INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
2013, Vol. 51, No. 3, 176–189

DOI: 10.1352/1934-9556-51.3.176

Transferring Young People With Profound Intellectual and Multiple Disabilities From Pediatric to Adult Medical Care: Parents' Experiences and Recommendations

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Abstract

Many children with profound intellectual and multiple disabilities (PIMD) now reach adulthood. The aim of this study was to elicit parents' experiences with the transfer from pediatric to adult medical care. A convenience sample of 131 Dutch parents of young people with PIMD (16–26 years) completed a web-based questionnaire. Twenty-two percent of the young persons were still in pediatric care; 22% of the others had no care coordinator, although their health needs were the same. Parents valued the care provided by the pediatrician, and wished to see it continued. They were critical about how they had been prepared for transfer to adult care. Parents provided suggestions to improve transitional care, such as early start, information provision, and a joint consultation between pediatric and adult care.

Key Words: *medical care; transition; adolescent; parents; severe generalized cerebral palsy; intellectual disability; unmet needs*

People with profound intellectual and multiple disabilities (PIMD) are, according to the definition of Nakken and Vlaskamp (2007), characterized by a maximum developmental age of 2 years or an intellectual quotient of less than 30 *and* a Gross Motor Functioning Classification Scale (GMFCS) Level IV or V (Palisano et al., 1997; Palisano et al., 2000). The condition is also referred to as severe motor and intellectual disability (SMID), severe neurological impairment and intellectual disability (ID) and "severe generalized cerebral palsy." In the literature, PIMD is the most frequently used term. The most recent statistics for the Netherlands estimated the number of children (0–18 years) with PIMD at 2,000; that of adults at 2,700 (Health Care Inspectorate IGZ, 2000). However, the actual numbers are probably higher, since the estimations only include children visiting special day care and school facilities, and adults in residential care.

The International Classification of Functioning, Disability, and Health (ICF) (World Health Organization [WHO], 2001 provides a framework for functioning and disability in which problems in body function or structure are classified as impairments that affect activities and participation. Clinical experience and literature suggest a high rate of comorbidities in people with PIMD, independent of the etiology of the condition. Frequently reported comorbid impairments include epilepsy, spasticity, visual and hearing impairments, recurrent airway infections, feeding and growth problems, gastro-esophageal reflux, constipation, osteoporosis, scoliosis, and contractures (Liptak et al., 2001; Oeseburg, Dijkstra, Groothoff, Reijneveld, & Jansen, 2011; Seddon & Khan, 2003; Sullivan et al., 2000; van der Heide, van der Putten, van den Berg, Taxis, & Vlaskamp, 2009). Active health management is needed to prevent, detect, and treat these impairments, especially because the persons in question cannot report them (Oeseburg et al., 2011; van Schrojenstein Lantman-de Valk & Walsh, 2008). Due to the complex nature of the neurological impairment, the profound intellectual disability, and the comorbidities, these persons usually receive medical care from various specialists in hospitals. Children with PIMD consult a medical specialist with a mean of 7.5 times a year, and half of them are hospitalized 1.5 times in one year, mostly due to

DOI: 10.1352/1934-9556-51.3.176

epilepsy and pneumonia. On average, between three and four different specialists are involved in their care: these may include a pediatrician, a neurologist, a rehabilitation specialist, an orthopedic surgeon, and possibly an ophthalmologist and an ear, nose, and throat (ENT) specialist (Sarneel et al., 2005). Good coordination of care therefore seems crucial. In the Netherlands, it is usually a pediatrician who coordinates care for patients under 18 years old, but there is no guideline regarding to whom and how the pediatrician should transfer patients from pediatric care to adult care.

Due to improved neonatal and general medical care, many children with PIMD now reach adulthood (Strauss, Brooks, Rosenbloom, & Shavelle, 2008; Westbom, Bergstrand, Wagner, & Nordmark, 2011). Health professionals therefore face the challenge of providing continued, adequate medical care for these persons. As early as 1965, Pearson recognized already that "with the larger numbers of the profoundly retarded and physically handicapped who are surviving infancy and having increasing longer lifespan … we must become more concerned with the medical needs of the rapidly rising population of adult retarded persons" (p. 916). Nevertheless, this topic has received relatively little attention in the literature until recently. From the growing body of literature on transition of care for children with special health care needs in general, we know that the transition to adulthood and the transfer to adult care is challenging, not only to the children, but also to their parents and health care providers. In the United States, 50–66% of adults with hydrocephalus and spina bifida received ad hoc and fragmented medical care (Simon et al., 2009). Health care providers were unable to recognize surgical or associated complications of hydrocephalus diagnosed and treated in childhood or could not help prevent secondary conditions, resulting in increased morbidity and mortality. Simon and colleagues (2009) therefore recommended setting up integrated adult health care teams and having adult health care providers collaborate with pediatric specialists. Binks, Barden, Burke, and Young (2007) reviewed 149 studies about transition of adolescents with cerebral palsy and spina bifida from 1990 to 2006. They identified such barriers as: difficulty of the pediatric professionals "to let go," reluctance of adolescents and parents "to move on," and inexperience with and limited resources to take care of the complex health needs. Five key elements for positive transition were identified: (1) good preparation, (2) flexible timing, (3) efficient care coordination, (4) joint transition clinics, and (5) sufficient interest from adult-centered health care providers.

