

Clinical transition for adolescents with developmental disabilities in Hong Kong: a pilot study

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ABSTRACT

Introduction: Children with developmental disabilities usually move from the paediatric to adult health service after the age of 18 years. This clinical transition is fragmented in Hong Kong. There are no local data for adolescents with developmental disabilities and their families about the issues they face during the clinical transition. This pilot study aimed to explore and collect information from adolescents with developmental disabilities and their caregivers about their transition from paediatric to adult health care services in Hong Kong.

Methods: This exploratory survey was carried out in two special schools in Hong Kong. Convenient samples of adolescents with developmental disabilities and their parents were taken. The questionnaire was administered by interviewers in Cantonese. Descriptive statistics were used to analyse the answers to closed-ended questions. Responses to open-ended questions were summarised.

Results: In this study, 22 parents (mean age \pm standard deviation: 49.9 ± 10.0 years) and 13 adolescents (19.6 ± 1.0 years) completed the face-to-face questionnaire. The main diagnoses of the adolescents were cerebral palsy (59%) and cognitive impairment (55%). Of the study parents, 77% were reluctant to transition. For the 10 families who did move to adult care, 60% of the parents were not

satisfied with the services. The main reasons were reluctant to change and dissatisfaction with the adult medical service. The participants emphasised their need for a structured clinical transition service to support them during this challenging time.

Conclusions: This study is the first in Hong Kong to present preliminary data on adolescents with developmental disabilities and their families during transition from paediatric to adult medical care. Further studies are required to understand the needs of this population group during clinical transition.

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New knowledge added by this study

- These results are the first published findings on clinical transition for adolescents with developmental disabilities in Hong Kong.
- Dissatisfaction with the adult health services and reluctance to change were the main barriers to clinical transition.
- The concerns and needs of the families were similar regardless of whether adolescents had physical or cognitive disabilities.

Implications for clinical practice or policy

- A structured clinical transition service is required for adolescents with developmental disabilities and their parents.
- Further in-depth studies are required to examine the needs for and concerns about clinical transition for all those involved. This should include adolescents with developmental disabilities, their parents or caregivers, and service providers in both paediatric and adult health services.

Introduction

Advances in medical management now enable children with developmental disabilities (DD) who may previously have died to live well into adulthood.¹ Such disabilities are defined as any condition that is present before the age of 22 years

and due to physical or cognitive impairment or a combination of both that significantly affects self-care, receptive and expressive language, mobility, learning, independent living, or the economic independence of the individual.² The transition from adolescence to adulthood is a critical period

香港對於有發展障礙的青少年臨床過渡的初步研究

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引言：有發展障礙的兒童滿18歲後會從兒童及青少年科轉移至成人科健康服務。香港對於這臨床過渡階段所提供的服務很分散，目前也沒有關於受影響青少年及其家屬在這過渡階段的本地研究數據。這初步研究旨在探索並搜集關於有發展障礙的青少年及其家屬從兒童及青少年科轉移至成人科健康服務的初步數據。

方法：這探索性研究於香港兩間特殊學校內進行。研究人員以廣東話進行問卷調查，對象為有發展障礙的青少年及其家屬，然後以描述性統計來分析封閉式問題的回答，並總結開放式問題的回答。

結果：研究中有22名父母（平均年齡49.9歲，標準差10.0歲）和13名青少年（平均年齡19.6歲，標準差1.0歲）透過面訪完成問卷。有發展障礙的青少年主要診斷為腦癱（59%）和認知功能障礙（55%）。受訪父母中有77%不願意從兒童及青少年科轉移至成人科健康服務。10名已轉移至成人科健康服務的青少年病例中，60%的父母對於所提供的服務感到不滿，主要原因是不同意改變和不滿成人科所提供的健康服務。他們認為臨床過渡期充滿挑戰，所以為他們提供有系統的轉移服務是相當重要的。

