Hollung for helping me on various occasions in the process, from start to finish. Especially Torstein Vik, who guided me through my troubles with the statistics.

I would like to thank Trude Reinfjell for her excellent guidance throughout the writing process. Her knowledge into HRQOL and the PedsQL used in the study was of great value to me. Also, I would like to thank Odin Hjemdal for great help with the statistics when SPSS and I didn't see eye to eye.

And last but not least, I would like to thank Olav for bearing with me this time, and for being patient when having to read through the paper several times and checking my spelling.

Abstract

Adolescents with cerebral palsy meet great challenges in the transition from childhood to adulthood. As young adults they lag behind their able-bodied peers in housing, employment and intimate relationships, and their health-related quality of life (HRQOL) is more impaired than in healthy individuals. Previous studies have yielded evidence for gross motor functioning as a predictor for impaired HRQOL for individuals with cerebral palsy. In this study we therefore examine the predictability of gross motor functioning, as measured by the Gross Motor Function System (GMFCS) and transition phase, as measured by the Rotterdam Transition Profile (RTP) on HRQOL, as measured by the Pediatric Quality of Life Inventory 4.0 (PedsQL). 57 Norwegian adolescents between the ages of 15 to 17 years drawn from the Norwegian Cerebral Palsy Register (CPRN) participated in the current study. Results showed significant effects of the GMFCS as a predictor for HRQOL. Transition phase had very little effect on HRQOL. It is suggested that the RTP is more suitable for measuring older subjects.

Keywords: health-related quality of life, Pediatric Quality of Life Inventory, Rotterdam Transition Profile, Gross Motor Function System, cerebral palsy, adolescence

Effects of gross motor functioning and transition phase on health-related quality of life in Norwegian adolescents with cerebral palsy

Cerebral palsy is a group of permanent disorders of the development of movement and posture. Disturbances of sensation, perception, cognition, communication, behavior, epilepsy, and secondary musculoskeletal problems often accompany the motor disorders (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). Results from the Cerebral Palsy Registry of Norway, who registered all Norwegian children with cerebral palsy born between January 1996 and December 1998, showed a prevalence of 2.1 per 1000 live births (Andersen et al., 2008). The prevalence rates of cerebral palsy in 13 countries varies from 1.5 to 3 per 1000 live births (Cans, 2000), making it the most common causation of motor deficiency in children. The network Surveillance of Cerebral Palsy in Europe (SCPE), has divided cerebral palsy into three groups based on the predominant neuromotor abnormality; spastic, ataxic and dyskinesia (Cans, 2000).

In research and in clinical practice there is a need to classify the motor abilities of children with cerebral palsy with a standardized system that measures the severity of movement disability. The Gross Motor Function Classification System (GMFCS) was developed in response to this need (Palisano et al., 1997). The GMFCS divides the physical abilities into five levels, ranging from age appropriate performance with some difficulty with balance, speed and coordination in Level I, to difficulty with voluntary control of movement and posture in Level V (Palisano et al., 1997). The GMFCS was originally developed and validated for children, but has been found to be valid and reliable for adults with cerebral palsy as well (Jahnsen, Aamodt, & Rosenbaum, 2006). The GMFCS is an attempt to classify cerebral palsy in a functional approach. It is a common indicator that classifies the subject in terms of gross motor functioning.

An increasing number of individuals with cerebral palsy are living well into adulthood (Frisch & Msall, 2013; Hutton, Cooke, & Pharoah, 1994; Oskoui, 2012), with a survival rate close to average for those not most severely affected (Day, Reynolds, & Kush, 2015). Knowledge of the long-term outcomes for adults with cerebral palsy is inadequate (Frisch & Msall, 2013; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009), and we know little when it comes to health related quality of life (HRQOL) in adults with cerebral palsy (van der Slot et al., 2010). It has been suggested that among other factors, a delayed transition into adulthood, where they lag behind in central areas, can lead to a low quality of life for adults with cerebral palsy (Bottos, Feliciangeli, Sciuto, Gericke, & Vianello, 2001; Chamberlain & Kent, 2005). Health related quality of life (HRQOL) includes those aspects in life connected to a person's

health status (Guyatt, Feeny, & Patrick, 1993), and is not identical to global quality of life (QOL), which refers to the concept of holistic well-being (Albrecht & Devlieger, 1999). HRQOL is often defined as a multidimensional concept that includes both the social, physical and psychological dimensions of health (Patrick & Chiang, 2000; Rajmil et al., 2004)

Adult outcomes

Adults with cerebral palsy perceive their HRQOL to be lower than reference groups, and experience difficulties in social participation (Jahnsen, Villien, Aamodt, Stanghelle, & Holm, 2005; Roebroeck et al., 2009; van der Slot et al., 2010). Factors associated with low HRQOL are unemployment, fatigue, pain, deterioration of function, a low sense of coherence and living alone (Jahnsen et al., 2005). Adults with cerebral palsy are in a disadvantaged position compared with healthy peers, in regards to employment, civil status, having children, and living independently (Alriksson-Schmidt, Hägglund, Rodby-Bousquet, & Westbom, 2014; Rutkowski & Riehle, 2009; van der Slot et al., 2010). In the Danish Cerebral Palsy Registry, only 29% of the participants aged 21 to 35 years were employed, compared to 82% in the control group (Michelsen, Uldall, Kejs, & Madsen, 2005). Factors that impact being employed, and living with a partner as an adult in a negative direction have been found to be a low level of education, severe physical disability, epilepsy and severe cognitive impairment (Bottos et al., 2001; Liptak, 2008; Murphy, Molnar, & Lankasky, 2000). A significant number of participants in the study of van der Slot et al. (2010) reported having hardship with daily activities and social participation. Other studies have found congruent results (Andersson & Mattson, 2001; Andren & Grimby, 2004; Murphy et al., 2000; van der Dussen, Nieuwstraten, Roebroeck, & Stam, 2001). Studies have indicated a connection between the need for assistance (physical disability) and the likelihood of having intimate and sexual relationships (Howland & Rintala, 2001; MacDougall & Morin, 1979; Taleporos & McCabe, 2003). Bottos et al. (2001) indicate that individuals with severe motor impairment are more inclined to live independently and meet a partner if they have a close to average intelligence.

The research into long-term consequences for individuals with cerebral palsy is limited. Current knowledge indicates that adults with cerebral palsy face challenges in regard to social and sexual relations, independent living and employment. Based on the available literature, the transition period in adolescence appears to be critical when it comes to the development of these difficulties. In the following section, we will take a closer look at the transition period for adolescents with cerebral palsy.

Transition process

The rising number of people with cerebral palsy living into adulthood accentuates the transition period from childhood to adulthood (Wiegerink, Roebroeck, Donkervoort, Cohen-Kettenis, & Stam, 2008), and the challenges met in this period. Understanding this time span can be essential to ensure a healthy development and transition for adolescents with cerebral palsy. The evolution to adulthood demands achievement of independence, identity consolidation, finding an occupation and forming adult and intimate relationships (Chamberlain & Kent, 2005), and adolescence has been recognized as a transitional period with significant changes (Davis et al., 2009; Livingston, Rosenbaum, Russell, & Palisano, 2007). It is a complex phase, and Chamberlain and Kent (2005) report that individuals with disabilities and health problems experience challenges in these aspects due to a shortage of social opportunity. Others have pointed at additional disadvantage due to physical impairments, poor knowledge of sexuality, parental stress, overprotective parents, dependence of others, scarcity in experience when it comes to activities, gap in services, as well as social isolation (Ansell & Chamberlain, 1998; Blum, Resnick, Nelson, & St Germaine, 1991; Chamberlain & Kent, 2005; Hallum, 1995; Magill-Evans, Wiart, Darrah, & Kratochvil, 2005; Marn & Koch, 1999; Morgan & Balandin, 1997; O'Grady, Crain, & Kohn, 1995; Stevens et al., 1996). During the transition process there is often no structured rehabilitation treatment, as the individual leaves pediatric rehabilitation (Donkervoort, Wiegerink, van Meeteren, Stam, & Roebroeck, 2009; Oskoui, 2012). Combined with the major changes adolescents face in this period, this may be an additional disadvantage.