Several studies reported on how parents of children with ID experienced their child's transition to adulthood and to adult care (Bhaumik et al., 2011; Griffith et al., 2011; Udwin, Howlin, Davies, & Mannion, 1998; Young et al., 2009). It appeared that most parents were not satisfied with information provision, coordination of care, access to adult health care providers, and the latter's awareness of the health care needs of their offspring. In the Netherlands, little is known about what happens with young adults with PIMD after they leave pediatric care. Even though access to health care is ensured through universal coverage of health insurance, only a few multidisciplinary teams provide coordinated medical care for adults with specific syndromes and/or motor disability, combined with ID. Also, specific transition experiences of their parents have not been reported.

The aim of the present study was to explore (1) parents' experiences with and their appreciation of different health care services in a sample of young people with PIMD, and (2) to collect parents' recommendations for transfer to adult medical care.

Methods

Recruitment and Participants

Parents of young people with PIMD were invited to fill out a web-based questionnaire in the Dutch language. The inclusion criteria were having a child aged 16–26 years with a maximum developmental age of 2 years (or an IQ below 30) and a GMFCS Level IV or V.

We targeted three hospitals and seven institutions in the South-Holland South region, covering approximately one third of the total Dutch population, that deliver health care, housing, day care and/or special education to people with PIMD. Professionals searched their databases for clients who fulfilled the criteria of PMID and age, and sent out letters to the parents of these clients providing information about the study and the web link to the questionnaire. Furthermore, a Dutch national patient organization (BOSK) sent letters inviting parents to participate in the study (n = 203). In total, 583 letters were distributed. To ensure anonymity of the participants, the researchers did not receive their names and addresses. Consequent-

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ly, they could not send individual reminders. As a general reminder, Dutch patient organizations in the field of PIMD informed their members about the study on their websites and in their newsletters.

Measurements

Due to a lack of validated instruments for our purpose, we developed a web-based questionnaire assessing patient and parent characteristics, utilization of health care, parents' experiences with the health care for their child, and the preparation for the transfer to adult care. The questionnaire was based on the results of a qualitative pilot study in which five parents were interviewed in depth about their experiences with the transfer of their offspring to adult care (Bruin, 2008). The draft questionnaire was adapted after pilot testing with one mother, who was not invited to fill-out the final questionnaire during the formal study.

Domains of the Questionnaire

Characteristics of people with PIMD. Characteristics of people with PIMD included gender, age, type of day care activities, and living situation. We also collected responding parents' gender, educational level, and membership of a patient organization.

Health and functional status. Parents were asked to enter the underlying diagnosis and to select the current impairments from a long list. They were also asked to score the Katz Index of Independence in Activities of Daily Living (the Katz ADL). By measuring performance in bathing, dressing, toileting, transferring, continence, and feeding, this index assesses the ability to perform activities of daily living independently (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). We used a scale format with four options for six domains, in which a score of four indicates being fully dependent on others. The Katz ADL has good psychometric properties (Shelkey & Wallace, 2008).

Health care utilization. Parents were asked which type of physician currently coordinated their child's care and which other medical specialists, if any, were currently involved.

Experiences and satisfaction with health care. Based on a study by Bruin (2008) we constructed an eight-item scale intended to measure how parents perceive provision of care by the pediatrician (both at present and in the past). This Pediatric Physician Evaluation Scale addresses communication issues, expertise, skills, physician–patient relationship, and availability and is scored on a five-point Likert-scale (1 = totally disagree; 5 = totally agree) (Table 1). Factor analysis (maximum likelihood, oblique rotation) proved unidimensionality; the Cronbach's alpha was .89, indicating good internal consistency. Furthermore, parents were asked to rate their appreciation of their pediatrician or their current coordinating physician on a Visual Analogue Scale (VAS), range 1–10.

Feelings about and preparation for transfer to adult care. Three statements, based on the themes identified the qualitative pilot study (Bruin, 2008), were presented to parents whose children had

Table 1
Self-Constructed Scales Evaluating Pediatrician Care and Preparation for Transfer

A. Pediatrician Physician Evaluation Scale
1. The pediatrician communicates/communicated well with me.
2. The pediatrician pays/paid attention to the experiences and problems of my child.
3. The pediatrician has/had enough knowledge to treat my child adequately.
4. The pediatrician has/had enough skills to treat my child adequately.
5. The pediatrician deals/dealt with my child pleasantly.
6. I notice that my child responds/responded well to the pediatrician.
7. The pediatrician has/had enough time for my child.
8. The pediatrician is/was accessible in case of acute problems and questions.
B. Appreciation of Preparation for Transfer Scale
a. I received adequate information from the pediatrician regarding adult care.
b. I was emotionally prepared by the pediatrician regarding adult care.
c. I have no comments on the pediatrician's preparation for the transfer to adult care.

