### **GUIDELINE**



# A consensus statement on health-care transition of patients with childhood-onset chronic kidney diseases: providing adequate medical care in adolescence and young adulthood

Wataru Kubota<sup>1</sup> · Masataka Honda<sup>1</sup> · Hirokazu Okada<sup>2</sup> · Motoshi Hattori<sup>3</sup> · Masayuki Iwano<sup>4</sup> · Yuko Akioka<sup>5</sup> · Akira Ashida<sup>6</sup> · Yukihiko Kawasaki<sup>7</sup> · Hideyasu Kiyomoto<sup>8</sup> · Mayumi Sako<sup>9</sup> · Yoshio Terada<sup>10</sup> · Daishi Hirano<sup>11</sup> · Mikiya Fujieda<sup>12</sup> · Shouichi Fujimoto<sup>13</sup> · Takao Masaki<sup>14</sup> · Shuichi Ito<sup>15</sup> · Osamu Uemura<sup>16</sup> · Yoshimitsu Gotoh<sup>17</sup> · Yasuhiro Komatsu<sup>18</sup> · Shinichi Nishi<sup>19</sup> · Mitsue Maru<sup>20</sup> · Ichiei Narita<sup>21</sup> · Shoichi Maruyama<sup>22</sup>

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## **Preface**

#### Introduction

The present statement has been developed primarily for members of the Japanese Society for Nephrology (JSN) and the Japanese Society for Pediatric Nephrology (JSPN). Its objectives are to make it clear to all members that patients with CKD being transferred from pediatric to adult care require support and that transition programs are necessary for the transfer, to ensure that continued high-quality medical care is provided for these patients. The statement applies to patients who may develop independent living skills and does not apply to patients with severe intellectual disability or other relevant patients who require separate support. Throughout the text of the statement, the term "transfer from pediatric to adult care" includes the event of hospital transfer, although it should be noted that, strictly speaking, the transfers of treatment and hospital are different aspects of transition.

### **Background**

Along with advancement of medicine, pediatric patients with chronic diseases have experienced better prognosis,

The Japanese Society for Nephrology (JSN) and the Japanese Society for Pediatric Nephrology (JSPN) established the collaborative committee, and published the consensus statement in Nihon Jinzon Gakkai Shi. 2015;57(5):789–803. This manuscript is the English version of that statement.

Masataka Honda mhond@fol.hi-ho.ne.jp

Extended author information available on the last page of the article

requiring the continuity of care from childhood to adolescence and young adulthood. In the field of pediatric renal diseases, many diseases, including but not limited to childhood-onset nephrotic syndrome, chronic glomerulonephritis such as IgA nephropathy, CAKUT, CKD due to various diseases, and ESKD, persist after patients become adults. More than half of the children with frequently relapsing nephrotic syndrome experience relapse even in adulthood and use immunosuppressants [1]. The median age at which CAKUT progresses to ESKD was reported to be around 35 years [2].

However, there are many cases in which it is not easy for pediatric patients who had undergone long-term management at pediatric departments to be transferred to adult health-care services. Even if they are transferred to adult health-care units, some of them fail to adapt well to the adult services and return to pediatric departments, and what is worse, some of the patients drop out, which aggravates the underlying disease. In pediatric departments in which patients are closely connected to their families, the approach to patients is based on consideration of the children's development, causing parents be overprotective and/or exert too much control over their children, which may prevent pediatric patients from developing independent living skills. On the other hand, departments providing adult health-care services put importance on patients' autonomy and issues related to pregnancy, childbirth, and occupation, but tend to attach less weight to involvement in growth and development or relations with patients' families. A nationwide survey conducted by Hattori et al. with partial support in the form of an MHLW Research Grant and surveyed from the JSN, JSPN, and the Japanese Society of Pediatric Urology (JSPU) in 2014 demonstrated that only 31% of patients aged 20 years or older with childhood-onset chronic kidney diseases who had been managed at pediatric departments were



transferred to adult renal services over a period of 5 years [3]. The reasons for non-transfer included refusal of patients or their families to transfer (43%) and lack of concern about transfer or inability to decide on transfer (33%), which may serve to indicate a possibility that families' dependence on pediatricians or pediatricians themselves may hinder transfer from pediatric to adult renal services.

The most challenging issue is how to help CKD patients in adolescence and young adulthood who are able to live independently display their original capacities to the full, so as to live a life with maximum QOL secured. In their published Guidebook of the Transition Care for Adolescent Nurses, Ishizaki et al. [4] state the necessity of transfer to adult health-care services as below. Among the problems faced by pediatricians is the following: diseases peculiar to adults that patients face after they reach adulthood or pregnancy and childbirth are outside the expertise of pediatricians, and if patients need to be hospitalized, they cannot be admitted to pediatric units. On the other hand, the corresponding problems faced by adult care physicians are as follows: childhood-onset diseases are outside their expertise and they have difficulties in handling these diseases, and in addition, CKD patients in adolescence and young adulthood have less social experience than adults of the same age, and are likely to become immature adults and face difficulties in adapting themselves to society, and therefore, they are prone to rely on physicians and cannot get used to treatments at adult health-care services despite the fact that they are regarded as adults in terms of age and system. Ishizaki et al. state that, for the purpose of minimizing these problems, pediatricians need to train patients in age-appropriate disease knowledge, personal capacity, and communication required for participation in society, whereas adult care physicians need to deepen their understanding about medical care for childhood-onset chronic diseases that should be administered after children reach adulthood. Hattori et al. [3] reported that approximately 20% of patients aged 20 years or older were unemployed, and pointed out that the unemployed patients had financial difficulties. An important issue is to provide them with education that suits their abilities, so that they can be employed and become financially independent.

