Original Article

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Independence of young people with cerebral palsy during transition to adulthood: a population-based 3 year follow-up study

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Abstract

Background: This study describes developmental and service transitions during a 3-year period among young people with cerebral palsy (CP) as measured by the Rotterdam Transition Profile (RTP) and evaluates the test-retest reliability of the RTP. The RTP is a questionnaire developed to classify phases of transition across nine participation domains.

Methods: A three-step design was applied: Step I consisted of a translation and test-retest reliability study of the RTP, Step II was a comparison of independence between youth with and without CP and Step III was a follow-up survey of youth with CP describing changes of independence after a 3-year transition period. A sample of 103 typically developing youth were recruited for Steps I and II, and a population-based sample of 76 (response rate = 59%) youth with CP (males = 40) from

South-Eastern Norway aged 16–17 years were recruited for Steps II and III. The subtypes of CP were classified as spastic unilateral ($n = 30$), spastic bilateral ($n = 37$), dyskinetic ($n = 8$) and ataxic ($n = 1$) CP. The levels of gross motor function followed the categories of the Gross Motor Function Classification System (GMFCS) as level I ($n = 30$), level II ($n = 17$), level III ($n = 6$), level IV ($n = 8$) and level V ($n = 15$).

Results: Twenty-six participants had epilepsy and 13 had gastrostomy. Forty-four of the youth with CP (response rate = 58%) responded to the 3-year follow-up survey in Step III. The test-retest study of the RTP showed excellent reliability (Kw 0.76–0.93). At baseline (Step II), the reference group was significantly more independent than the youth with CP in all the participation domains. At the 3-year follow-up (Step III), the levels of independence had increased significantly for all the participation domains in the youth with CP except for transportation and leisure. Despite increased independence during the transition period regarding health services, only 25% independently formulated their own care needs or applied for services and assistance at 19–20 years of age. Youth who responded to the RTP by a caregiver proxy more often had a diagnosis of epilepsy and/or gastrostomy and higher GMFCS levels. These individuals were significantly less independent than those who self-reported, both at baseline and at follow-up.

Conclusions: In conclusion, the excellent test-retest results support the use of the RTP as a tool for classifying phases of transition among youth with CP. The youth with CP were significantly less independent than their typically developing peers at baseline, yet increased their independence during a 3-year period. Those who self-reported to the RTP were generally more independent than those who proxy-reported, which supports the need to distinguish between the service needs of subgroups during the transition phase.

Keywords: adult; autonomy; cerebral palsy; independence; participation; transition; youth

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Introduction

Children with chronic health conditions experience greater restrictions to participation in everyday life activities compared with their typically developing peers [1], and they generally do not catch up with their peers as they transition into adulthood [2]. Young adults with disabilities experience complex and unmet rehabilitation needs and are inclined to “grow into disability benefits” [3, 4].

As young people approach adulthood, they go through a period of several developmental transitions (e.g. shift towards working life, independent living and intimate relationships) in parallel with a period of service transitions (e.g. health care and school). For youth with disabilities, developmental transitions may be extra challenging, and the service transition is characterised by a lack of continuity between paediatric and adult health care [5, 6] and limited access to support and benefits [7]. The numerous challenges faced by these young people were recognized by researchers at the CanChild Centre for Childhood Disability Research in the late 1990s, when they followed a growing number of children with disabilities into adulthood [8]. Transition research developed as a research discipline, and the increasing number of transition studies has documented a need for better coordination of services, more systematic transition pathways between services and improvement of the assumed under-service for adults with disabilities [2, 5, 9]. Therapeutic focus on transition between paediatric and adult (re)habilitation has historically been on “transitioning a person” towards adult services and individual independence. The “life-course approach” to transition puts less focus on individual skills or independence and more on the fact that all human beings are dependent on others, and all young people depend on support from significant others during the transition process [5, 8]. In agreement with the life-course approach, independence thus refers to the process of gradually taking more responsibility of one’s own life and health, through various phases of developmental and service transition. A person who is able to reflect and make own decisions concerning everyday life domains (e.g. social interactions, domestic life, community life, education, work and economy), and who may act upon these decisions, may be viewed as autonomous in their transition [10]. A person who is independent and autonomous in their transition process may still be in need of help and support, yet has the freedom and ability to

make own decisions based on his or her own sets of values and beliefs [10, 11].

Cerebral palsy (CP) is a complex and life-long disorder of movement and posture caused by an early lesion to the developing brain. Additional challenges, such as seizures, sensory deficits and cognitive impairments, often accompany the motor disturbances and cause activity limitations and restricted participation [12]. Along with medical advances, more children with severe CP survive into adulthood [13]. Greater knowledge has been gained regarding challenges that arise among people with CP over the life-course [14, 15], and a wide range of specific rehabilitation and health-care services are often required in the adult population [9]. Along with knowledge of declining mobility and higher prevalence of pain, fatigue and medical conditions [7, 16, 17], evidence of increased unmet health-care needs among adults with CP exists [9].