Note. All items were scored on a Likert-scale from 1–5: 1 = totally disagree; 5 = totally agree.

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already transferred: "I felt let down by pediatric care," "I was ready to leave pediatric care," and "The transfer should have been smoother." Also, parents' appreciation of the preparation for transfer by the pediatrician was assessed in another three-item scale using a five-point Likert format (1 = totally disagree; 5 = totally agree). This self-constructed Appreciation of Preparation for Transfer scale (Cronbach's alpha .96) was presented only to those who were still in pediatric care, and to parents whose children had been treated by a pediatrician before (Table 1).

Open questions. Two open questions were included in the questionnaire: (1) Do you have any suggestions for the improvement of transition in care and (2) Could you state any preferences for future or current adult care?

Ethics

The Medical Ethical Committee of the Erasmus Medical Center Rotterdam approved the study protocol. All parents received information about the study and researchers had no access to personal and medical records.

Data Analysis

Descriptive statistics were used to summarize the basic characteristics of the young persons with PIMD and their parents, to show the frequencies or means of impairments, ADL restrictions, utilization of health care, and the appreciation of the contact with the pediatrician. In case of skewed distribution, the median score is given with the Inter Quartile Range (IQR). To analyze the different routes children can follow on the brink of adulthood, we created three groups: those whose care was coordinated by the pediatrician, those whose care was coordinated by another physician, and those who had not been assigned a coordinating physician. Differences between these three groups were tested by chi-square tests (nominal) or ANOVAs (scale). For ANOVA, post hoc comparisons were conducted using the Tukey HSD test. Scale differences between two groups were tested with *t*-tests. Differences in the general appreciation of the care provided by the former pediatrician and the current specialist were analyzed with paired *t*-tests. All quantitative analyses were performed with SPSS 17.0.

The responses to the two open questions were subjected to qualitative content analysis (Graneheim & Lundman, 2004). The first step in the analysis was the identification of meaning units (i.e., constellations of words or statements that relate to the same central meaning). Two researchers (KBdH, AvS) independently coded the meaning units. In the second step, the codes were sorted into themes. Then, the researchers compared and modified the themes until consensus was reached on two central themes demonstrating parents' major concerns in the transitional phase. Parents' suggestions for improvement were grouped into three other themes: care processes, interactions, and facilities.

Results

Sample

Of the 583 invited parents, 137 (24%) responded. Six respondents were excluded because their child did not meet the inclusion criteria for having a PIMD ($n = 2$), or was too young ($n = 4$). Hence, the study sample consisted of 131 participants. The majority (62%) lived in the catchment area of our university hospital. Response analysis revealed that response rates were highest among parents recruited through the hospitals (41%) and the patient organizations (34%). The mean age of the people with PIMD was 20.4 years ($SD = 2.9$). Other characteristics and those of their parents are detailed in Table 2. The most frequently reported etiological diagnoses were congenital brain disorder (28%), perinatal hypoxia (24%), and severe epilepsy (19%). For all Katz ADL domains, the young persons were highly dependent upon others (*median* = 3.83, *IQR* = 3.17–4.00, *range* = 1–4).

Coordinating physician and current medical care. Seventy-eight percent of all parents reported that a pediatrician had been or still was their coordinating physician. The pediatrician was still the coordinating physician for 29 (22%) persons of the total group; a variety of other specialists were labeled as the coordinating physician for another 56%. One in five parents (22%) reported that currently no physician coordinated their child's health care (Figure 1). Parents usually left pediatric care when their child was around 18 years old. Those who were still with the pediatrician were younger ($M = 18.38$ years, $SD = 1.99$) than those who had no coordinating physician ($M = 20.31$, $SD = 2.69$) and those who had other physicians coordinating their care ($M = 21.34$, $SD = 2.85$), $F(2, 125) = 12.91$, $p < .001$.

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Table 2
Characteristics of Young Persons With PIMD

	n	%
Age*		
16–18 years	19	15
18–26 years	109	85
Gender		
Male	70	53
Female	61	47
Fully dependent upon others in Activities of Daily Living		
Mobility	75	57
Eating and drinking	87	66
Going to the toilet	92	70
Being incontinent	96	73
Getting dressed	108	82
Washing/bathing	114	87
Living situation		
Living with parents/other caregivers	81	62
Living in institution	33	25
Living in private, small-scale initiative	17	13
Day care activities		
School	22	17
Day care center for children	25	19
Day care center for adults	78	60
No day care, stays at home	6	4
Hospital admissions in past 5 years*		
None	51	40
1–3 times	59	46
>3 times	18	14
Gender of parent who completed the questionnaire**		
Male	28	22
Female	101	78
Educational level of parent**		
Lower/middle	65	50
Higher	64	50
Member of patient organization (yes)	95	73

Note. The total number of respondents was 131; *missing: $n = 3$; **missing: $n = 2$.