Hallum (1995) has looked at the parental role in the transition period. Disabled adolescents often experience being treated in a more child-like way than their abled peers, for example with parents making choices for them that they could have made themselves and not expecting them to participate in chores (Hallum, 1995). The consequences of parental overprotection or excessive parental assistance may be lower happiness and self-esteem, a poor sense of personal competence and higher levels of anxiety (Blum et al., 1991; Goldcamp, 1984). A higher dependence on adult care can also hinder disabled adolescents' dating opportunities, and thus their chances for sexual experience (Cheng & Udry, 2002).
A complicating factor on this subject, is that services aimed at increasing independence, such as educational programs, can have a paradoxical effect by using different standards for disabled adolescents that are not consistent with societal expectations for more developed individuals (Darrah, Magill-Evans, & Galambos, 2010). This can in fact limit participation.

Peer contact is important for all youths, but is relatively limited for those with cerebral palsy (Blum et al., 1991). Disabled adolescents participate in fewer social activities, are less socially active and less skilled in social interaction, they start dating at a later time, date less often, and have less sexual experience and knowledge than their able-bodied age mates (Brown & Gordon, 1987; Stevenson, Pharoah, & Stevenson, 1997; Wiegerink, Roebroeck, Donkervoort, Stam, & Cohen-Kettenis, 2006). Yet they view sexuality as an important factor in their existence (Wiegerink et al., 2006). In a study on physically disabled adolescents in the United States, Cheng and Udry (2002) found that even though disabled adolescents were more socially isolated and developed slower, they were as sexually experienced as their nondisabled peers. Suris, Resnick, Cassuto, and Blum (1996), found no significant differences between adolescents with and without chronic conditions when it came to sexual involvement, but that those with chronic conditions were more likely to have been sexually abused. Cheng and Udry (2002) also found that disabled girls were more likely to experience forced sex than non-disabled girls. Both personal and environmental factors, such as self-esteem and parental behavior, have a direct and indirect influence on social and sexual relations (Wiegerink et al., 2006). The development of self-esteem has been linked to establishing the equilibrium between autonomy and connectedness during adolescence (Allen, Hauser, Bell, & O'Connor, 1994), and social self-efficacy is seen as a predictor for independence in adolescents with disabilities (King, Shultz, Steel, Gilpin, & Cathers, 1993). A limiting factor when it comes to social and sexual aspects of adolescents with cerebral palsy is that few studies have been done on adolescents with cerebral palsy exclusively (Wiegerink et al., 2006).

Palisano et al. (2009) discovered that adolescents with cerebral palsy in level I of the GMFCS were more likely to have done activities with friends and other nonfamily members than adolescents in levels IV and V, consistent with the finding that a higher level of mobility could favor the accomplishment of life habits (Lepage, Noreau, & Bernard, 1998). Darrah et al. (2010) report that participants stressed the significance of satisfying transportation options in order to accomplish and preserve an independent lifestyle. Most of the participants were relying on public transportation or transportation for individuals with disabilities, as few could drive or had access to private transportation (Darrah et al., 2010). For individuals who use a wheelchair, the lack of adequate transportation could disrupt the spontaneous nature of socialization that is typical among adolescents (Palisano et al., 2009). Young adults with motor disabilities also have difficulties in achieving independent living because of the low income and increased expenses they often have, and it is often the less physically disabled

that find it the hardest (Pascall & Hendey, 2004). During adolescence, self-evaluation and comparison with others become a concern for the disabled youth, as this forces him or her to become aware of the physical and social limitations associated with their condition (Magill & Hurlbut, 1986).

To better understand the transition process for youth with disability, the Dutch Transition Research Group developed the Rotterdam Transition Profile (RTP; Donkervoort et al., 2009). To our knowledge, this is the first instrument that attempts to measure the transition process in adolescence in youth with cerebral palsy. The transition from childhood to adulthood involves different developmental stages and domains of participation (Donkervoort et al., 2009). A follow-up study over two years showed that young adults with cerebral palsy without severe learning disability progressed towards the more advanced phases in most domains, except for housing and intimate relationships (Roebroeck et al., 2007). However, they still lagged behind their peers in employment, sexual relationships and independent living. These delays were associated with gross motor functioning, manual abilities, educational level and difficulties with activities relevant for domains of participation. According to Parkes et al. (2008), a significant distribution of children with cerebral palsy suffer from psychological symptoms or social impairment severe enough to authorize referral to specialist services. In addition to the challenges associated with the transition in adolescence already mentioned, many individuals with cerebral palsy experience a decline in physical function as well as musculoskeletal impairments from adolescence to adulthood (Bottos et al., 2001; Sandström, Alinder, & Öberg, 2004). Poor health can lead to limitations in ventures and participation (Andren & Grimby, 2004; Bottos et al., 2001), and may in that regard affect quality of life (Jahnsen, Villien, Stanghelle, & Holm, 2003; Liptak, 2008).

HRQOL

As medical advances have increased survival rates, it will be of increasing importance to look at the psychosocial aspects of individuals with cerebral palsy. In order to make informed choices in rehabilitation and health services, research must investigate all aspects of functioning. Measurements of QOL and HRQOL has been created in order to quantify the connection between clinical indicators of disability and the subjective experience of the impact of the disability on the individual and care takers (Bjornson & McLaughlin, 2001). Findings by Rosenbaum, Livingston, Palisano, Galuppi, and Russell (2007) indicate that QOL and HRQOL are separate constructs, even though they are considered related conceptually. Numerous measures are labeled as QOL or HRQOL in the literature, but most items in these

measures can be said to describe functional status (Edwards, Heubner, Connell, & Patrick, 2002). This makes comparisons between studies and cases challenging. In addition, the terms quality of life, health-related quality of life health status, functional status, and well-being, are often used synonymously (Bjornson, Belza, Kartin, Logsdon, & McLaughlin, 2008). However, investigations suggest that functional status, health status and QOL are separate constructs (Leplège & Hunt, 1997; Smith, Avis, & Assmann, 1999). Because the research on HRQOL in adolescents with cerebral palsy is very limited, the literature presented will include studies done on younger and older individuals, as well as global QOL.