Participation in everyday life varies largely in relation to social and physical environmental factors, and many adults with CP experience serious participation restrictions in most arenas in society due to increasing secondary impairments, personal factors and physical and social environmental barriers [18]. Gaining independence and autonomy with respect to service utilization and supports (e.g. work, education, community, and housing services) is a major goal, yet a large challenge, for young adults with disabilities [6]. How young people with disabilities are supported through the critical phases of transition may be essential for promoting both decisional and executional autonomy of participation, and thereby self-management and independence in daily life [11, 19].

In Norway, all children with CP born after 2002 (or 2006 in some regions) are invited to participate in the Cerebral Palsy Follow-Up Program (CPOP) and the Cerebral Palsy Registry of Norway (CPRN) [20]. The closely related CPOP and CPRN were developed from the original ideas of the Swedish Cerebral Palsy Follow-Up Program (CPUP) [21] and the Surveillance of Cerebral Palsy in Europe (SCPE) [22]. Together the CPOP and the CPRN ensure structured monitoring of function, development and interventions and thereby potentially contribute to the promotion of “the right interventions at the right time” for each child with CP [20]. Norway is a welfare state with equal access to public health and social services for all families at low costs. Habilitation services for children with CP up to 18 years of age are offered through regional “paediatric habilitation centres” in the specialist health care services in addition to the primary health care services in the municipalities. Whereas multidisciplinary paediatric habilitation centres

in Norway and other high-income countries often provide systematic follow-up of children with CP until the age of 18 years, services for adults are often based on requested needs from the individuals [15, 16].

To be able to evaluate whether interventions and follow-up programs for people with disabilities and their families make a difference in promoting developmental independence and successful transition from paediatric to adult services, valid and reliable instruments developed to cover these aspects are needed. Such evaluations are important at a population level for the planning of (re)habilitation services and at an individual level to allow monitoring over time and evaluation of the effectiveness of interventions and services applied during the various phases of transition. The Rotterdam Transition Profile (RTP) is a multidimensional instrument developed in the Netherlands to classify phases of the transition process for adolescents and young adults with CP [23]. In a construct validity study of the RTP, the authors found that young adults with CP and normal cognitive functioning in the Netherlands gained autonomy on the RTP later than their peers [23]. They also found that scores on the RTP corresponded to scores on other measures of function, and autonomous participation on the RTP increased over a 3-year period [23]. To our knowledge, no other questionnaire is internationally available for describing both developmental and service transition. However, additional investigation concerning the psychometric properties of the RTP is needed, such as test-retest reliability and the validity for use with individuals who have an intellectual disability and other diagnoses than CP [24]. Although the RTP has been used mostly in cross-sectional studies, its ability to detect change over time has been demonstrated in one longitudinal study [3]. Following further exploration of its psychometric properties, the RTP has the potential for more widespread use and may contribute to the development of evidence-based and goal-directed services and support during the transition phase across both professional and administrative borders.

The overall purpose of this study was to describe developmental and service transitions during a 3-year period among young people with CP using the RTP. More specifically, the aims were to describe (i) test-retest reliability of the RTP, (ii) phases of independence in different life domains among youth with CP compared with typically developing peers, (iii) potential differences in independence among youth who self-reported and youth who proxy-reported and (iv) change of independence as measured by the RTP during a 3-year transition period.

Materials and methods

Design and participants

The study was conducted in three steps during 2009 and 2012 (Figure 1).

Step I was a translation-back-translation and test-retest reliability study of the RTP. A convenience sample of typically developing youth ($n = 103$) aged 16–17 years were recruited from mainstream classes in one urban and one semi-rural high school in South-Eastern Norway. This sample served as the reference group for Step II.

Step II was a cross-sectional study aiming to describe independence in various life domains among 16–17 year-old youth with CP compared with a reference group of typically developing age-matched peers. Participants were recruited from the South-Eastern Health Region of Norway and major efforts were made to identify all youth with CP born in 1992 and 1993. A population of 128 potential participants was identified following mail requests to all general practitioners and the units for special education in the municipalities and by close collaboration with the Norwegian CP association and project co-workers in the 10 regional pediatric habilitation centres. The invitation to participate was sent by surface mail.

Step III was a prospective follow-up survey of the youth with CP, which aimed to describe changes in independence within different life domains across a 3-year period, between the ages of 16–17 and 19–20 years. When the youth consented to participate in Step II, they also

Figure 1: Study design and included participants.

T1: Test 1 (baseline); T2: Test 2 (3 year follow-up); CP, Cerebral Palsy.

^aPercentage from the total population of 128 youth with CP born 1992–1993.

accepted to be invited to take part in the follow-up study in Step III.

Inclusion criteria for Steps II and III were a diagnosis of CP, living in the South-Eastern Health Region of Norway and aged 16–17 years at inclusion for Step II. The only exclusion criterion for the three studies was too limited knowledge of the Norwegian language to complete the questionnaires.

Outcome measures

The Rotterdam Transition Profile

The RTP questionnaire was used to describe the level of independence during the developmental and service transition period. The RTP gives insight into the transition phase as a developmental process from being dependent on caregivers to a more or less independent adult life with autonomous participation within six life domains: education and work, finances, housing, intimate relationships, transport and leisure. In addition, the RTP gives insight into services and systems transition, such as defining care needs, applying for services and assistance and consulting (re)habilitation services [23].