Impairments. Figure 2 shows the young persons' impairments as reported by the parents. Epilepsy (70%) and spasticity in all four limbs (57%) ranked highest. The mean number of impairments was 4.66 ($SD = 2.76$), ranging from 0 to 12. Only four parents reported no major impairments. The number of impairments did not differ between the three groups mentioned above, $F(2, 128) = 0.43$, $p = .65$.

Health care utilization. On average, 2.47 ($SD = 1.45$) different specialists had been involved in the patients' medical treatment in the past year. Mean numbers of medical specialists involved in current care did not differ between the three groups, $F(2, 128) = 1.99$, $p = .14$) (Table 3). Not surprisingly, type of specialist most frequently involved in current care differed between the groups. In the group whose care was coordinated by the pediatrician, this specialist was more frequently involved in care than in the other groups, $\chi^2(2, N = 131) = 53.51$, $p < .001$. Also, the pediatric neurologist was more frequently involved in this group, $\chi^2(2, N = 131) = 19.59$, $p < .001$.

Appreciation of Care

Overall, parents were satisfied with the former and current care provided by the pediatrician. Level of satisfaction did not differ between the three groups, both in terms of the VAS-score, $F(2, 82) = 1.94$, $p = .15$, and the Pediatric Physician Evaluation Scale scores, $F(2, 85) = 0.54$, $p = .59$. (Table 4)

Almost half of the parents (47%) of children now in adult care felt that their current coordinating physician was capable of taking over care from the pediatric department, while 33% took a neutral stance, and 20% disagreed. Parents who had already left pediatric care had less appreciation for their current coordinating physician ($M = 7.04$, $SD = 1.63$) than for their former pediatrician ($M = 7.98$, $SD = 1.21$), paired $t(46) = 3.04$, $p = .004$ (Table 4).

Preparation for the transfer to adult care. The mean score on the Appreciation of Preparation for Transfer (by the pediatrician) scale was precisely in the middle: 7.83 ($SD = 3.06$, theoretical range 3–15). In particular, the items on information provision and the emotional impact of the transfer were scored low. There were no differences between the three groups, $t(59{,}940) = 0.01$, $p = .99$ (Table 4).

Two thirds of the parents whose child was still treated by the pediatrician had not yet been prepared for transfer to adult care. For 21% of all

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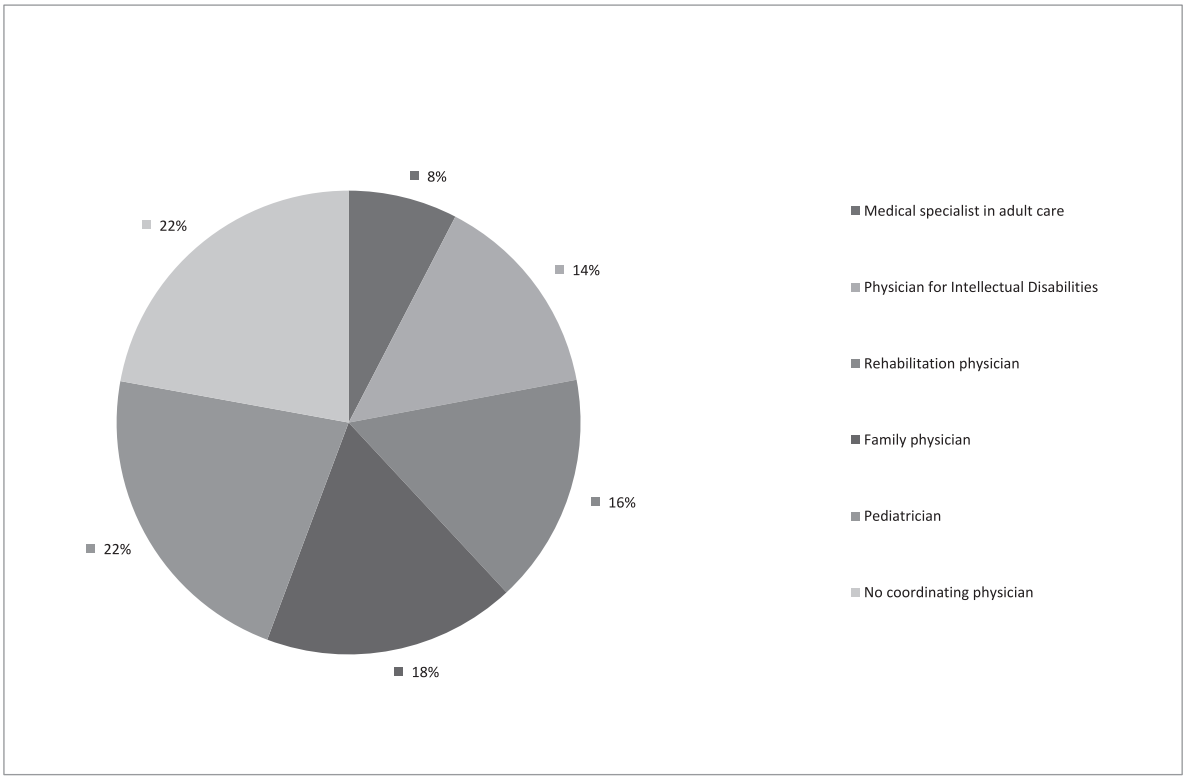

Figure 1. Coordinating physician of the young person with PIMD (%).

parents whose child had completed the transfer, preparation had mostly consisted of the simple announcement of the impending transfer. Of the parents who did not have a coordinating physician, 28% felt there had been no preparation at all.