Clinicians have long suspected a relation between a decrease in physical function and a lower quality of life or well-being. Instruments developed in the later years have allowed research to investigate this suspected association. Several studies have investigated the relation between HRQOL/QOL and GMFCS (Liptak et al., 2001; Tuzun, Eker, & Daskapan, 2004; Vargus-Adams, 2005; Young et al., 2010). Tuzun et al. (2004) found correlations between GMFCS level and Child Health Questionnaire (CHQ)-measured physical functioning, physical role functioning, and social role functioning, as well as with self-esteem, health and behavior. They argue that gross motor functioning is associated with both physical wellbeing and psychological wellbeing. Vargus-Adams (2005) reported significant relations between gross motor function and physical functioning, health, physical role functioning, behavior and impact on parents' time, as reported by the parents of the children studied. She did not, however, find associations between GMFCS and psychosocial wellbeing. The results indicated that an increasing severity in motor impairment lead to a decreased HRQOL. Psychosocial HRQOL was better than physical HRQOL in this study (Vargus-Adams, 2005). Liptak et al. (2001) discovered that children with a more severe cerebral palsy, as measured by the GMFCS had a lower QOL than those with a less severe cerebral palsy. Young et al. (2010) researched QOL in Canadian youth and young adults with cerebral palsy. They found that the most important predictor for QOL outcomes was the GMFCS level from childhood, and not their age or sex. They found no explanation for half of the variance in their QOL, opening for other contributing factors. Varni et al. (2005) documented self-reported HRQOL in 69 children and adolescents with cerebral palsy aged 5 to 18 years across using the Pediatric Quality of Life Inventory 4.0 (PedsQL). Individuals with cerebral palsy reported a significantly lower HRQOL than healthy individuals, and those diagnosed with quadriplegia reported a more impaired HRQOL than those diagnosed with diplegia and hemiplegia (Varni et al., 2005).

Not all studies have reported a relation between gross motor functioning and HRQOL or QOL. Pirpiris et al. (2006) investigated the associations between function and well-being in children, aged 4-18 years old, with mild to moderate cerebral palsy, using the PedsQL as one of the HRQOL measurements. They found no associations between age or sex and physical functioning or psychosocial well-being, nor a significant correlation between psychosocial well-being and physical function. Bjornson et al. (2008) discovered no associations between GMFCS level and QOL, as measured by the Youth Quality of Life (YQOL). They suggest GMFCS level may influence HRQOL, but not more global QOL, independent of health (Bjornson et al., 2008). Psychosocial health, measured by the Child Health Questionnaire, of children with mild cerebral palsy has been shown to be as low as, or lower than, that of children with severe cerebral palsy, measured by the GMFCS (Wake, Salmon, & Reddihough, 2003). Similar results were reported in the population-based study by Kennes et al. (2002) on Canadian children, who reported no relation between GMFCS level and pain or emotional state. Schneider, Gurucharri, Gutierrez, and Gaebler-Spira (2001) recommend that one should measure both HRQOL and function, as disability and HRQOL did not correlate well in their study. The literature is not in complete agreement in regards to the relation between gross motor functioning and HRQOL. However, the majority of the literature reviewed support a relation between the two factors.

Livingston et al. (2007) found in their review of QOL and HRQOL in youth with cerebral palsy, which included some of the studies reported in this article, that they had reduced QOL and HRQOL in some, but not all areas, compared to the normative population. Functional status was related to physical, but not always to psychosocial well-being. Pirpiris et al. (2006) demonstrated that children with cerebral palsy had a lower HRQOL than normative values, as measured by the PedsQL. In a study of pediatric patients with ten types of chronic disorders, including cerebral palsy, patients with cerebral palsy reported the most impaired HRQOL, as measured by the PedsQL (Varni, Limbers, & Burwinkle, 2007). These studies emphasize the importance of investigating the HRQOL of this group.

Livingston et al. (2007) point out the lack of research into factors contributing to the QOL and HRQOL for this age group. In particular, few studies investigate the HRQOL of adolescents with cerebral palsy. There are also a large number of instruments used to tap QOL or HRQOL, making it difficult to compare between samples and draw conclusions based on the literature available. The Pediatric Quality of Life Inventory 4.0 (PedsQL; Varni, Seid, & Kurtin, 2001), used in some of the studies reported, as well as in our study, is seen as one of the most promising HRQOL instruments for children and adolescents. The 4.0 version was

designed to measure the core health dimensions delineated by WHO (1948), and builds on 15 years of research, starting with an instrument directed at investigating pain in juvenile rheumatoid arthritis (Varni, Thompson, & Hanson, 1987).

In a qualitative study by King, Cathers, Polgar, MacKinnon, and Havens (2000), examining 10 older adolescents (18-20 years) with cerebral palsy, two types of themes emerged when defining their success in life. The first type was instrumental themes regarding employment, schooling, and independent living. The second type was psychosocial themes involving happiness, interpersonal relations, attitudes, and perceptions of support (King et al., 2000). These themes are in some ways comparable to two of the factors examined in this study: Transition profile and HRQOL. The fact that these themes emerge in a qualitative study, points to the need to investigate further using quantitative measures. The purpose of this study is to describe the HRQOL outcomes of youth who have cerebral palsy. We also seek to explore the impact of two factors (severity of cerebral palsy and transition phase) on HRQOL outcomes. The intent is to generate evidence and promote optimal health for persons who have cerebral palsy.

It is not clear from the presented research how the transition phase of adolescents with cerebral palsy affects their HRQOL. We hypothesize that transition phase from the RTP would predict variance in HRQOL, as measured by the PedsQL, and that a higher transition phase will predict HRQOL in a positive direction. Extending on previous work, the current investigation examine the relation between GMFCS level and HRQOL, excluding age and sex from the analysis. It is expected that the severity of cerebral palsy as measured by the GMFCS will predict variance in the total scale score of HRQOL, as measured by the PedsQL, and that a higher GMFCS level will predict a lower HRQOL.

To our knowledge, our study is the first to attempt to document the relationship between transition phase and HRQOL in adolescents with cerebral palsy.

Method

Procedure

This investigation is part of the Cerebral Palsy Registry of Norway (CPRN), which comprises data of all children diagnosed with cerebral palsy, born after 1996 in Norway. Each county has a CPRN contact person, who is responsible for the coordination of completing and submission of the forms of consent and registration. The contact persons are mainly pediatricians. A physician holds the responsibility for the information submitted to the CPRN. The CPRN has a contact person in all 21 rehabilitation centers for children in Norway.

Medical data are registered at the time of diagnoses, at five years of age and at fifteen to seventeen years of age (CPRNung). For the CPRNung, health personnel complete four forms (motor functioning, physician form, cognition and speech/communication), parents or caretakers complete five forms (cognition, speech/communication, mental health – SDQ, health related quality of life – PedsQL and a parent form) and the adolescent complete four forms (participation – RTP, mental health – SDQ, health related quality of life – PedsQL and quality of life – Fatigue Severity Score). The results presented in this study are based on the CPRNung-data, specifically the PedsQL completed by the adolescents/self report scales and the RTP.

Measurements

Gross motor functioning was classified with the Gross Motor Function Classification System (GMFCS), which has proven to be a valid and reliable way to predict functional ability in children (2-12 years) with cerebral palsy (Palisano et al., 1997).

The Rotterdam Transition Profile (RTP; Donkervoort et al., 2009) was used to summarize where the subjects were in their transition from childhood to adulthood. The RTP includes the participation domains; finances, housing, education and employment, intimate relationships, sexual development, leisure activities and transportation, and the health service domains; care needs, service and assistance and rehabilitation services. For every domain, the person is categorized into a phase of transition. In phase one, the adolescent is dependent on adults. In phase two, the youth move towards more independence, and in phase three the adolescent is relatively independent and self reliant (Donkervoort et al., 2009). The RTP was intended for use on adolescents and young adults, and has shown construct validity for classification of the transition of young adults (18-22 years) with cerebral palsy, normal intelligence and without learning disabilities (Donkervoort et al., 2009).