結論：這是對於有發展障礙的青少年及其家屬從兒童及青少年科轉移至成人科健康服務的初步數據的首項研究。進一步研究或有助了解他們在臨床過渡期間的需要。

for all young people.³ In a clinical context, adult transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems”.⁴ In 2001, a consensus statement with guidelines was endorsed to ensure adolescents with DD, who depend on coordinated health care services, make a smooth transition to the adult health care system in order to receive the services that they need in developed countries such as the United States.⁵

Researchers have identified needs and factors necessary for the successful transition of adolescents with DD.^{6,7} From the adolescent’s perspective, barriers to success include their dependence on others, reduced treatment time and access to specialists in the adult health service, lack of information about transition, and lack of involvement in the decision-making process. Parents of adolescents with DD were reluctant or confused about changing responsibilities during the transition period. The majority of challenges came from the service systems and included unclear eligibility criteria and procedures, limited time and lack of carer training, fragmented adult health service provision, lack of communication between service providers, and inaccessibility to resources including information.^{6,7}

Based on the 2015 census of ‘Persons with disabilities and chronic diseases in Hong Kong’ from the Hong Kong Census and Statistics Department,

there were 22100 (3.8%) people with disability (excluding cognitive impairment) aged between 15 and 29 years, ie who were transitioning from the paediatric to adult health service.⁸ According to the Hospital Authority, Hong Kong, all public hospitals, and specialist and general out-patient clinics are organised into seven hospital clusters based on geographical location.⁹ The Duchess of Kent Children’s Hospital (DKCH) is a tertiary centre that provides specialised services for children with orthopaedic problems, spinal deformities, cerebral palsy and neurodevelopmental disorders, and neurological and degenerative diseases. Unlike overseas health care, there is no children’s hospital in Hong Kong that provides an acute health service. All paediatric patients go to the same hospital as adult patients but are triaged into the paediatric section for management by both in-patient and out-patient services. The specialised out-patient clinic list under each hospital cluster varies. Children with DD might receive services from general paediatrics clinic, a cerebral palsy clinic, Down’s clinic, behavioural clinic, or paediatric neurology out-patient clinic. Once a child reaches the age of 18 years, they are referred to the adult section of the same hospital for continued care. They will be followed up in neurology or movement disorder clinics, where other patients with adult-onset neurological conditions or movement disorders, such as stroke, Parkinson’s disease, multiple sclerosis are followed up. There is no separate specialised clinic for complex child-onset DD.¹⁰

Although adult transition for adolescents with DD has been recognised as a crucial area in health care overseas, it is an under-developed service in Hong Kong.¹¹ A local study found that there is a service gap in adult transition for young people with chronic medical conditions, such as asthma, diabetes, and epilepsy. Training and education are urgently required for both service providers and young people with chronic health conditions and their families.¹¹ It is unclear if the challenges and barriers identified in overseas literature^{6,7} are applicable to Hong Kong, where the paediatric and adult health services, especially the medical services, are located in the same building. At present, no study has been conducted with adolescents with DD and their families in Hong Kong about the issues they face during clinical transition. As a start, in this pilot study, we aimed to explore the acceptance of clinical transition and identify the main barriers to successful clinical transition for adolescents with DD and their caregivers in Hong Kong.

Methods

Participants

A survey study was conducted on a convenience

sample of adolescents and/or their caregivers, who were recruited from two special high schools (Hong Kong Red Cross John F Kennedy Centre [JFK] and Haven of Hope Sunnyside School [HOH]) in Hong Kong. Students from JFK have primarily physical and multiple disabilities including cerebral palsy or muscular dystrophy and those from HOH have severe cognitive impairment. Both schools provide rehabilitation services on site including physiotherapy, occupational therapy, speech therapy, nursing support, and family support via the school social workers. The medical out-patient services for the students fall under different hospital clusters, depending on where the students' families live. The parents are responsible for taking their adolescent children for medical review. As there was no previous study on which basis to calculate the required sample size and as a pilot study, we aimed to recruit 10 adolescents and their parents/caregivers in each school.

The inclusion criteria of the adolescents were: (1) aged 16 to 19 years and (2) a diagnosis of DD. All participating adolescents and/or their parents or legal guardians gave written informed consent before the survey. For adolescents with severe cognitive impairment, consent was sought from their parents as proxy and only their parents participated in the survey. This pilot study was approved by the Human Subjects Ethics Sub-committee of the Hong Kong Polytechnic University.