The RTP classifies a person's level of independence according to an ordinal three- or four-graded scale reported as "phases". Phase 0 implies "no experience" of being responsible for the target life domain. Phase 1 implies "dependent on adults", phase 2 implies "experimenting and orientating to the future" and phase 3 implies being "independent or autonomous" [23]. The RTP is shown to be a valid tool for classifying phases of transition into adulthood [24].

The English RTP version 0.2 June 2007 was translated into Norwegian, including forward and backward translation and a consensus process with the authors of the RTP from The Transition Research Group in the Netherlands. The final Norwegian version was piloted with six adolescents with CP and six typically developing peers prior to data collection for this study. One adjustment was made to accommodate the inclusion of adolescents with CP regardless of intellectual functioning. A phase 0 for the leisure domain was added, as some participants with an intellectual disability in the pilot study had no experience with arranging leisure activities on their own.

For test-retest reliability in Step I, the RTP was completed as a questionnaire during two school lessons with 2 weeks in between. One of the authors (RJ or GM) was present and available for questions during the two test situations. For Step II, the RTP was completed as an interview with the adolescents with CP or their caregiver proxies.

At follow-up (Step III), the RTP was completed as a written postal survey.

The participants with CP responded to the RTP either by self-report or with assistance from a caregiver (proxy report). The ability to self-report was judged by the youth themselves, their caregivers and the multi-professional research team. The proxy report included both participants who were assisted by a caregiver in the response and participants whose caregivers responded on their behalf.

Since all the participants in Step I attended high school, it was not relevant to perform an agreement test on the education and work domain. Further, since the reference group included typically developing youth with general health-care needs, the health services domains were not assessed in the test-retest reliability study and therefore not compared between the reference group and participants with CP in Step II.

Clinical assessment

The research team (pediatrician, physical therapists and occupational therapists) administered clinical assessments and a structured interview according to the standard CPOP protocol and confirmed the CP diagnosis and the CP subtype according to the SCPE [22].

Gross motor function was classified by a physical therapist according to the Gross Motor Function Classification System E&R (GMFCS), which describes gross motor function according to five functional levels [25]. Hand function was classified by an occupational therapist according to the five-level Manual Ability Classification System (MACS) [26]. For both the GMFCS and MACS, level I describes the highest functional level and level V describes the lowest.

Ethical aspects

Informed consents were signed by all the parents and the participants who could sign for themselves. The study was approved of the Medical Regional Ethics Committee (REC: 6.2008.2164) and the Data Commissioner for Protection of Privacy in Research at Oslo University Hospital (CPPR: 08/6949). In most cases, parts of the assessment replaced routine controls at the pediatric habilitation centre. The results were reported in a summary and sent to the participants shortly after the assessment for potential use as documentation towards new health care providers during the transfer to adult care.

Statistical analyses

Descriptive statistical analyses were applied for participant characteristics, CP subtypes, functional levels and the distribution of participants in the different phases of the RTP. Agreement between the test-retest results in Step I was analysed with linear weighted Kappa and interpreted with the method by Fleiss, where ≤ 0.40 indicates low agreement, $0.40-0.75$ fair to good agreement and ≥ 0.75 excellent agreement. Comparisons of categorical data between the independent groups were performed with the Mann-Whitney U test for ordinal data and chi-square test or Fisher's Exact Test for nominal data. To assess change of the RTP between baseline and 3-year follow-up, the Wilcoxon Signed Ranks test for paired-wise samples was used. The McNemar-Bowker statistical test for cross-tabulated data from paired-wise samples was also explored, but it was unsuited due to lacking observations for all the phases. Statistical analyses were computed using the statistical software program IBM SPSS Statistics version 21, and the level of significance was set at $p < 0.05$. The weighted Kappa analysis was conducted using the following resource: <http://vassarstats.net/kappa.html>.

Results

Step I: test-retest reliability of the Rotterdam Transition Profile

Ten (out of 103) participants did not respond to the retest survey; hence, 93 youth (57 females, 36 males) aged 16 ($n = 49$) and 17 ($n = 44$) years were included in this analysis. The results showed excellent test-retest reliability on all domains with weighted kappa ranging from 0.76 to 0.93 (Table 1).

Table 1: Test-retest reliability of the Norwegian version of the Rotterdam Transition Profile in typically developing 16–17 year-old youth ($n = 93$).

Independence	Weighted kappa	CI
Education and employment	n.a.	n.a.
Finances	0.84	0.74–0.94
Housing	0.78	0.54–0.99
Intimate relationship ($n = 91$)	0.93	0.86–0.99
Transportation	0.76	0.64–0.88
Leisure	0.82	0.71–0.94

CI, 95% Confidence Interval; n.a., not applicable since all participants were high-school students.

Step II: Independence of youth with CP compared with typically developing peers

Seventy-six youth with CP, representing 59% of the eligible population (36 females, 40 males), aged 16 ($n = 36$) and 17 ($n = 40$) years participated in the baseline assessment and were compared with the reference group of 103 typically developing age-matched youth (64 females and 39 males) who participated in the test-retest reliability study at baseline. The participants with CP were classified as having spastic unilateral ($n = 30$), spastic bilateral ($n = 37$), dyskinetic ($n = 8$) or ataxic ($n = 1$) CP, and covered all five GMFCS and MACS levels (Table 2). Forty-four (58%) of the participants with CP self-reported on the RTP, whereas 32 (42%) responded by caregiver proxy.