Forty out of 67 (60%) parents disagreed with the statement "I feel/felt ready to leave pediatric care," 12 (18%) agreed, and the rest were neutral. Of the parents whose child had been transferred to adult care, 35% agreed with the statement "I felt let down by the pediatrician," while 43% disagreed. Still, half of the parents felt that the transfer should have been smoother. Five parents reported that a joint consultation of the pediatrician and the adult physician had taken place. Most parents who had left pediatric care confirmed that the pediatrician had transferred their child's medical history to adult care, but only 13 parents had actually received a copy.

Parents' Opinions and Wishes

Eighty-six percent of the parents responded to the open question: "What are your wishes regarding future care for your child?" The qualitative content analysis revealed two major themes related to parents' preferences and concerns.

Continue care (like it used to be) with the pediatrician was the first theme. Parents whose child was still in pediatric care were especially reluctant to leave the pediatrician: "We want to stay with the pediatrician. Our son is 22 years old, but his mental age is 15 months." A parent stated: "We regret having to leave the pediatrician. We were very satisfied, but now we wonder how things will go, in view of our son's life expectancy" and "we want one good doctor who plays the same role as the pediatrician does now." Several parents who had already transferred to adult care wished for "a kind of pediatrician but then for adults, someone you can ask all your questions and who checks your child's overall condition and who refers you to a specialist if necessary." One parent was satisfied with the new care coordinator (an ID physician) and praised her collaboration with the specialist for internal medicine, but missed "a team of doctors like we used to have in pediatric care." Other parents simply stated they wanted "the best care" for their

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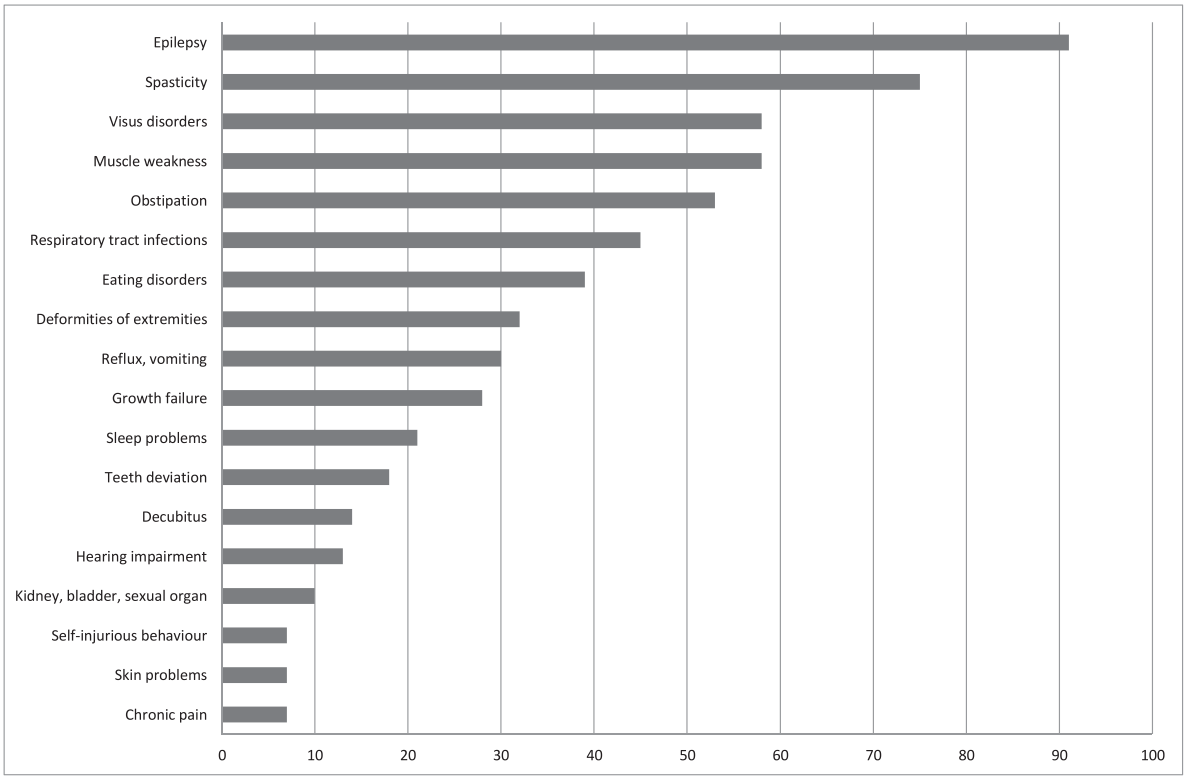

Figure 2. Reported impairments of young people with PIMD (%).

child. Examples of what best care implies are given in Table 5.