The Pediatric Quality of Life Inventory, 4.0 (PedsQL; Varni et al., 2001) for youth (13-18 years) was used to measure the health related quality of life of the participants. The 23-item self-rapport PedsQL can be divided into four domains: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items) and school functioning (5 items). In addition, one operates with a psychosocial health summary score and a total scale score. Items are reversed scored and linearly transformed to a 0 to 100 scale, where 0 = 100, 1 = 75, 2 = 50, 3 = 25 and 4 = 0. A score of 100 represents optimal quality of life. If more than 50% of the items in the scale are missing, the total scale score is not computed. The PedsQL was originally developed by Varni et al. (2001), and was translated into Norwegian and validated

for the age group of 13 to 15 years in Norway ($\alpha \geq 0.77$) by Reinfjell, Diseth, Veenstra, and Vikan (2006).

Statistical analysis

Analyses were conducted using IBM SPSS Statistics version 21.0.0 for Mac OS X. Descriptive analyses were used to present participant characteristics, their gross motor functioning, their cognitive resources and the distribution on the RTP and the PedsQL. In addition, correlation analyses between the RTP, the GMFCS and the PedsQL were executed to examine the relationship between the variables prior to the regression analyses.

Analyses were undertaken to test the following hypotheses: a) a low transition phase in the RTP for adolescents with cerebral palsy will predict a lower total sum score on the PedsQL, and b) more severe gross motor functioning, as measured by the GMFCS, will predict a lower PedsQL total sum score.

Hierarchical multiple regression was conducted to examine the relationship between HRQOL, and transition phase and gross motor functioning, with the total summary score of the PedsQL as the dependent variable. A critical value of 5% or less was considered as statistically significant. In step one, the GMFCS was assigned as the first predictor variable. In step two, the RTP domains were assigned as the second predictor variable, and separate regression analyses were conducted for each of the domains.

Due to a lack of findings in earlier studies with regards to the predictive value of age and gender (Pirpiris et al., 2006), these factors were excluded from the regression analyses.

Because there were a large number of missing responses to the PedsQL and the RTP, we performed crosstab analyses to see if the results could be biased. There were some significant differences ($p > .05$) between respondents and non-respondents, in which the non-respondents were skewed in the direction of a more severe cerebral palsy diagnosis, a higher frequency of anti epilepsy medication, and a higher GMFCS level. The possible impact on the results will be discussed.

Ethical aspects of the study

The Regional Committee for Medical and Health Research Ethics (REC) approved this study (REC-number: 2011/754). The register is based on consent, and has a joint consent with the Norwegian Cerebral Palsy Follow-Up Program (CPOP). The consent form clarifies that the CPRN and the CPOP have separate purposes and computing personnel. It is possible to consent to one or both registers.

Results

Demographic characteristics

The sample consisted of 57 adolescents (30 males, 27 females) with cerebral palsy, aged between 15 and 17 years (M = 15.93, SD = 1.038). The distribution of cerebral palsy diagnosis was 14% right hemiplegia, 19.3% left hemiplegia, 45.6% diplegia, 10.5% quadriplegia, 7% dystonia, and 3.5% ataxic cerebral palsy. Five (8,8%) participants were born outside Norway. Of those tested for cognitive resources by medical professionals (n=34), 2.9% were unknown, 44.1% had an IQ>85, 26.5% had an IQ 70-85 and 26.5% had an IQ<70. Of those not tested (n=9), the clinical assessment by health personnel indicated that 66.7% had an IQ>85, 11.1% had an IQ 70-85 and 22.2% had an IQ<70.

Table 1 shows the characteristics of the HRQOL, transition phases, and gross motor functioning of the sample.

Predictability of the RTP and the GMFCS

Hierarchical multiple regression was calculated to assess the ability of the GMFCS and the RTP to predict HRQOL. Preliminary correlation analyses were performed to see if the dependent and independent variables were correlated. As seen in Table 2, we found significant correlations ($p < .01$) between the GMFCS and PedsQL total sum score and between the GMFCS and the RTP sexual development domain. In addition, several of the RTP domains were correlated significantly ($p <. 01$ and $p <. 05$) with other RTP domains. Because many of the RTP domains were correlated with each other, separate regression analyses were conducted for all the RTP domains. The GMFCS was entered into Step 1, and explained 25.1% of the variance in HRQOL. After entry of the RTP domains at step 2, the total variance explained by the model did not change by more than 4.7% (the RTP education and work domain), leaving most of the variance unexplained. Three RTP domains predicted 0% variance change in Step 2; the RTP leisure domain, the RTP intimate relationship domain, and the RTP rehabilitation services domain. Regression coefficients are shown in Table 3.

Discussion

Few studies have investigated the HRQOL of adolescents with cerebral palsy. In the literature available, the GMFCS stands out as an important predictor of HRQOL. No studies have investigated the RTP as a possible predictor of HRQOL for adolescents with cerebral palsy, even though transitional challenges in adolescence have been suspected to impact HRQOL in a negative direction. In the present study we therefore examined the predictor value of the GMFCS and the RTP on HRQOL, measured by the PedsQL. Analyses confirmed

our second hypothesis, regarding the impact of gross motor functioning on the HRQOL of adolescents with cerebral palsy, which has also been found in the studies by Vargus-Adams (2005), Liptak et al. (2001), and Young et al. (2010). We found no support for our first hypothesis stating that transition phase will predict HRQOL in adolescents with cerebral palsy. In the following section, limitations of the study and implications of the findings will be discussed.

Gross motor functioning

Cerebral palsy is a very diverse diagnosis, or set of diagnosis. There has been little consensus in regards to definitions and ways to classify the different types of cerebral palsy. The consensus surrounding the GMFCS makes it possible to compare different populations and study samples. Because gross motor functioning has proved to be an important factor when it comes to HRQOL, it is central to report in studies of individuals with cerebral palsy, in addition to subtypes of cerebral palsy, as the subtype and GMFCS level are not always correlated.

Gross motor functioning was a significant predictor for HRQOL in our study, despite the fact that our sample was only mildly limited compared to other samples, such as the ones in the studies by Rosenbaum, Livingston, et al. (2007) and Westbom, Hagglund, and Nordmark (2007). Although the GMFCS level may change somewhat during the lifespan, it is not something that is easily manipulated. In such, the results are discouraging in terms of implications for clinical use. However, it is possible that interventions, such as physical therapy, intended to improve physical functioning may in turn improve HRQOL. Motor activity, often a part of a physical therapy program, may lead to better health and augment cognitive functioning (Damiano, 2006), and might therefore impact HRQOL in adolescents with cerebral palsy. Recent research suggests that activity-based strategies have a promising future in the treatment of cerebral palsy (Damiano, 2006). Much of the variance in HRQOL remains unexplained for by the severity of gross motor functioning, suggesting that other factors, such as pain, may also influence HRQOL. Pain has been shown to impact children's QOL and participation in a negative direction (Houlihan, O'Donnell, Conaway, & Stevenson, 2004), and is connected to severity of motor impairment. In addition to the predictor variables mentioned already, multilevel surgery has been found to impact HRQOL and functioning in ambulatory children with cerebral palsy (Cuomo et al., 2007). Not all with cerebral palsy are eligible for this type of intervention, but for some this may be a way to improve HRQOL. These factors may give caregivers, clinicians and the adolescent additional opportunities to affect HRQOL outcomes in a positive direction, and should be researched further. Our sample

was relatively mildly limited with relatively low GMFCS levels, but had the GMFCS as a significant predictor of their HRQOL. One explanation for these results may be that those mildly affected are expected to participate and perform equally to body abled peers, and experience a lack of understanding and consideration from their surroundings, as their disability is less visual. This, in turn, might affect HRQOL in a negative direction.