As can be seen in Table 3, the reference group was significantly more independent than the participants with CP in all the participation domains assessed in the RTP. All the participants with CP and nearly all the participants in the reference group attended general education and lived

Table 2: Characteristics of the youth with cerebral palsy at baseline ($n = 76$) and 3-year follow-up ($n = 44$).

	Baseline, n (%)	Follow-up, n (%)
Gender		
Male	40 (53)	23 (52)
Female	36 (47)	21 (48)
Type of CP ^a		
Spastic unilateral	30 (40)	19 (43)
Spastic bilateral	37 (49)	22 (50)
Dyskinetic	8 (10)	2 (5)
Ataxic	1 (1)	1 (2)
Gross motor function Classification System (GMFCS)		
GMFCS I	30 (39)	20 (46)
GMFCS II	17 (22)	10 (23)
GMFCS III	6 (8)	2 (5)
GMFCS IV	8 (11)	4 (9)
GMFCS V	15 (20)	8 (18)
Manual Ability Classification System (MACS)		
MACS I	20 (26)	10 (23)
MACS II	29 (38)	14 (32)
MACS III	8 (11)	6 (14)
MACS IV	7 (9)	5 (11)
MACS V	12 (16)	9 (20)
Epilepsy		
Yes	26 (34)	16 (36)
No	50 (66)	28 (64)
Gastrostomy		
Yes	13 (17)	6 (14)
No	63 (83)	38 (86)

^aCerebral palsy (CP) sub-type classified according to the Surveillance of Cerebral Palsy in Europe.

Table 3: Levels of independence according to the Rotterdam Transition Profile in 16–17 year-old youth with cerebral palsy (n = 76) and a reference group of age-matched typically developing peers (n = 103).

RTP – Independence	Youth with CP, n = 76				Reference group, n = 103				Comparison	
	phase 0 n (%)	phase 1 n (%)	phase 2 n (%)	phase 3 n (%)	phase 0 n (%)	phase 1 n (%)	phase 2 n (%)	phase 3 n (%)	z	p-Value ^a
Education and employment	n.a.	72 (95)	4 (5)	0 (0)	n.a.	103 (100)	0 (0)	0 (0)	2.348	0.019
Finances	35 (46)	29 (38)	12 (16)	0 (0)	7 (7)	61 (59)	33 (32)	2 (2)	5.368	<0.001
Housing	n.a.	76 (100)	0 (0)	0 (0)	n.a.	93 (90)	8 (8)	2 (2)	2.787	0.005
Intimate relationship	53 (75) ^b	9 (13) ^b	5 (7) ^b	4 (5) ^b	23 (23) ^c	12 (12) ^c	33 (33) ^c	32 (32) ^c	6.954	<0.001
Transportation	n.a.	40 (53)	14 (18)	22 (29)	n.a.	26 (25)	18 (18)	59 (57)	4.070	<0.001
Leisure	29 (38)	19 (25)	16 (21)	12 (16)	0 (0)	5 (5)	32 (31)	66 (64)	8.316	<0.001

RTP, Rotterdam Transition Profile; CP, cerebral palsy; phase 0, no experience; phase 1, dependent on caregivers; phase 2, orientation towards increasing independence; phase 3, more or less independent; n.a.: not applicable. ^aAnalysed with Mann-Whitney U Test, $p < 0.05$; ^bn = 71; ^cn = 101.

with their parents (phase 1). Approximately half of the participants with CP (54%) had their own pocket money (phase 0), compared with 93% of the reference group, of which 34% also had some type of work income or student grant (phases 2 and 3). While 20% of the participants with CP had experience with dating (phases 1 and 2) and 5% with sexual relationships (phase 3), the proportion for the reference group was 45% and 32%, respectively. The vast proportion (71%) of the participants with CP was transported by their caregivers (phases 1 and 2), whereas 57% of the reference group arranged their own transport (phase 3). While 37% of the participants with CP arranged leisure activities with peers outside of the home themselves (phases 2 and 3), 95% of the reference group did so.

Step III: changes in independence during the transition to adulthood at 3-year follow-up

Forty-four of the youth with CP (58%) participated in the follow-up 3 years later (23 males, 21 females) (Table 2). Twenty-eight of the participants were then 19 years of age and 16 were 20 years of age. The proportion of participants who self-reported (57%) and reported by proxy (43%) was similar to the baseline. No significant difference was noted between the participants at follow-up and those who dropped out on gender ($p = 1.0$), CP subtype ($p = 0.297$), GMFCS level ($p = 0.223$), MACS level ($p = 0.077$) or epilepsy ($p = 0.827$).

As shown in Table 4, the levels of independence changed significantly between the baseline and follow-up

Table 4: Levels of independence in 16–17 year-old youth with cerebral palsy according to the Rotterdam Transition Profile at baseline (n = 76) and 3-year follow-up (n = 44).