Listen to parents and value their expertise was the second major theme in parents' answers. Many parents claimed to be "the experts of our child" and urged professionals to "listen, listen, and listen again to what parents tell about their child!" Parents want "direct action to be taken when parents sound the alarm." This is particularly important "because our son cannot express his wishes or needs, parents should be involved and listened to AT ALL TIMES." Apart from prompt attention to medical problems, parents also would like to see a more holistic understanding of their child's needs and support for their families as well.

Suggestions for improvement of care were collected in the second open question from almost all parents. They were not specifically asked for positive or negative experiences. Parents provided detailed suggestions for improvement, the care processes, the interactions with health care providers and the facilities. These are summarized in Table 5. In addition, five recommendations were given for the transition to adult care: (1) give more information to parents about the options and make clear why the transfer is necessary, (2) make transition a gradual process, (3) organize a joint consultation between pediatrician and the new specialist, (4) give parents a copy of the medical history and referral letter, and (5) consider other, concurrent transitions as well: "Not only the transition in care was difficult! The transfer of our child to the adult day care centre also was a big shock."

Discussion

Most of the young persons (16–26 years) with PIMD in our sample had been treated in pediatric care, and 22% was still under medical supervision of a pediatrician. Another 22% had no care coordinator and different specialists coordinated care for the rest. Almost all parents reported major health impairments in their offspring; 60% had been hospitalized once or more in the past five years. These young people appear to have the same health needs after leaving the pediatrician as before, requiring continuation of adequate medical care. Inadequate transfer to and provision of adult

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Table 3
Medical Specialists Involved in Care During the Past Year

	Pediatrician coordinating care (n = 29)		Another physician coordinating care (n = 73)		No coordinating physician (n = 29)		Total (n = 131)	
Medical specialist	*n*	%	*n*	%	*n*	%	*n*	%
Pediatrician	29	100	6	8	1	3	36	28
Neurologist	9	31	28	38	11	38	48	37
Pediatric neurologist	12	41	4	5	7	24	23	18
Orthopedist	13	45	22	30	8	28	43	33
Rehabilitation physician	6	21	27	37	6	21	39	30
Physician for Intellectual Disabilities	6	21	21	29	3	10	30	23
Internist		—	7	10	1	3	8	6
Other specialists*	13	45	38	52	17	59	68	52
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Average number of involved medical specialists *(mean ± SD)***	2.9	1.4	2.4	1.5	2.2	1.3	2.5	1.4

*Other specialists: Gastroenterologist, ophthalmologist, otolaryngologist, cardiologist, urologist (pediatric), general surgeon, dermatologist, endocrinologist (pediatric), plastic surgeon, pulmonologist.
**There are no differences between the three groups with respect to the average number of medical specialists involved in the current care.

medical care may unnecessarily pose health threats. In general, as in an earlier Dutch study (Bruin, 2008), parents stressed the importance of continuity of specialist care and of being listened to by the professionals, who should acknowledge the parents' expertise and involve them in decision making.

The experiences we collected from Dutch parents are quite similar to those reported in

Table 4
Parents' Appreciation of Their Contact with the Pediatrician

	Pediatrician coordinating care (n = 29)		Another physician coordinating care (n = 73)		No coordinating physician (n = 29)		Total (n = 131)	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Pediatric Physician Evaluation Scale*	33.4	6.7	33.6	5.2	32.1	5.3	33.2	5.2
General appreciation of pediatrician (VAS 1–10)	8.5	1.1	8.0	1.4	7.7	1.3	8.1	1.3
General appreciation of current coordinating physician (not being the pediatrician) (VAS 1–10)			7.1	1.8	—			
Appreciation of Preparation for Transfer Scale (as given by the pediatrician)**	7.9	2.2	7.9	3.4	—			
	Missing values n = 5		Missing values n = 32					

*8 items; theoretical and actual range: 8–40; self-constructed; α = .89.
**3 items; theoretical and actual range: 3–15; self-constructed; α = .96.

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Table 5
Parents' Suggestions for Improvement of Care for Young People With PIMD

Care processes

- Have one care coordinator, who is accessible to parents at all times and responsible for their child
  - ''A Physician for ID in the hospital could be more efficient when consultations with other specialists or investigations are needed.''
- Ensure that the provider is knowledgeable and experienced with respect to persons with PIMD
  - ''Our new specialist, an internist, had no idea what to do with our child.''
- Ensure continuity in health care providers
- Prepare the consultation, read the files
- Work in multidisciplinary teams
  - ''We had to start all over and compose a new multidisciplinary team all by ourselves.''
- Have structural follow-up: yearly screening and checkups, preventive care
- Do not automatically give adult dosages to our children

Care interactions

- Dialogue with parents
  - ''I would like to be taken seriously as a parent.''
  - ''We wish to make decisions together.''
  - ''We need guidance and advice in difficult decisions, but make them ourselves.''
- Be a compassionate listener and supporter of parents
- Provide information to parents
- Take the young persons' cognitive disabilities and social functioning into account
  - ''See our child as a whole person: do not only consider his medical problems, but also his autism and cognitive dysfunction.''
- Take your time, be involved and proactive
- Personal approach, suited to people with ID
  - ''Our child understands more than most people think.''