Survey

A specific questionnaire was developed for this pilot study to collect information relative to: (1) demographic characteristics of the participants; (2) whether or not the study participants were aware of the transition and the information source(s); (3) if the study participants were willing to transition to the adult health service and the underlying reasons; (4) for those who had transitioned, if they were satisfied with the adult health service and the underlying reasons; and (5) the opinion of the study participants of the clinical transition service. As a pioneer pilot study, health service included both medical and rehabilitation services and the study aimed to explore the general issues faced by this group of adolescents and their families during clinical transition. Lastly, as we predicted that the competency level of the adolescents and their caregivers in managing their disabilities might influence their perception of clinical transition, information about their self-rated competency level was also collected. Questions in the latter part were based on information from the Adolescent Transition Care Assessment Tool and were designed to assist health care professionals to provide a better transition for adolescents with chronic illness.¹² The whole survey was administered by interviewers for the study adolescents and/or their

caregivers separately in Cantonese. All interviews were recorded for data analyses.

The survey comprised closed- and open-ended questions. The closed-ended questions were designed to require a dichotomous answer, ie 'yes' or 'no', or an answer from a set of choices. For example, when asked about the sources of information about clinical transition, the study participants could choose their answers from a list of professionals such as paediatricians, social workers, physiotherapists, and school teachers. The open-ended questions focused on the reasons for an earlier response. For example, when asked if they wished to move to the adult health service, the individual would first answer 'yes' or 'no', then give their reasons. For the questions about self-perceived competency level, study participants read a number of statements (8 for the adolescents and 14 for parents) and indicated how much they agreed with the statement using a Likert-scale from 'strongly disagree' to 'strongly agree'.

Data analyses

Descriptive statistics—including mean, median, standard deviation, or quartiles—were used to analyse the responses to the closed-ended questions. Discussion of the open-ended questions was transcribed and summarised by five team members (CLC, KHF, KHWF, LKL, and TCLT). The content was analysed and themes were identified independently by two other team members (TWP and WLSC). These themes were discussed and a consensus reached by all team members.

Results

Thirteen potential families were approached at the JFK via the physiotherapist of the school anticipating possible refusal by some. All the students and their parents agreed to participate, so all were included. Ten families were approached at the HOH via the social worker at the school but one parent declined the offer and no other family was interested in participating in the study. Since the students from HOH, who were cognitively impaired, were not able to be interviewed, only their parents/caregivers were interviewed. As a result, 22 parents (13 from the JFK and 9 from the HOH) and 13 adolescents (all from the JFK) were asked to complete the face-to-face survey. The demographic data of the participants are listed in Table 1. Cerebral palsy and cognitive impairment were the principal types of DD. All adolescents received rehabilitation from the Hospital Authority and/or from their special school. All the adolescents accessed between four and seven paediatric medical specialists (eg paediatrician, neurologist, orthopaedic surgeon) and rehabilitation services (eg physiotherapy, occupational therapy, speech therapy) indicating their complex needs.

Over 90% of the JFK students were followed up at the DKCH that is within walking distance of the school (personal communication, Senior Physiotherapist at JFK).

Table 2 summarises the participant responses about clinical transition. The majority of the parents (77%) and adolescents (85%) knew that clinical transition to adult care would occur at 18 years of age. They were mainly informed by their paediatrician (50% of parents and 69% of adolescents). Most parents (77%) were reluctant to make this move. Ten parents stated that their adolescent child was already receiving care from the adult sector and over half of them (60%) were dissatisfied with the service. Four of the 13 adolescents clearly stated that they had transitioned to the adult health service during the survey and all of them were happy with the transition. Among those 17 families who knew that clinical transition to adult care would occur at 18 years of age, 10 adolescents were all over 18 years old, whereas those in another seven (41%) families were also over 18 years old and still receiving services from the paediatric sector at the time of the study.