Independence (RTP)	Baseline, n = 76				3-year follow-up, n = 44				Comparison	
	Phase 0 n (%)	Phase 1 n (%)	Phase 2 n (%)	Phase 3 n (%)	Phase 0 ^a n (%)	Phase 1 n (%)	Phase 2 n (%)	Phase 3 n (%)	z	p-Value ^b
Participation										
Education/employment	n.a.	72 (95)	4 (5)	0 (0)	4 (9)	22 (50)	15 (34)	3 (7)	2.428	0.015
Finances	35 (46)	29 (38)	12 (16)	0 (0)	5 (12)	14 (32)	5 (11)	20 (46)	4.339	<0.001
Housing	n.a.	76 (100)	0	0	n.a.	32 (73)	4 (9)	8 (18)	3.176	0.001
Intimate relationship	54 (75) ^c	92 (12) ^c	52 (7) ^c	4 (5) ^c	26 (59)	7 (16)	2 (5)	9 (21)	2.754	0.006
Transportation	n.a.	40 (53)	14 (18)	22 (29)	n.a.	17 (39)	8 (18)	19 (43)	1.758	0.079
Leisure	29 (38)	19 (25)	16 (21)	12 (16)	15 (34)	2 (5)	13 (30)	14 (32)	1.628	0.104
Health services										
Care needs	n.a.	42 (55)	34 (45)	0	na	19 (43)	14 (32)	11 (25)	3.900	<0.001
Services and assistance	n.a.	61 (80)	12 (16)	3 (4)	n.a.	26 (59)	9 (21)	9 (20)	3.127	0.002
Rehabilitation services	n.a.	51 (67)	20 (26)	5 (7)	n.a.	11 (26) ^d	12 (29) ^d	19 (45) ^d	4.427	<0.001

RTP, Rotterdam Transition Profile; Phase 0, no experience; phase 1, dependent on caregivers; phase 2, orientation towards independence; phase 3, independent; n.a., not applicable. ^aPhase 0 added following comments from the participants; ^bComparison between baseline and follow-up, analyzed with Wilcoxon Signed Ranks test, $p < 0.05$; ^cn = 72; ^dn = 42.

in all domains except transportation and leisure. At follow-up, 18% ($n = 8$) of the young adults with CP lived independently (phase 3), 34% ($n = 15$) had vocational training (phase 2) and 50% ($n = 22$) still attended high school (phase 1). A total of 9% ($n = 4$) did not attend education or work activities (phase 0), and 7% ($n = 3$) had paid work (phase 3). Moreover, 46% ($n = 20$) had become financially independent (phase 3), although 44% still had no pocket money or clothing allowance (phases 0 and 1). Regarding intimate relationships, 59% ($n = 26$) still had no experience with dating, yet 21% ($n = 9$) had sexual relationships (phase 3). In terms of transportation, 39% ($n = 17$) were still transported by their caregivers (phase 1) and a similar proportion (34%) did not arrange social activities with peers by themselves (phase 0).

With respect to health care services, the parents formulated the care needs (phase 1; 55%) or they did so together with the youth (phase 2, 45%) at baseline. Yet, at follow-up, 25% ($n = 11$) formulated their own care needs (phase 3). Whereas 4% ($n = 3$) applied for services and

aids independently at baseline (phase 3), 20% did so at follow-up.

Independence among youth with CP who self-reported or reported by proxy

When comparing participants who self-reported on the RTP at baseline with those who proxy-reported, no significant differences were noted regarding gender ($\chi^2 = 0.00$, $p = 1.0$) or MACS level ($z = -1.824$, $p = 0.68$). However, a greater number of participants were classified at GMFCS levels I and II among those who self-reported ($p < 0.001$) and a larger proportion of participants who proxy-reported had spastic bilateral CP ($p = 0.013$), epilepsy ($p < 0.001$) and/or gastrostomy ($p = 0.013$).

The results from the comparison between participants who self-reported or proxy-reported are shown in Table 5. In the education and employment domain at baseline, participants who self-reported more often had

Table 5: Comparison of levels of independence between youth who self-reported and youth who reported by proxy on the Rotterdam Transition Profile at baseline and 3-year follow-up.