Hospital facilities

- Reduce waiting times
- Combine outpatient clinic appointments
- Provide parents with good access to services, especially in acute situations (24/7)
- Supply better inpatient facilities for people with ID, for ADL as well as entertainment
- Allow us to be with our child at all times (including inpatient wards)
- Improve supervision during admission

international studies involving people with rare syndromes and/or ID, to some degree comparable with our PIMD group. In a study of 70 parents of adults with Williams syndrome, a rare genetic syndrome associated with ID and specific medical conditions (Udwin et al., 1998), the parents perceived that the adult-care professionals had little knowledge of the syndrome—witness the fact that cardiac and renal check-ups were no longer performed after transfer. In a recent qualitative study, eight mothers of adults with rare genetic syndromes with ID reported comparable negative experiences with adult medical care (Griffith et al., 2011). They ascribed delay in diagnosis and treatment to insufficient knowledge and experience of medical staff. These mothers also struggled to be heard and felt they continuously had to act as advocates of their adult offspring, which contributed to chronic stress and health issues of their own. In a UK study among parents of teenagers with ID and a

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range of complex medical and social issues, only a quarter were satisfied with the transfer process (Bhaumik et al., 2011). Like in the present study, parents pointed out lack of information, lack of coordinated planning, difficulties in accessing services, and unmet needs in multiple areas. These findings indicate that young persons with ID combined with impairments continue to have multiple and complex health care needs that adult health care should meet.

The parents of persons with PIMD in the present study were more reluctant to leave pediatric care than were the parents of young people with chronic conditions without ID in a previous study (van Staa, Jedeloo, van Meeteren, & Latour, 2011). This discrepancy is probably related to the fact that the young persons in the present study have severe ID. Parents experience little change in their caregiving tasks as the child grows into an adult, other than that these tasks require more physical strength (Shearn & Todd, 1997). To them, transfer to adult health care services feels unnatural as their child will not develop beyond a young child's developmental age and therefore will never become self-reliant. However, both legal issues and changing medical needs in adulthood force pediatricians to transfer medical care for these people with PIMD to adult services.

For parents, the medical transfer is complicated by concomitant transfers in other domains such as the transition from special schools or children's day care to adult day care facilities, moving out of the parental home to a guarded life environment or residential care, and all sorts of legal and financial changes (Neece, Kraemer, & Blacher, 2009). Under these circumstances, parents prefer to remain with their trusted pediatrician.

Pediatric specialists also seem to be reluctant to let go of these vulnerable patients; in part because they do not know to whom they could transfer them. Camfield, Gibson, and Douglass reported in 2011 that 44% of 133 pediatric neurologists still treated adults with Lennox-Gastaut syndrome and related neurological disorders up to the age of 24 years. Most pediatric neurologists had attempted to transfer their patients to adult neurologists, but almost 60% of these pediatric neurologists had not been satisfied by this process. The authors concluded that transfer is complicated by the presence of ID and suggest that a good transition program should include: identifying a willing adult service, adopting a multidisciplinary approach, addressing legal and psychosocial issues, and celebrating rites of passage. Parents in our study and studies from the UK (Bhaumik et al. 2011, Griffith et al., 2011) and the United States (Neece, Kraemer, & Blacher, 2009) report comparable experiences and challenges in transition, as well as solutions for improving the process—despite the large differences in health care systems. Even though the Dutch health care system provides universal coverage and access to care, it does not fully succeed in providing continuous high-quality care to this challenged group.

The parents in our study underline that good understanding of the ramifications of ID is important. In 1991, a new medical profession emerged in the Netherlands: the physician for people with Intellectual Disabilities (ID physician) (Evenhuis & Penning, 2009). More or less the same professions exist in the UK, Australia, and Germany. Dutch ID physicians are working in residential care, outpatient clinics, and multidisciplinary teams for children and adults with specific syndromes associated with ID, such as Down syndrome and Prader-Willi syndrome (Schrander-Stumpel et al., 2007). In 2012, 211 ID physicians were registered in the Netherlands. The Royal Dutch Medical Association (KNMG) judges this number to be insufficient. Furthermore, most of the ID physicians do not work in hospital settings. While some parents in our study had positive experiences with ID physicians, others did not know where to find them.

Strengths and Limitations of the Study

This is the first study that gave Dutch parents of young people with PIMD the opportunity to voice their experiences with transitional care. It clearly demonstrated the need to make the transitional process smoother and improve the organization of adequate specialist care.