When asked why they were not willing to the transition or why they were dissatisfied after the transition, the parent responses could be summed up as two main areas of concern: reluctance to change and dissatisfaction with the adult health services. Most parents (16/22, 73%) did not want to change their existing care circumstances. When asked why, some parents cited dissatisfaction with the adult health service or health system (for the latter, 13/22, 59% of parents). For example, parents found it difficult to attend the follow-up appointments using public transport. Although there was a free shuttle bus service for families who needed it, parents were frustrated by the limited service.

Some parents also wanted more flexible visiting hours in the adult hospital so that they could look after their adolescent children, especially those who were cognitively impaired. The parents worried about the quality of care for their children who were entirely dependent for their daily activities. They were also unhappy about the waiting time for medical appointments and stated that their children with DD had a short attention span and were unable to control their behaviour. Long waiting times in a crowded waiting area, which is commonly observed in the adult setting, could easily trigger their behavioural problems.

There was also dissatisfaction with the adult health service providers (13/22, 59% of parents). Parents often found that the adult medical staff demonstrated limited understanding and knowledge of their child's clinical presentation and abilities, especially for those with severe cognitive impairment. The adult health service providers did not know how to communicate with the cognitively

TABLE 1. Demographic information of study participants

Demographics	Data*
Interviewee relationship with study adolescents	
Father	7 (32)
Mother	13 (59)
Grandmother	1 (5)
Sister	1 (5)
Age (years)	
Adolescents	19.6 ± 1.0
≤18 years	5 (23)
>18 years	17 (77)
Parents / guardians	49.9 ± 10.0
Parent's / guardian's education level	
Primary school	2 (9)
High school	11 (50)
Diploma or equivalent	3 (14)
Degree or equivalent	6 (27)
Types of developmental disabilities	
Cerebral palsy	13 (59)
Cognitive impairment	12 (55)
Language delay	9 (41)
Developmental delay	8 (36)
Visual impairment	7 (32)
Dyslexia	6 (27)
Attention deficit hyperactivity disorder	3 (14)
Hearing impairment including deafness	3 (14)
Muscular dystrophy	3 (14)
Others	7 (32)
Main caregivers	
Parents	20 (91)
Grandparents	3 (14)
Siblings	2 (9)
Domestic helpers	9 (41)
Others	3 (14)
Time spent in caring activities (hours/day)	13.1 ± 10.0
Time in accessing paediatric services (years)	15.1 ± 4.9
Person accompanying to paediatric services	
Parents / guardians	22 (100)
Self	0

* Data are shown as No. (%) or mean ± standard deviation; because of rounding, not all percentages total 100

impaired adolescents and treated them as other normal adults.

There is no formal clinical transition service in Hong Kong but when asked, the majority of parents (21/22, 95%) and adolescents (11/13, 85%) stated that they would welcome such a service. About two

TABLE 2. Summary of responses to questions about clinical transition

Response to questions	Parents/guardians (n=22)*	Adolescents (n=13)*
Knowledge on transition to adult health services after 18 years of age		
Yes	17 (77%)	11 (85%)
No	5 (23%)	2 (15%)
Sources of this information		
Medical doctor	11 (50%)	9 (69%)
Therapist	1 (5%)	1 (8%)
Social worker	2 (9%)	0
Peers	3 (14%)	1 (8%)
Leaflet	0	0
Internet	0	0
Others	4 (18%)	2 (15%)
Missing data	1 (5%)	0
Willingness to transition to adult health service		
Yes	2 (9%)	-
No	17 (77%)	-
No comment	3 (14%)	-
Feelings about transitioning to adult health services		
Happy	-	4 (31%)
No feeling	-	4 (31%)
Unwilling	-	2 (15%)
Confused	-	1 (8%)
Others	-	2 (15%)
Currently receiving adult health services		
Yes	10 (45%)	4 (31%)
No	12 (55%)	8 (62%)
Not sure	0	1 (8%)
Among those adolescents who had transitioned to the adult health service in the survey	Parents/guardians (n=10)	Adolescents (n=4)
Adult health services accessed		
Medical specialties	9 (90%)	4 (100%)
Physiotherapy	3 (30%)	2 (50%)
Occupational therapy	3 (30%)	2 (50%)
Speech therapy	1 (10%)	0
Clinical psychology	1 (10%)	0
Social work	0	1 (25%)
Dietetics	0	0
Satisfaction with adult health services		
Yes	3 (30%)	4 (100%)
No	6 (60%)	0
No comment	1 (10%)	0

* Because of rounding, not all percentages total 100

thirds of the study parents and adolescents (23/35, 66%) would like the clinical transition service to support them during the clinical transition. About one third of the parents (7/22, 32%) believed that the service could act as a bridge linking the paediatric

and adult health services, providing information about available services in the adult sector.