Independence (RTP)	Baseline ^a				Comparison ^b		3-year follow-up ^c				Comparison ^b	
	Phase 0 n (%)	Phase 1 n (%)	Phase 2 n (%)	Phase 3 n (%)	z	p-Value	Phase 0 ^d n (%)	Phase 1 n (%)	Phase 2 n (%)	Phase 3 n (%)	z	p-Value
Education/employment					2.06	0.04					1.35	0.18
Self-reported	n.a.	40 (91)	4 (9)	0 (0)			1 (4)	12 (48)	10 (40)	2 (8)		
Proxy-reported	n.a.	32 (100)	0 (0)	0 (0)			3 (13)	10 (53)	5 (26)	1 (5)		
Finances					5.31	<0.001					0.52	0.60
Self-reported	9 (20)	23 (52)	12 (27)	0 (0)			2 (8)	7 (28)	5 (20)	11 (44)		
Proxy-reported	26 (81)	6 (9)	0 (0)	0 (0)			3 (16)	7 (37)	0 (0)	9 (47)		
Housing					0.00	1.0					0.55	0.59
Self-reported	n.a.	44 (100)	0 (0)	0 (0)			n.a.	19 (76)	2 (8)	4 (16)		
Proxy-reported	n.a.	32 (100)	0 (0)	0 (0)			n.a.	13 (68)	2 (11)	4 (21)		
Intimate relationship					3.83	<0.001 ^e					2.55	0.01
Self-reported	23 (58)	8 (20)	5 (12)	21 (47)			11 (44)	4 (16)	2 (8)	8 (32)		
Proxy-reported	31 (97)	1 (3)	0 (0)	0 (0)			15 (79)	3 (16)	0 (0)	1 (5)		
Transportation					6.20	<0.001					3.66	<0.001
Self-reported	n.a.	10 (23)	13 (30)	21 (47)			n.a.	6 (24)	1 (4)	18 (72)		
Proxy-reported	n.a.	31 (97)	1 (3)	0 (0)			n.a.	11 (58)	7 (37)	1 (5)		
Leisure					6.95	<0.001					3.32	0.001
Self-reported	2 (45)	14 (32)	16 (36)	12 (27)			5 (20)	0 (0)	7 (28)	13 (52)		
Proxy-reported	27 (84)	5 (16)	0 (0)	0 (0)			10 (52)	2 (11)	6 (32)	1 (5)		
Care needs					6.65	<0.001					4.35	<0.001
Self-reported	n.a.	10 (23)	34 (77)	0 (0)			n.a.	4 (16)	10 (40)	11 (4)		
Proxy-reported	n.a.	32 (100)	0 (0)	0 (0)			n.a.	15 (79)	4 (21)	0 (0)		
Services and assistance					3.65	<0.001					3.66	<0.001
Self-reported	n.a.	29 (66)	12 (27)	3 (7)			n.a.	9 (36)	7 (28)	9 (36)		
Proxy-reported	n.a.	32 (100)	0 (0)	0 (0)			n.a.	17 (89)	2 (11)	0 (0)		
Rehabilitation services					1.91	0.06					0.39	0.69 ^f
Self-reported	n.a.	25 (57)	17 (39)	2 (4)			n.a.	4 (16)	9 (38)	11 (46)		
Proxy-reported	n.a.	26 (82)	3 (9)	3 (9)			n.a.	7 (39)	3 (17)	8 (44)		

RTP, Rotterdam Transition Profile; Phase 0, no experience; phase 1, dependent on caregivers; phase 2, orientation towards independence; phase 3, independent; n.a., not applicable. ^aSelf-report, $n = 44$; Proxy-report, $n = 32$; ^bComparison between self-reported and proxy-reported data, analyzed with Wilcoxon Signed Ranks test, $p < 0.05$. ^cSelf-report, $n = 25$; Proxy-report, $n = 19$; ^dPhase 0 added following comments from the participants; ^eSelf-report, $n = 40$; ^fSelf-report, $n = 24$; Proxy-report, $n = 18$.

some type of work activity and were financially more independent than those who proxy-reported. At follow-up, however, the difference between the groups was no longer significant. All participants lived with their parents at baseline, and although some participants had transitioned into independent living at follow-up, no significant difference between the two groups was found. In intimate relationships, participants who self-reported were significantly more experienced than those who proxy-reported, both at baseline and at follow-up. Participants who self-reported were also more independent than those who proxy-reported in transportation, in arranging leisure activities with peers and in describing health-care and service needs, both at baseline and at follow-up. For the rehabilitation services domain, no significant difference between those who self-reported and proxy-reported was evident either at baseline or at follow-up.

Discussion

The participants with CP in our study represented 59% of the identified population of 16- and 17-year-old youth with CP in the investigated region at baseline. The cohort was representative of the total population of people with CP regarding CP subtypes at both baseline and follow-up, yet included a somewhat lesser proportion of people classified at GMFCS and MACS level I [27]. One strength of the study regarding external validity, however, is the inclusion of youth with CP and an intellectual disability, which is in contrast to former studies that only included youth with typical intellectual functioning [23].

As illustrated in Table 3, the difference between youth with and without CP regarding education and employment was mainly due to four youth with CP who had vocational training as a substitute for general education (phase 2) at baseline. In Norway, there is a legal right to attend 3 years of high school (5 years for persons with disabilities), which is a likely explanation to the similar results for the two groups (Table 3). After the 3-year follow-up period, a significant shift towards work placement or a paid job in the youth with CP was noted, even among those who proxy-reported and thus had a more complex disability (Tables 4 and 5). Four youth with CP did not participate in either education or work at follow-up; hence, we included a phase 0 also for the education and employment domain. Although several people with disabilities get sheltered work, earlier studies that have described unfavourable education and employment rates for young adults with CP show that the change towards employment is likely not enough to catch up with their typically developing peers

[3, 16, 28]. This may be illustrated by national data from Statistics Norway, which shows that 44% of people with disabilities were employed in 2018 compared with 74% of the general population [29]. The transition from general education to employment implies a major cultural change with greater autonomy from parents, and therefore (re)habilitation services must provide sufficient support during this phase to prevent occupational disability [3].