Some limitations of this study need to be addressed. First, technical problems with the routing in the web-based survey resulted in missing data. Second, the response rate was rather low. Unfortunately, the research team could not send reminders since we did not have access to the respondents' names and addresses. Selection bias cannot be excluded: it is possible that parents who experienced more problems were more prone to fill out the survey, but it may also be that exhausted parents could not muster the will to participate.

DOI: 10.1352/1934-9556-51.3.176

Parents of non-Dutch-speaking background are probably less inclined to respond to (internet) questionnaires in the Dutch language, but we do not have data on ethnicity. Over 70% of all respondents were members of a patient organization, but it is unknown whether this percentage is representative for parents of children with PIMD.

Recommendations for Improvement of Transition

Considering the experiences of the surveyed parents, our own know-how, and findings in other studies of young people with intellectual and/or neurological disabilities (Bhaumik et al., 2011; Binks et al., 2007; Camfield & Camfield, 2011; Schrander-Stumpel et al., 2007; Simon et al., 2009; Stewart, 2009), we propose the following recommendations on the organization of transitional care for people with PIMD:

1. **Parents** should prepare themselves by sharing experiences with fellow parents, by raising the subject with the pediatrician, and by asking for copies of the referral letter and the medical history summary. Parent organizations could also help develop a transition program or standard including checklists and names of experienced adult specialists or clinics.
2. **Pediatricians** should create a network of trusted and experienced adult specialists in their own regions, start discussing future care at the latest by the age of 16, and involve parents in decisions about future medical care. They should prepare an extended summary of the medical history with advice for special follow-up aspects, and give a copy to the parents, if necessary with relevant literature attached. They should be aware that parents and providers alike highly appreciate a joint pediatric/adult consultation or transition clinic (Camfield & Camfield, 2011).
3. **Adult specialists** have to learn to listen to the parents as the expert caregivers of their grown child, who never will be able to speak for himself/herself. Education on relevant medical and communicative aspects should be integrated in medical school curriculums and relevant residencies. Also, setting up multidisciplinary teams of pediatricians, ID physicians, neurologists, orthopedic surgeons and rehabilitation physicians may improve health management. Adequate hospital facilities for this specific group of young people should be available and the nursing staff should be trained to provide care to hospitalized patients. Parents should be allowed to be present at their child's bedside at all times.
4. **Medical care in general**. In the Netherlands, the provision of adequate specialist care for this group with complex health care needs is a big challenge, even though there are no financial restrictions in access to specialist care. Internists are more and more sub-specialized and cannot provide integrative care. Much is expected of ID physicians as they combine expertise on health management with knowledge of ID (Evenhuis & Penning, 2009). However, there are still not many ID physicians and their integration into the hospital care system is reason for concern.

Conclusion

Considering the persisting impairments of young people with PIMD, their vulnerability, and the caregiving burden upon parents, our study clearly demonstrates the need for better preparation and a smoother transfer to adult specialist services. Almost a quarter of the persons with PIMD in this study lacked a medical coordinator after leaving the pediatrician, but nevertheless they had the same number of impairments and similar health utilization as the others. Parents generally were not satisfied about the transitional process and only half of them were satisfied with their current specialist care. Parents experienced fragmented care instead of adequate and integrated health management. Parents should be actively encouraged to anticipate transfer; pediatricians need to incorporate systematic preparation for parents to optimize transfer to adult care. A physician for people with intellectual disability could improve access and quality of care.

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Received 5/21/12, first decision 11/27/12, accepted 3/20/13.

Editor-in-Charge: Glenn Fujiura.

For this project no external funding was received. We are grateful to all parents who participated and to Gabriëlle Bruin for the pilot study. For support in developing the questionnaire and/or distributing the invitation to parents, we thank Mieke van Leeuwen (PlatformVG); Twink Hoeksema and Renate Winkels (BOSK); Andre Oosterlee (Philadelphia Support); Marga Nieuwenhuijse (EMG Platform); Carsten Lincke (Maasstad Hospital, Rotterdam); Wim Huijbers (RIVAS Beatrix Hospital, Gorinchem); Jos Hiel, Tia Bouma, Joke Lemeij, J.C.M. Hoekx, and G.J. Dogterom (Gemiva-SVG Groep, Gouda); James Schot, Alexandra Guldemeester, Saskia Voerman and Aart van der Stel (Pameijer, Rotterdam); Luc Imschoot, Michiel Vermaak, Sandra Mergler, and Daphne Konz (ASVZ, Sliedrecht); Anemone Linthorst and Leonore Kuijpers (Ipse-de Bruggen, Nootdorp); Liesbeth Vorselen (Syndion, Gorinchem); Leo van den Broek (Tyltylschool Rotterdam); Eric Boldingh and Frederike van Markus (Sophia Rehabilitation Centre, The Hague). Special thanks go out to Ko Hagoort and Sam Adams for editing.

DOI: 10.1352/1934-9556-51.3.176

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