The Figure summarises the responses of adolescents for self-perceived competency in managing their disability, and Table 3 summarises

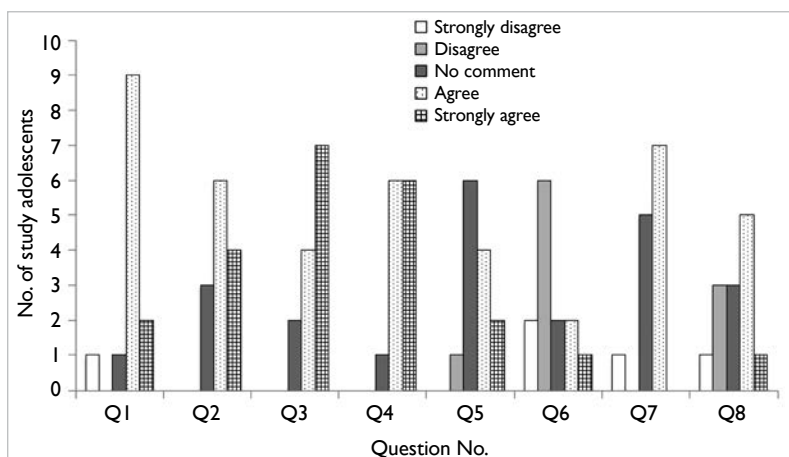


FIG. Responses of study adolescents about their self-perceived competency in managing their disability
 Q1 I can understand the explanations/instructions from medical staff
 Q2 I can explain my conditions to medical staff
 Q3 I understand the impacts of disease to my future
 Q4 I understand the importance of therapy to my health condition at this instant/in the future
 Q5 I can seek help from different medical specialties based on my health condition
 Q6 I can attend medical appointment by myself
 Q7 I can make medical decision by myself
 Q8 I worry that the medical staff in adult health services are not familiarised with my medical history

the study parents' responses. Most adolescents demonstrated understanding of instructions (11/13, 85%), confidence in communicating with the service providers about their condition (10/13, 77%), and understanding the importance of treatments for their condition (12/13, 92%) [Fig]. About half were confident in seeking help from different specialties according to their condition (6/13, 46%) and making medical decisions (7/13, 54%) [Fig]. Over half of the adolescents, however, lacked the confidence to attend routine medical visits on their own (8/13, 62%) and worried about the unfamiliar adult medical service (6/13, 46%) [Fig]. Most parents stated that they were familiar with their children's medical conditions and treatments (20/22, 91%) and able to seek help from different medical specialties based on their child's condition (14/22, 64%) [Table 3]. Only a minority of parents (1/22, 5%), however, believed that their children were capable of attending medical appointments on their own. Less than half of the parents believed that their children would be able to explain their medical condition (9/22, 41%) or make independent clinical decisions in the future (7/22, 32%). None of the parents of an adolescent with

TABLE 3. Summary of responses of study parents about their self-perceived competency in managing the disability*

Question No.†	Strongly disagree / disagree		No comment		Strongly agree / agree	
	JFK	HOH	JFK	HOH	JFK	HOH
Q1	0	0	2	0	11	9
Q2	0	0	1	0	12	9
Q3	0	0	0	0	13	9
Q4	0	0	1	0	12	9
Q5	3	2	2	1	8	6
Q6	3	5	4	1	6	3
Q7	0	0	0	0	13	9
Q8	2	1	4	5	7	3
Q9	9	9	3	0	1	0
Q10	6	9	7	0	0	0
Q11	3	9	4	0	6	0
Q12	2	9	2	0	9	0
Q13	4	9	6	0	3	0
Q14	2	9	4	0	7	0