The transition to higher education or work is often paralleled by the transition to independent living and financial independence. At baseline, all the youth with CP lived with their parents, as did also most of the reference group (Table 3). However, during the 3-year follow-up period, the percentage of youth with CP that either lived independently or sought independent housing changed from 0% at baseline to 27% 3 years later. Whereas the typically developing youth took greater responsibility for their financial situation than the youth with CP at baseline, almost 50% of those with CP were financially independent at follow-up (Table 4). Interestingly, the shift in housing and financial independence among youth with CP was particularly evident for those who proxy-reported. This finding may reflect the fact that many youth with chronic and complex disabilities often move into housing with individually adapted service options, receive more disability benefits and/or perform sheltered employment compared with individuals with a less complex disability. A Norwegian survey from 2004 showed that 46% of adults with CP (mean age 34 years) had disability benefits [16], and as our study indicates, this may have started at 18 years of age for some participants, making even those with a more complex disability financially independent.

Nevertheless, many of the youth with CP who self-reported may also be in need of personal assistance and a flat with a universal design to live independently. This may be a larger process with a longer timeline than our study provided. The young people with CP and more complex disabilities may still be in need of a guardian to, for example, pay bills and do shopping, even though they have their own income. This latter need is an aspect that is not reflected in the finances domain of the RTP.

Independent access to transportation may be an important factor for social participation, as social relationships among young people are often shaped by informal meetings and unplanned activities at arenas where caregivers are not present. Compared with the reference group, only a small proportion of the youth with CP arranged their own transport at baseline and were less independent than their peers in “leisure activities” and “intimate relationships”. Despite the importance of friends and peer relations for young people, it was discouraging to find that the

youth with CP were still largely dependent on their caregivers for leisure participation at 19 and 20 years of age, and many of the young adults with CP were dependent on others for transportation still at follow-up (Table 4). Our results illustrate how dependence on others for transportation may be a potential environmental barrier for leisure and social participation [30]. Since the eligible age to attain a driver's licence in Norway is 18 years, it could not be expected that the participants should be independent drivers at baseline. Nevertheless, the Norwegian Equality and Anti-Discrimination Act states the obligation of our society to actively promote universal design in public transportation [31], which might potentially enhance independent transportation for young people with CP. However, Statistics Norway documents that among people with physical disabilities, 64% have problems using public transport [32].

The fact that only a minor proportion of the youth with CP had been involved in dating and sexual relationships at both baseline and follow-up (phases 2 and 3) may again be linked to the limited independence that was found for transportation and leisure activities. In typically developing Norwegian youth, more than half of the population has their sexual debut by 18 years of age [33]. Developing privacy and romantic relationships may be particularly challenging for youth with a disability when their social participation is hindered by dependency on caregivers. Although intimate relationships increased among the participants with CP between baseline and follow-up, their participation in romantic relationships was still lower at follow-up than for their non-disabled peers at baseline. Our findings of restricted intimate relationships support earlier results from a Dutch study, which also showed that youth with CP present with the same sexual interests as their peers [34]. Personal factors are shown to be particularly important for developing social and intimate relationships, although both physical and social environmental factors (e.g. peers, attitudes from others, transportation and access to social and dating arenas) may also influence personal factors and thereby impact social and intimate relationships indirectly [35]. Sexuality is only very briefly discussed in rehabilitation programs, and a Dutch survey showed that among as much as 90% of the youth, sexuality had never been addressed by the rehabilitation teams [36]. For preventing sexual difficulties and promoting participation within all life areas for young people with CP, health care professionals ought to open-mindedly address sexuality issues and provide assistance on how and where to retrieve useful information.

In addition to the discrepancy between youth with CP and their typically developing peers, a discrepancy was

noted between the youth with CP who self-reported and those who reported by a proxy. The decision regarding the participants' ability to self-report was based on the parents' and the research team's clinical judgements, as no other information was available regarding their cognitive functioning. In accordance with previous research that has illustrated how transitional delay may be associated with motor functioning, educational levels and specific cognitive and performance difficulties etc. [23], the youth who self-reported in our study were generally more independent than those who proxy-reported at baseline. However, at follow-up, the difference was no longer significant in the domains in which the welfare system provides services.

For both the self-reporting and the proxy-reporting participants, a significant shift towards more independence in all domains at follow-up was noted; yet, in all other participation domains than housing and finances, the improved independence was mostly seen among the group who self-reported. For the health services domains, however, there was no significant difference between the two groups, and the results illustrate how young adults with CP, still in their early twenties, depend on their caregivers for describing care needs and applying for services and aids, regardless of the complexity of their disability. Whether this latter need is due to a lack of competency among the young adults with CP, complicated and bureaucratic procedures or parental resistance to "let go" of their youngsters remains to be addressed in future research.

The "rehabilitation services" domain of the RTP is somewhat different from the two other health services domains. Whereas the three phases of "care needs" and "services and assistance" represent levels of increasing independence, the phases of "rehabilitation services" reflect whether the young person has consulted pediatric (re)habilitation care (phase 1) or not (phase 2), or consulted the adult (re)habilitation services (phase 3) during the past year. It cannot be interpreted from these phases whether this is due to the individual not being in need of such services or the organization of services as well as to what extent the person independently consults such services. Only 7% of the youth with CP had consulted adult services (phase 3) at baseline, with a shift to 45% at follow-up. To obtain a score of phase 3 there must have been a perceived *need* to consult adult (re)habilitation services, which might not have been the case for many participants at baseline (e.g. if their needs were met in the pediatric services).