Transition

Theory proposed by earlier research (Bottos et al., 2001; Chamberlain & Kent, 2005) state that a delayed transition to adulthood could lead to a poorer HRQOL/QOL. In the RTP, a higher phase indicates a more self-sufficient way of life. In the housing domain of the RTP, the adolescent must live independently to achieve the highest phase. In the age group we have investigated (15 to 17 years), it is unusual also for able-bodied youths in Norway to live alone, unless they are required to do so in order to attend high school. Given that independent living is unusual at this age, you will not expect a low transition phase in this domain to affect HRQOL to a large degree. As the results show, the low phases in our sample had no significant effect on the total sum score in the PedsQL.

In the domain of employment in the RTP, the adolescent needs a paid or voluntary occupation to reach the highest phase. Statistics Norway (2015a) inform that 39 000 of 325 000 Norwegians between the ages of 15 and 19 years were working in 2014, and not studying. In addition, 67 000 of 267 000 of Norwegians between the ages of 15 and 19 years had a part time job in addition to their studies (Statistics Norway, 2015a). 27% of Norwegians over the age of 16 have elementary school as their highest completed education, and between 38% of women and 45% of men over the age of 16 have high school as their highest completed education (Statistics Norway, 2015b). In the Norwegian population, only 27% will have completed their education by the ages of 15 to 17 years, and of those who continue their education, only 25% work part time. This would suggest that the norm is to attend school, and not work part time, and that this domain might not be critical for the transition process for youth as young as 15 to 17 years of age. Although this domain did not predict HRQOL in this study, one could imagine a different result if the mean phase was higher, or the participants were older. A high phase could have a positive impact on HRQOL. A low phase combined with a higher age might have a negative impact on HRQOL, as the contrast with peers would be more pronounced.

In the domain of finances, the adolescent must be economically independent with an income derived from work or social benefits to reach the highest phase in the RTP. As already discussed in the domain of education and work, few adolescents in the ages of 15 to 17 years

have completed their education (Statistics Norway, 2015b) and are eligible for an income based on an occupation or social benefits large enough to make them economically independent. Some youth work part time in addition to their studies (Statistics Norway, 2015a), but one would have to work a considerable amount of hours in order to achieve economically independence. In sum, few adolescents in the ages of 15 to 17 years are economically independent, and one would therefor not expect a low phase in this domain to have a large impact on HRQOL in this group. The domain of economy did not predict HRQOL significantly.

In the domain of sexual development, the adolescent must have sexual experience to achieve the highest phase in the RTP. In Norway, the median age at first intercourse is 16.7 years among girls and 18.0 years among boys (Pedersen & Samuelsen, 2003). At the age of 17 years, 61% of girls, and 40% of boys have had sexual intercourse (Rossow & Bø, 2003). This might suggest that this is a part of the transition process that takes place at the late stage of adolescence for most people. The mean phase in the domain of sexual development of the RTP in our sample was low, and did not predict HRQOL. In the intimate relationship domain, the highest phase requires the adolescent to have or have had a boyfriend/girlfriend. In the ages of 16-19 years, 78% of Norwegian girls and 71% of Norwegian boys had been in or was in a steady relationship (Rossow & Bø, 2003), suggesting that someone who lacks experience with this might be considered as lagging behind. However, a low phase in the intimate relationship domain in the RTP did not predict HRQOL in our sample.

In the domain of transportation, a high phase requires the adolescent to arrange necessary transportation. In order to get a driver's license for driving a car, one has to be older than 18 years old in Norway. This means that no one in our sample has a driver's license, and that independent arrangement of transportation might include collective transportation, private transportation with others, transportation by foot, bicycle and by moped. The quality of collective transportation varies in a large degree based on geography, where the inhabitants of the largest cities in Norway have the best quality (Vågane, Brechan, & Hjorthol, 2011). Of those who have physical issues, most rapport difficulties with walking and riding a bicycle, and a very small number have difficulties with being a passenger in a car (Vågane et al., 2011). This may lead to a trend where those who are physically impaired lose some independence in the transportation area, and let others, such as parents, arrange transportation. However, transportation was the domain with the highest mean phase in our study, indicating that our sample is relatively independent in regards to transportation. This may be seen in connection to the majority of low GMFCS-levels in our sample, which indicates that our

sample may be relatively mobile. It is unknown what type of transportation the adolescents in our sample use the most. A high mean phase in this domain did not predict variance in HRQOL significantly.

In the leisure domain, the adolescent must go out regularly at night to achieve the highest phase. Since the 1980's, there has been a decrease in the number of youths (aged 16-19 years) that have social activities as their main leisure activity (Vaage, 2013). Many spend their free time watching television, participating on social media and playing computer games, and wish for more time to spend with friends, being physically active and for educational purposes (Vaage, 2013). This trend of less time spent with friends, and more time spent at home in front of a screen may serve to isolate individuals more, or it may be a relief for those who struggle with transportation, especially spontaneously, but who can communicate through social media and mobile phones. The mean phase in our sample was relatively high compared to the other domains. This may be connected to the low GMFCS-levels in our sample. It should be mentioned that in this domain, there is no precision of how much time is spent being social, only in what degree the adolescent arranges these activities independently.

In the health care domains, the adolescent must formulate his or her own needs, seek out services and assistance and consult with habilitation or rehabilitation services for adults. The mean phase of the care demands domain is the second highest of all domains, whereas the other health care domains have relatively low means. This may indicate that while the adolescent formulates his or her needs independently, he or she has not yet learned the process of seeking assistance or services, and perhaps has not yet made the leap from pediatric services to adult health services. Chamberlain and Kent (2005) has pointed out that there is a gap in services for youth who are in the process of transition from childhood to adulthood. Neither of the health service domains predicted HRQOL significantly in our study. Whether or not the gap of services in adolescence predicts HRQOL is unknown, but is seems that it does not matter if the adolescent is consulting with rehabilitation or habilitation services for children or for adults.

The lack of significant results may be interpreted to mean that transition phase does not predict HRQOL. A different interpretation is that the RTP is not suitable for investigating transition phase in youths as young as 15-17 years, but rather young adults between the ages of 18 to 22 years, as seen in the RTP validation study by Donkervoort et al. (2009). Many of the domains' highest phases involve goals of independence that are not normal to reach even for the norm population in Norway at 15 to 17 years of age. After high school, the potential

lag will be more pronounced, as many continue their education, get an occupation, and establish a family with a partner and children. We know many adults struggle in some of these areas, and it is likely that this will predict HRQOL in some extent. What is unclear is at what age we will see this effect. Donkervoort et al. (2009) found that young adults between the ages of 18 and 22 years lagged behind their peers in the domains of employment, housing and intimate relationships. It may be that at this age, you will be able to see if the young individual is lagging in the transition process or not, and that it is too early to see who will struggle with the transition process at the ages of 15 to 17 years.