Abbreviations: HOH = Haven of Hope Sunnyside School; JFK = Hong Kong Red Cross John F Kennedy Centre

* JFK (n=13) and HOH (n=9)

† Questions:

- Q1 I can understand my child's health condition
- Q2 I can explain my child's conditions to medical staff
- Q3 I understand the impacts of disease to my child's future
- Q4 I understand the importance of therapy to my child's health condition at this instant/in the future
- Q5 I am able to seek help from different medical specialties based on my child's health condition
- Q6 The communication among different medical professions is enough
- Q7 I believe I can accompany my child to attend medical appointment at this moment
- Q8 I believe I can accompany my child to attend medical appointment in the coming 10 years
- Q9 I believe my child can attend medical appointment by himself/herself at this moment
- Q10 I believe my child will be able to attend medical appointment by himself/herself in the future
- Q11 I believe my child is able to explain his/her condition to medical staff at this moment
- Q12 I believe my child will be able to explain his/her condition to medical staff in the future
- Q13 I believe my child is able to make medical decision at this moment
- Q14 I believe my child will be able to make medical decision in the future

cognitive impairment believed that the child would ever be able to manage their own health.

Discussion

The present pilot study aimed to determine how adolescents with DD and their parents in Hong Kong accept the clinical transition and identify the main barriers to successful transition. This was the first step to understanding the issues of this population group during clinical transition and to enable planning for the future. As far as we know, this study is the first to be conducted in Hong Kong for this population group. Overall, 22 parents and 13 adolescents were recruited from two special schools (one for primarily physically disabled children and the other for severe physically and/or cognitively impaired individuals), aiming to understand what was the acceptance level and barriers faced by these two vastly different groups with DD. The results were very similar between these two subgroups, indicating that the study parents had similar issues during clinical transition, regardless of the type of DD of their child. Hence, the results from these two subgroups were discussed as one group.

Most of the study participants were aware of the clinical transition necessary at the age of 18 years. Only 10 (45%) of the 22 families shifted to the adult health service, despite the fact that their adolescent child was close to or over 18 years old (Tables 1 and 2). The reasons for this delay were not thoroughly explored but it has been suggested that medical practitioners in the paediatric service felt that the adolescents were not ready for the transition so they continued to see them well into adulthood while the parents and the adolescents were reluctant to make the move.¹¹ The latter appeared to be true because when asked, most study participants did not want to change and move to the adult health service. This contradicts the results of a previous local study of adolescents with chronic medical conditions, in which over 80% of the study participants (adolescents and parents) were willing to move to the adult health service.¹¹ The difference is likely due to the complexity of the health conditions of the present cohort. Adolescents with DD usually have varying degrees of physical and/or cognitive impairment and so depend more on others for managing their health condition, making them and their carers more anxious about any change.^{6,7} For those with chronic medical conditions, the physical and cognitive abilities of the adolescent were unlikely affected and hence the adolescents could manage their condition more independently and more readily after the transition.¹³ This speculation was supported by the findings about self-perceived competency level. Most study adolescents, who had mainly physical disabilities, were not confident about attending a medical appointment alone because of their limited

physical abilities (Fig). The reluctance for change may also be due to fear of the unknown and of not being well prepared.¹¹ In Hong Kong, clinical transition is non-structured and unplanned.¹¹ Parents are often informed just before the transition, leading to poor preparation and confusion. Early and continuous clinical transition from early adolescence can enable parents and adolescents with DD to be prepared and actively participate in the transition planning.^{7,14} Although the clinical transition service is not well-known in Hong Kong, the study participants had a positive attitude towards a clinical transition service to help them navigate the process by bridging the paediatric and adult health services. In addition, the study parents wished to have more information about available adult health services, eg rehabilitation services, wheelchair maintenance services, etc. More information about the unknown has been shown to reduce the reluctance of parents and adolescents to change and to further improve their confidence about moving to adult care.^{5,6,15,16}