Valid and reliable assessment tools are important to acquire more knowledge of the transition experience. Along with the earlier Dutch validity study [23], our results

support the use of the RTP as a sound multidimensional tool to describe independence during the transition into young adulthood, although more research on its psychometric properties is still needed [24]. However, based on the pilot testing of the RTP, we found it necessary to include a phase 0 for the leisure domain, and our results support this adaptation since almost 40% of the youth recorded phase 0 for this domain. Following comments from four participants in the follow-up study who neither participated in education nor employment activities, we included a phase 0 also for the education and employment domain. If the RTP is to be used within the population of youth with CP regardless of cognitive ability and with a complexity of disabilities and needs, such adaptations of the questionnaire are recommended.

On the other hand, there might be limitations to the applicability of the RTP related to various cultural contexts [37]. In Western cultures, independent participation and autonomy are often viewed as evidence of a successful transition process, for example, when a young girl finishes college and starts working. In some non-Western cultures, however, college education may not be accessible for all females and a more important transitional step into adult roles may be to get married and to create a family. Furthermore, transition into adulthood is not a linear process, but rather individual processes where people may proceed through the various phases at different points in life. Thus, the use of the RTP should be considered with respect to cultural sensitivity, and results from the RTP must be viewed as descriptions of phases of independence within the specific context rather than normative levels of a universal standard [37].

A life-course approach to developmental and service transition recognizes that everyone relies on support at different stages and transitions during life and emphasizes the need to differentiate services during these periods according to functional levels and complexity of needs [8]. Several studies have shown how interactions among personal and environmental factors are important for a successful transition and support a life-course approach that is non-categorical regarding diagnosis [5, 6, 38]. Structured services that aim to respectfully and successfully guide young people with CP through the transition phase between paediatric and adult (re)habilitation services are needed, and the Ontario Best Practice Guidelines provide suggested strategies for such services by the following key principles: (i) collaboration between sectors and services, (ii) building capacity among people and communities, (iii) the role of a “community navigator”, (iv) providing information and education to everyone involved and (v) evaluation of transitional

service programs [8]. For a successful transition across administrative and professional borders, these guidelines should form the basis of any transition or follow-up program between paediatric and adult (re)habilitation care. To be able to provide the right support to the right youth at the right time, systematic mapping of the transition phases over time is necessary. The RTP has been pilot tested in the CPRN protocol for the youth [39], and as the oldest participants in the CPOP turns 18 years in 2020, it is considered to be part of the CPOP protocol for adults.

Our findings that young people with CP were less independent during the transition to adulthood compared with their non-disabled peers are in line with previous research and illustrate the need for a life-course approach [3, 19, 23]. Despite positive changes in participation during a 3-year transition period, significant restrictions were found on participation among the young adults with CP in many domains of the RTP. The identified differences between the youth with CP and their non-disabled peers illustrate the need for a life-course approach to transition. All human beings are dependent on others and all young people depend on support from significant others during the transition process. For many young people with CP and complex disabilities, participation in various life situations may be strongly facilitated by the support from others, as they may never be able to live autonomous lives without extensive assistance [3, 7, 9, 16, 23, 28].

The limitations of this study are primarily related to the low response rate at the 3-year follow-up. Despite major efforts to include a geographical age cohort, 32 participants (41%) were lost at follow-up and this limits the external validity of the results. No significant differences, however, were noted between the groups with CP at baseline and follow-up, although there was a somewhat larger proportion classified at lower functional levels at follow-up. Generally, a somewhat smaller proportion of youth was classified at GMFCS level I in our study than expected in a population [27]. Furthermore, the fact that the follow-up assessment was performed as a postal survey while the baseline assessment was an interview might also have influenced the response rate and the answers. The reference group of typically developing youth was not included in the follow-up study; hence, we do not know whether the difference between 16 and 17-year-old youth with CP and their non-disabled peers persists into adulthood. However, a visual comparison between the RTP scores of the 19–20-year-old youth with CP and the 16–17-year-old non-disabled peers showed less independence among the older youth with CP, particularly in the social domains. Comparison with data from Statistics Norway furthermore confirms these differences.

Conclusions

In conclusion, our results show that youth with CP increased their independence during a 3-year transition period, although they were significantly less independent than their non-disabled peers at 16–17 years of age. Our findings show that the youth with CP who self-reported on the RTP showed greater independence than those with more complex disabilities who proxy-reported, thus illustrating the importance of distinguishing between the service needs of subgroups. The study underlines the need for a life-course approach on transition periods, with focus on both personal and environmental factors that facilitate autonomy of participation throughout life. Goal-directed, continuous and coordinated services and support during all the transition phases are needed, both to promote developmental transitions and service or system transitions. To close the service gap between pediatric and adult follow-up of people with CP in Norway, work is in progress to include adults in the CPOP with tailored surveillance of their specific needs.

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