HRQOL

Because the PedsQL is a generic HRQOL assessment instrument, we can compare HRQOL across populations and samples. We sought to compare our HRQOL scores with those from other diagnostic groups. The literature can provide PedsQL total sum scores for a healthy population (age: 8,11-15,0) in Norway (M = 85,3, SD = 11,1) (Reinfjell et al., 2006), cancer survivors (age: 8,5-15,4) in Norway (M = 81.7, SD = 12,6) (Reinfjell, Lofstad, Veenstra, Vikan, & Diseth, 2007) and kidney transplanted children (age: 3-19) in Norway (M = 69.1, SD = 18) (Diseth, Tangeraas, Reinfjell, & Bjerre, 2011). We can from these studies see that our study sample has the lowest total sum score of all these groups. This is an important finding, emphasizing the need to investigate further the HRQOL of this group. We know already from past research that adults with cerebral palsy have a lower HRQOL than healthy individuals (Jahnsen et al., 2005; Roebroeck et al., 2009). And that this is already present at the age of 15 to 17 years. Generally speaking, we would be looking to increase the HRQOL of individuals with cerebral palsy. In order to do this, we must identify the areas or factors that contribute to a lower HRQOL, something we attempted to do in this study. The role of gross motor functioning was confirmed. We hypothesized that transition phase also would be an important predictor of variance in HRQOL, but this was not confirmed. As previously discussed, this may prove to be more important at a later age. Further research will be necessary to identify other factors. Hopefully, factors that are possible to manipulate, so that the individual, the care takers and clinicians may affect the outcome. We can see some promising results in the search for predictor variables in relation to functioning. This may provide information on how to improve HRQOL in adolescents with cerebral palsy. For example, if the problem lies within school functioning, interventions could be directed at reducing pain and fatigue (Berrin et al., 2007). If one identifies challenges in physical functioning, physical therapy (Damiano, 2006) or multilevel surgery (Cuomo et al., 2007) could provide relief and improve functioning. If the problem lies with social functioning, a

physical activity stimulation program could increase participation in this area (Van Wely, Balemans, Becher, Dallmeijer, & 2014). One has, however, found no change in QOL after this type of program (Van Wely et al., 2014). These results may indicate that there is not necessarily a direct link between participation in a domain, and HRQOL. The fact that there is still much we do not know about the HRQOL of adolescents with cerebral palsy, emphasizes the need for extensive research into contributing factors.

The fact that the PedsQL presents not only the total sum score, but also sum scores of each factor, may be an advantage in research. Each sum score can provide useful information regarding in what area the problem lies. Identifying if the challenges lie in the domains of school functioning, social functioning, physical functioning, or emotional functioning can direct interventions and guidance. The PedsQL has not yet been validated for the age group of 15 to 17 years in Norway.

Strengths and limitations

In viewing the results from this study, one must consider certain limitations. The cross-sectional design and the small sample size limit the generalizability of the findings. In addition, there were a large number on non-responses in the PedsQL and the RTP. Crosstab analyses revealed that the group of non-respondents were more severely limited in gross motor functioning, and had a higher frequency of severe cerebral palsy diagnoses. The sample used in the analyses was more mildly limited than the non-respondents. A measurement challenge for adolescents with cerebral palsy is that some of those we would like to obtain information from may be unable to provide this due to great communication disability. This may be problematic, as we seek to present a representable sample of the Norwegian adolescent population with cerebral palsy. However, in reviewing the literature, one would expect that a more severely affected group would have a lower HRQOL and be in a lower transition phase than a more mildly affected group. The fact that the GMFCS still proved to be an important predictor of HRQOL may indicate that it is a robust predictor regardless of diagnosis and gross motor functioning. It could be proposed that the RTP would have explained a larger portion of variance in HRQOL if the more severely affected individuals had been included in the analyses.

In addition to a lack of respondents, some of the respondents on the RTP had answered that the adolescent was in phase zero in a domain where this was not an option. This could be the result of a misunderstanding, as there is the possibility to choose phase zero even though there is no definition of a phase zero in the particular domain. It could also be a typing error, where they meant to choose phase one, and accidently crossed in the wrong space. The

mistake could also be that the respondents believed that they should choose phase zero when neither of the other phases appeared suitable, or the adolescent had no experience with the domain in question. The fact that some answered phase zero even when that was not an option could point to a limitation in the questionnaire, in the sense that the explanation given to the respondent was not adequate, or in the sense that there should have been a phase zero in the domains in question to better describe the respondent's situation.

The pooled data from Westbom et al. (2007) and Rosenbaum, Livingston, et al. (2007) indicates that the distribution of GMFCS levels I through V in youth with cerebral palsy is 22%, 12%, 18%, 25%, and 22%, respectively. In our sample, the distribution was 47,3%, 25,5%, 3,6%, 12,7% and 10,9%, respectively. Compared with the data from Westbom et al. (2007) and Rosenbaum, Livingston, et al. (2007), the lower levels (I and II) are dominant relative to the higher levels (III, IV and V) in the presented sample. It seems our sample is skewed towards mild limitations, as opposed to more severe limitations. However, the Norwegian population with cerebral palsy, as reported by the CPRN register, indicate a distribution of GMFCS levels I through V as 50,7%, 16,7%, 7,5%, 9,2% and 15,4%, respectively. It may seem as if our sample is more similar to the Norwegian population with cerebral palsy when it comes to GMFCS, indicating a representative study sample in regards to this factor. Our sample is also very similar compared to the general population with cerebral palsy in Norway (born 1999-2009; The Cerebral Palsy Register of Norway, 2014) when it comes to cerebral palsy diagnosis. In the general population, the distribution of cerebral palsy diagnosis is 87% spastic, 7% dyskinesia, and 5% ataxic. In our sample, the distribution of diagnosis is 89% spastic, 7% dyskinesia, and 4% ataxic. What can be drawn from these comparisons is that the Norwegian population with cerebral palsy seems to be more mildly limited than the samples presented by Westbom et al. (2007) and Rosenbaum, Livingston, et al. (2007), and that our current sample is representative for the Norwegian population diagnosed with cerebral palsy. Note that our sample was born some years earlier (<10 years) than those presented here as the general population of Norwegians diagnosed with cerebral palsy.

Even though a generic HRQOL instrument has the advantage of being able to compare populations and samples, some argue that disease specific measurements are preferable (Bjornson & McLaughlin, 2001), as they are more sensitive to particular challenges faced by a disease group. In addition to the generic PedsQL, a module for cerebral palsy (PedsQL 3.0 Cerebral Palsy Module) has been developed (Varni et al., 2006). An integrated measurement model, consisting of scores from both the generic PedsQL and the cerebral

palsy module would provide researchers with the advantages of both generic and disease specific instruments (Varni et al., 2006).

In reviewing the literature, it is clear that there is a great variety of inclusion criteria. In addition, some studies have only included specific diagnoses of cerebral palsy or certain GMFCS levels. If learning disabilities are used as exclusion criteria, up to 35% of the sample may be excluded, as seen in Wiegerink et al. (2008). The results may not be representative of the general population with cerebral palsy if the exclusion criteria are too strict. Our study excluded neither GMFCS levels, cerebral palsy diagnoses, severe learning disabilities nor any intellectual levels. As such, the results from the present study may be representative of a larger group of adolescents with cerebral palsy. As stated earlier, the complexity in diagnoses, the number of HRQOL and QOL instruments, and the variety in samples complicate comparisons between studies.