Another barrier was dissatisfaction with the health care system and service providers in the adult setting (Table 2), and is in line with present literature.⁷ Some parents found it difficult to arrange transport to the adult hospital for follow-up while most of the appointments were currently at the special school. More accessible public transport might help, especially in Hong Kong, where private vehicles are not a common option. Flexible visiting hours in the adult hospital that would enable parents to care for their dependent adolescent child may also reduce their dissatisfaction. Longer waiting times for medical appointments in the adult setting was frequently mentioned by the study parents. In the adult sector, patients with all kinds of neurological conditions, both child-onset and adult-onset, are reviewed in the same clinic. The number of patients attending the clinic is vastly increased compared with the paediatric setting. In addition, patients with adult-onset neurological conditions and their family may not understand the characteristics of DD. Stressed behaviour of an adolescent child with DD may be perceived by other families as impatience. In the paediatric clinic, where all clinic attendees were children or adolescents with DD and their parents, the waiting time was shorter. Families as well as clinic staff had a full understanding of DD and would be more tolerant. It is likely that this lack of support in the adult setting further discouraged the study parents to make the transition willingly. Changes to the existing health care system, such as a separate clinic for child-onset DD conditions, may be a possible small step to assist this group in making a smooth transition. Education about clinical transition for staff in both the paediatric and adult settings allows them to prepare the families in advance. Education about paediatric conditions and

communication with adolescents with DD can also equip adult staff with confidence so they develop a strong rapport with the families.¹⁶

Interestingly, from the perspective of the adolescents, the four adolescents who had transitioned stated that they were happy with the adult health service. Two (50%) adolescents indicated that because the 'new' doctors did not know them well, they paid more attention to them and one adolescent did not give any reason to support his statement. It is likely that in the paediatric sector, these adolescents had been followed up from early childhood by the same medical staff who virtually watched them grow up. A change of scene and people in the adult sector is welcomed by these adolescents. In addition, they might welcome the idea that they have started to actively participate in the consultation as a 'patient', unlike in the paediatric sector, where the consultation was directed at their parents, not them.¹⁴

Parents of adolescents who had physical and/or cognitive impairment had a similar perception of their adolescent child, that they would never be able to attend a medical appointment alone, presumably because of their disability (responses to questions 9 to 10 in Table 3). None of the parents of a cognitively impaired adolescent child believed their child to be capable of explaining their medical condition to others or making an independent medical decision. On the contrary, parents of a physically disabled child thought that while it may not apply at present, their child would be able to make their own decisions in future (responses to questions 11 to 14 in Table 3). Nonetheless, there was a discrepancy in this perception between the study adolescents and parents (Fig and Table 3). Most adolescents believed they could explain their condition to others (question 2 in the Fig) and over half believed that they could make an independent medical decision at the time of the study (question 7 in the Fig). Further studies are needed to determine whether this discrepancy is due to confusion on the part of the parents because of changing responsibilities during the transition.¹³ While western literature emphasises the importance of active participation by adolescents during clinical transition,¹⁴ it would be interesting to see if this can be endorsed in a parent-dominant Chinese society such as Hong Kong, where cultural differences may influence attitudes towards clinical transition.¹⁷

We were unable to analyse other challenges identified in overseas literature, such as unclear eligibility criteria and procedures and limited time for clinical transition, because comparable data were not available for Hong Kong. In other developed countries, adolescents are shifted with the assistance of a clinical transition service based in the children's hospital (if any) or by applying clinical guidelines for best service.¹⁸ In Hong Kong, adolescents are referred

from the paediatric section to the adult section within the same hospital. Each hospital cluster may have different procedures for this 'transition' and there is no defined department within the hospital structure to assist adolescents and their families through this process. Nor do the families receive any advice about how to negotiate this process. A future in-depth study is recommended to understand the existing situation of clinical transition in different hospital clusters and determine how to establish a more formal approach among all the hospital clusters in Hong Kong to support this group of adolescents and their families during this confusing time.