The RTP was created by a group that studies individuals with cerebral palsy and normal intelligence, and was validated on a sample where 75% had a GMFCS level of I, and no learning disabilities (Donkervoort et al., 2009). The RTP might not be suitable for investigating the transition process of individuals with more severe disabilities. However, the RTP can be a valuable measurement, as it allows one to identify which domain the individual is struggling with. If we can understand when the individual starts lagging behind, and which area is most problematic, interventions and guidance can be offered to the individual and their parents so that we may avoid adults with cerebral palsy that continue to struggle with the transition process. The RTP should be validated for further use in assessing Norwegian adolescents with cerebral palsy.

The CPRN already measures individuals with cerebral palsy at three points of time. In the future, one may consider expanding this registration into adulthood. With a lifespan perspective, one would get valuable information concerning the outcomes of areas already measured, and would be able to identify problematic areas in the lives of those with cerebral palsy with greater precision. One could consider removing the measurement of transition phase from the CPRNung, and instead perform this measurement at a later age, such as early adulthood.

Generally, there is little research into adolescents with cerebral palsy. A literature search reveals many articles regarding the physical status and physical challenges, and the transition from pediatric health services to adult health services. Of those articles concerning adolescents with cerebral palsy, cerebral palsy is often one of more diagnoses included. As the population with cerebral palsy live longer and have a high survival rate, research into

psychosocial aspects and wellbeing will be of increasing importance in order to ensure a better life for those affected. It is, however, important that we are careful not to be too eager in the search of challenges in the lives of those with cerebral palsy. Life span disabilities can create a tendency to contribute problems to the disability, and forgetting that there may be other explanations not related to the cerebral palsy. But given the fact that Norwegian adolescents with cerebral palsy have a low HRQOL, it is of importance that we find ways to increase their HRQOL so that they may have a good life and not just a good life expectancy.

Conclusion

The GMFCS proved to be a robust predictor of HRQOL in adolescents with cerebral palsy. Neither of the RTP domains predicted variance in HRQOL significantly. It is suggested that the RTP might be more suitable for investigations directed at older individuals. In further research, measurements of transition in younger adolescents should be a priority. Resources should also be implemented in the search for an improved HRQOL in adolescents with cerebral palsy. In the pursuit of an improved HRQOL, it is suggested that focus should lie on specific domains of HRQOL and factors influencing these.

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Table 1

Descriptive Characteristics Of The Transition Domains, HRQOL Domains And Gross Motor Functioning

Variable	n	M	SD
RTP education and work domain	34	1.00	.35
RTP finances domain	35	.86	.55
RTP housing domain	34	1.12	.33
RTP intimate relationships domain	32	1.00	.95
RTP sexual development domain	32	1.09	.64
RTP transportation domain	35	1.86	.94
RTP leisure domain	32	1.41	.95
RTP care needs domain	35	1.77	.77
RTP service and assistance domain	33	1.03	.47
RTP rehabilitation services domain	35	1.11	.58
PedsQL school functioning	37	63.7	18.4
PedsQL social functioning	37	73.3	18.1
PedsQL emotional functioning	36	74.1	17.8
PedsQL physical functioning	37	64.9	27.9
PedsQL psychosocial health summary score	37	64.3	17.8
PedsQL total sum score	37	68.2	17.2
GMFCS	55	2.15	1.42

Note. RTP = Rotterdam Transition Profile; PedsQL = Pediatric Quality of Life Inventory; GMFCS = Gross Motor Function Classification System.

Table 2

Correlations between predictor variables and dependent variable

Variables	PedsQL	GMFCS	RTP ed.	RTP fi.	RTP hs.	RTP int.	RTP se.	RTP tra.	RTP le.	RTP ca.	RTP as.	RTP re.
PedsQL	1	-.501**	.320	.119	.075	.122	.309	-.097	.084	.180	.248	.003
GMFCS	-.501**	1	.016	.004	-.098	-.254	-.594**	.002	-.090	.077	.060	-.012
RTP ed.	.320	.016	1	.156	.000	-.108	-.179	.276	-.158	-.113	-.213	.000
RTP fi.	.119	.004	.156	1	.264	.207	.122	.073	.219	.198	.506**	-.223
RTP hs.	.075	-.098	.000	.264	1	.230	-.049	.444**	.241	.112	.438*	.240
RTP int.	.122	-.254	-.108	.207	.230	1	.439*	.036	-.051	.044	.154	.215
RTP se.	.309	-.594**	-.179	.122	-.049	.439*	1	-.024	.074	.228	.325	.096
RTP tra.	-.097	.002	.276	.073	.444**	.036	-.024	1	.510**	.358*	.160	.512**
RTP le.	.084	-.090	-.158	.219	.241	-.051	.074	.510**	1	.424*	.189	.301
RTP ca.	.180	.077	-.113	.198	.112	.044	.228	.358*	.424*	1	.447**	.257
RTP as.	.248	.060	-.213	.506**	.438*	.154	.325	.160	.189	.447**	1	-.011
RTP re.	.003	-.012	.000	-.223	.240	.215	.096	.512**	.301	.257	-.011	1

Note. GMFCS = Gross Motor Function Classification System; RTP = Rotterdam Transition Profile; PedsQL = Pediatric Quality of Life Inventory; RTP ed. = education and work domain; RTP fi. = finances domain; RTP hs. = housing domain; RTP int. = intimate relationship domain; RTP se. = sexual development domain; RTP tra. = transportation domain; RTP le. = leisure domain; RTP ca. = care needs domain; RTP as. = service and assistance domain; RTP re. = rehabilitation services domain.
* = $p < .05$. ** = $p < .01$.

Table 3

Hierarchical Multiple Regression Analyses Predicting HRQOL

Step	Predictor variables	F change	R^2 change	β	t
1	GMFCS	11.062*	.251	-.501	-3.326
2	RTP education and work domain	1.914	.047	-.216	-1.384
2	RTP finances domain	.456	.011	.106	.675
2	RTP housing domain	.140	.004	.060	.374
2	RTP intimate relationships domain	.002	.000	-.007	-.039
2	RTP sexual development domain	.465	.013	-.140	-.682
2	RTP transportation domain	.391	.010	-.099	-.625
2	RTP leisure domain	.008	.000	-.014	-.088
2	RTP care needs domain	.444	.011	.105	.666
2	RTP service and assistance domain	1.503	.039	.197	1.226
2	RTP rehabilitation services domain	.007	.000	.013	.084

Note. GMFCS = Gross Motor Function Classification System; RTP = Rotterdam Transition Profile.

- $p < .05$.

Appendix A

Rotterdam Transisjonsprofil

Versjon 0.3
Mars 2010

Dept og Rehabilitation Medicine, Erasmus MC–University Medical Center, Rotterdam
Norsk oversettelse: Reidun Jahnsen, Oslo universitetssykehus og
Irmelin Skjold, Sykehuset i Vestfold

Hva er transisjon?
Transisjon er overgangen fra en livsfase til en annen, og er ledsaget av forandringer i en persons omgivelser eller krav til nye ferdigheter. For ungdommer betyr dette å bevege seg mot selvstendighet med hensyn til arbeid, bolig, utvikling av intime relasjoner, og økonomi. De tar kontroll over sitt eget liv, for eksempel ved å gjøre sine egne valg.

Livsfaseovergangen inn i voksenlivet er ikke det samme for alle ungdommer. Forandringer på ulike områder behøver ikke å skje på samme alder eller samtidig. Disse forandringene er ikke nødvendigvis problematiske.

Transisjonsprofil
For livsfaseovergangen inn i voksenlivet er følgende aspekter viktige:

A. Overgangen skjer på ulike deltakelsesområder. Forskning viser at overgangen ikke skjer på alle områder samtidig. Det vil også bli overgangsfaser på helserelaterte områder.
B. Overgangen er en utviklingsprosess som kan deles inn i tre tydelige faser:
    0. Ingen erfaring
    1. Avhengig av foreldrene
    2. Eksperimentering og orientering mot framtiden
    3. Selvstendig liv

I fase 2 eksperimenterer ungdommene med økende grad av selvstendighet. Derfor må de utvikle nye ferdigheter og muligens oppleve problemer. I denne perioden blir foreldrene klar over det faktum at barnet deres må lære å ta selvstendige valg for å kunne ta kontroll over sitt eget liv. Å fylle ut Transisjonsprofilen gir ungdommen innsikt i overgangsfasen for hvert område.

Rotterdam Transisjonsprofil er en oversikt over overgangsfasene på ulike deltakelsesområder. Utviklingen av Transisjonsprofilen er en pågående prosess som vil bli evaluert regelmessig basert på forskning og klinisk praksis.

Vi ser fram til dine erfaringer og forslag til forbedringer.

www.erasmusmc.nl/revalidatie/research

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Deltakelse	0	1	2	3
Utdanning og arbeid 1. Generell utdanning 2. Yrkesopplæring, arbeidsutplassering 3. Betalt jobb, frivillig arbeid				
Økonomi 0. Ingen lommepenger 1. Lommepenger, egne penger til klær 2. Bijobb, studielån 3. Økonomisk uavhengig: arbeidsinntekt, trygd				
Bolig 1. Bor hos foreldre eller i bofellesskap, ikke ansvarlig for husholdningsaktiviteter 2. Søker etter bolig, hjemmeopplæring eller delvis ansvarlig for husholdningsaktiviteter 3. Bor selvstendig				
Intime relasjoner 0. Ingen erfaring med å være forelsket 1. Erfaring med forelskelse 2. Erfaring med dating 3. Erfaring med å ha/ha hatt kjæreste				
Seksuell utvikling 0. Ikke deltatt i seksualundervisning 1. Deltatt i generell seksualundervisning 2. Deltatt i seksualundervisning relatert til egen diagnose. Erfaring med å kysse/kline 3. Har seksuell erfaring				
Transport 1. Foreldre eller omsorgspersoner transporterer ungdommen 2. Foreldre eller omsorgspersoner arrangerer transport 3. Ungdommen arrangerer transport selv				
Fritid (sosiale aktiviteter) 0. Foreldre eller omsorgspersoner arrangerer fritidsaktiviteter med jevnaldrende 1. Ungdommen avtaler fritidsaktiviteter med jevnaldrende hjemme 2. Ungdommen avtaler fritidsaktiviteter med jevnaldrende utenfor hjemmet 3. Ungdommen går jevnlig ut om kvelden				
Helsetjenester	0	1	2	3
Omsorgsbehov 1. Foreldre eller omsorgspersoner formulerer omsorgsbehov 2. Foreldre eller omsorgspersoner og den unge voksne formulerer behovene sammen 3. Ungdommen formulerer omsorgsbehovene sine selv				
Tjenester og assistanse 1. Foreldre eller omsorgspersoner søker om tjenester og assistanse 2. Ungdommen lærer seg søknadsprosedyrene for tjenester og assistanse 3. Ungdommen søker om tjenester og assistanse selv				
Rehabiliteringstjenester 1. Ungdommen konsulterte barneavdeling/habiliteringstjeneste det siste året 2. Ingen konsultasjon ved barneavdeling/habiliteringstjeneste det siste året 3. Ungdommen konsulterer re/habiliteringstjenester for voksne				

Appendix B

ID: _____

Dato:_____

PedsQL™

Livskvalitet hos barn

Versjon 4.0 – norsk

TENÅRINGSRAPPORT (alder **13-18**)

VEILEDNING

På den følgende side er det en liste med ting som kan være et problem for deg. Vennligst fortell oss **hvor stort problem** hver av dem har vært for deg i løpet av **den SISTE MÅNEDEN** ved å sette en ring rundt

0 hvis det **aldri** er et problem
1 hvis det **nesten aldri** er et problem
2 hvis det **noen ganger** er et problem
3 hvis det **ofte** er et problem
4 hvis det **nesten alltid** er et problem

Det er ingen rette eller gale svar.
Hvis det er spørsmål som du ikke forstår, så vær så snill å spørre om hjelp.

PedsQL 2

*Hvor stort **problem** har dette vært for deg i løpet av den **SISTE MÅNEDEN**…*

OM MIN HELSE OG MINE AKTIVITETER ***(problemer med…)***	**Aldri**	**Nesten aldri**	**Noen ganger**	**Ofte**	**Nesten alltid**
1. Det er vanskelig for meg å gå mer enn 100 m					
2. Det er vanskelig for meg å løpe	0	1	2	3	4
3. Det er vanskelig for meg å drive med sport eller trening	0	1	2	3	4
4. Det er vanskelig for meg å løfte tunge ting	0	1	2	3	4
5. Det er vanskelig for meg å bade eller dusje uten hjelp	0	1	2	3	4
6. Det er vanskelig for meg å hjelpe til hjemme	0	1	2	3	4
7. Jeg har vondt forskjellige steder	0	1	2	3	4
8. Jeg har lite krefter og orker ikke så mye	0	1	2	3	4

OM FØLELSENE MINE ***(problemer med…)***	**Aldri**	**Nesten aldri**	**Noen ganger**	**Ofte**	**Nesten alltid**
1. Jeg føler meg redd eller skremt	0	1	2	3	4
2. Jeg føler meg nedfor eller trist	0	1	2	3	4
3. Jeg føler meg sint	0	1	2	3	4
4. Jeg har vansker med å sove	0	1	2	3	4
5. Jeg bekymrer meg over hva som vil skje med meg	0	1	2	3	4

OM HVORDAN JEG HAR DET SAMMEN MED ANDRE ***(problemer med…)***	**Aldri**	**Nesten aldri**	**Noen ganger**	**Ofte**	**Nesten alltid**
1. Jeg har vansker med å komme overens med andre tenåringer	0	1	2	3	4
2. Andre tenåringer vil ikke være venner med meg	0	1	2	3	4
3. Andre tenåringer erter og plager meg	0	1	2	3	4
4. Jeg klarer ikke å gjøre ting som andre tenåringer på min alder klarer å gjøre	0	1	2	3	4
5. Jeg har vansker med å holde følge med andre tenåringer	0	1	2	3	4

OM SKOLEN ***(problemer med…)***	**Aldri**	**Nesten aldri**	**Noen ganger**	**Ofte**	**Nesten alltid**
1. Det er vanskelig for meg å følge med i timen	0	1	2	3	4
2. Jeg glemmer ting	0	1	2	3	4
3. Jeg har vansker med å få gjort alt arbeidet på skolen	0	1	2	3	4
4. Jeg er borte fra skolen fordi jeg ikke føler meg i form	0	1	2	3	4
5. Jeg er borte fra skolen for å dra til legen eller sykehuset	0	1	2	3	4