Limitations of the present study

There may have been a selection bias in the study sample as the families were approached by convenience through the school staff. Due to the small sample size, no statistical analysis was conducted to compare the subgroups of adolescents with physical and cognitive impairments. Although the sample size was small, the purpose of the present pilot study was not to generalise the findings to all adolescents with DD but to begin to understand the acceptance of clinical transition and the main barriers to success for adolescents with DD and their family in Hong Kong. The present results are also in line with the literature in this area.^{4,7,11,14,17} Future studies with a larger sample size and more in-depth qualitative data are required to verify the present results. The potential subjective bias of the results, especially for the open-ended questions, was another limitation but we attempted to minimise this through consensus agreement among the team.

Conclusions

In the present explorative study, close to half of the study families had a delayed clinical transition to the adult health service. Most study parents were reluctant for their adolescent children to shift to the adult health service due to unwillingness to change and dissatisfaction with the adult medical service. A structured and well-planned clinical transition was urged by the study participants to bridge the paediatric and adult health services and to provide support to the family. Further studies are required to analyse the needs and concerns of adolescents with DD and their families as well as the service providers in the adult medical setting to facilitate the future development of a clinical transition service in Hong Kong.

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Declaration

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References

1. Westbom L, Bergstrand L, Wagner P, Nordmark E. Survival at 19 years of age in a total population of children and young people with cerebral palsy. *Dev Med Child Neurol* 2011;53:808-14.
2. Public Law 98-527, Developmental Disabilities Act of 1984.
3. Staff J, Mortimer JT. Diverse transitions from school to work. *Work Occup* 2003;30:361-9.
4. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health* 1993;14:570-6.
5. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 2002;110(6 Pt 2):1304-6.
6. Bindels-de Heus KG, van Staa A, van Vliet I, Ewals FV, Hilberink SR. Transferring young people with profound intellectual and multiple disabilities from pediatric to adult medical care: parents' experiences and recommendations. *Intellect Dev Disabil* 2013;51:176-89.
7. Stewart D, Stavness C, King G, Antle B, Law M. A critical appraisal of literature reviews about the transition to adulthood for youth with disabilities. *Phys Occup Ther Pediatr* 2006;26:5-24.
8. Persons with disabilities and chronic diseases in Hong Kong. Hong Kong: Hong Kong Census and Statistics Department; 2016. Available from: <http://www.statistics.gov.hk/pub/B71501FB2015XXXXB0100.pdf>. Accessed Jul 2016.
9. Clusters, hospitals & institutions. Hospital Authority. 2016. Available from: http://www.ha.org.hk/visitor/ha_visitor_index.asp?Content_ID=10036&Lang=ENG&Dimension=100&Parent_ID=10004. Accessed Jul 2016.
10. Hospital Authority Statistical Report 2012-2013. Hong Kong: Hospital Authority; 2013.
11. Wong LH, Chan FW, Wong FY, et al. Transition care for adolescents and families with chronic illnesses. *J Adolesc Health* 2010;47:540-6.
12. Hong Kong Society for Adolescent Health. Adolescent Transition Care Assessment Tool, Public Education Series No. 12 (2013). Available from: <http://hksah.blogspot.hk/2013/11/adolescent-transition-care-assessment.html>. Accessed 6 Feb 2016.
13. Stewart DA, Law MC, Rosenbaum P, Willms DG. A qualitative study of the transition to adulthood for youth with physical disabilities. *Phys Occup Ther Pediatr* 2002;21:3-21.
14. Viner RM. Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Arch Dis Child* 2008;93:160-3.
15. Blum RW. Introduction. Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. *Pediatrics* 2002;110(6 Pt 2):1301-3.
16. Stewart D. Transition to adult services for young people with disabilities: current evidence to guide future research. *Dev Med Child Neurol* 2009;51 Suppl 4:169-73.
17. Barnhart RC. Aging adult children with developmental disabilities and their families: challenges for occupational therapists and physical therapists. *Phys Occup Ther Pediatr* 2001;21:69-81.
18. Department of Health. National Service Framework for Children, Young People and Maternity Services. Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services. 2006. Available from: http://dera.ioe.ac.uk/8742/1/DH_4132145%3FIdcService%3DGET_FILE%26dID%3D23915%26Rendition%3DWeb. Accessed Jul 2016.