A consensus statement issued by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians–American Society of Internal Medicine (AAP/AAFP/ACP-ASIM) in 2002 set the goals as follows: to ensure that "by the year 2010", all physicians who provide primary or subspecialty care to young people with special health-care needs (1) understand the rationale for transition from child-oriented to adult-oriented health care; (2) have the knowledge and skills to facilitate that process; and (3) know whether, how, and when transfer of care is indicated [5]. Everyone passes through

adolescence and young adulthood, a time of life characterized by psychological instability of variable degree. In this period, the continuity of high-quality medical care must not be disrupted. For the purposes of filling gaps between the medical care provided in childhood and adolescence/young adulthood and providing medical care appropriate for adulthood, it is necessary to develop transition programs and start the transition process early in accordance with such transition programs, which requires cooperation among patients, their families, health-care providers, administrative personnel, government, and medical societies/associations to facilitate adequate transition.

### **Definition of transition**

In 1993, a position paper by the Society for Adolescent Medicine (SAM) defined that "Transition is a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system" [6]. The transfer from pediatric to adult health-care services is an "event" in the transition process.

In 2011, the International Society of Nephrology and International Pediatric Nephrology Association (ISN/IPNA) announced a consensus statement for pediatric patients with CKD [7]. In the statement, it is indicated that transfer from pediatric to adult nephrology services should occur only after preparation and assessment have been performed and that the transfer should take place when patients have completed school education, have attained sufficient social and psychological development, and are stable in terms of symptoms and psychological status. In the statement, it is recommended to create an organization consisting of physicians (transition champions), nurses, psychological specialists, social workers, and other relevant persons who have all been well trained in transition programs to support the transition and to implement transition programs through collaboration with adult health-care units.

In Japan, in 2014, the Japan Pediatric Society announced a "Statement of health-care transition of patients with child-hood-onset diseases" [8]. This statement proposes that in transition, health-care professionals involved in the two areas of pediatric and adult medical care should achieve seamless provision of medical care during transition from pediatric to adult care services as disease conditions change and patients themselves mature. It also describes that, depending on the patient's maturity or individual disease, an adequate medical care system (e.g., the patient is managed and/or treated jointly by the pediatric and the adult units) should be selected.

It is stated that when formulating transitional programs, action plans for each of the matters listed below will be developed, implemented, and evaluated [9].



- The patients themselves can describe their own health status.
- The patients can ask questions during each visit and understand what medication is needed.
- The patients can discuss sexual capabilities, including safe sex and the impact of the condition and/or medications, for example, whether the condition will affect fertility.
- The patients can talk to friends and supportive relationships about any concerns and identify any need for help.
- The patients can discuss employment options and plan to work—what kind of work do they want to do? Are there any restrictions, for example, on the number of hours they can work?
- The patients can discuss any restrictions on mobility and their interests caused by their condition.

#### **Content**

# Transfer from pediatric to adult care

- (1) Ensure that the transfer from pediatric to adult care does not cause disruption to advanced, high-quality medical care.
- (2) Transfer patients from pediatric to adult care after they have achieved sufficient psychological and social development as well as relevant education. Avoid the transfer as far as possible if the patient's symptom(s) or psychological status is unstable.
- (3) Transfer from pediatric to adult care should occur only after preparation and assessment have been made. It is important to implement transition programs.

### **Transition programs**

- (1) Transition programs should be started as early as possible.
- (2) Physicians who are familiar with transition programs should be made available on both sides, for pediatric and adult care. A team consisting of nurses, psychological specialists, social workers, and other relevant persons should be organized. Measures to support the transition, e.g., establishing a transition clinic, should be formulated.
- (3) Patients, their families, and health-care providers should always consider, from the start of a transition program, that a patient should be independent in the future. The patient him/herself should be at the center of the program, independent from his/her family, to participate in decision making.

- (4) Health-care providers and patients' families should not be overprotective and/or exert too much control over their children only, because they worry about disease aggravation, so that before transfer to adult care services, patients can become able to adequately live their lives on their own and receive medical care.
- (5) Health-care providers should take time to discuss with patients the changes that are expected to occur in the future (e.g., explanation on adult medical care) and the patients' future, before transfer to adult care, so as to share information.
- (6) Health-care providers should provide, as appropriate, patients with information about health insurance and medical expenses.
- (7) Support to help patients develop independent living skills should include support to help them receive adequate education and to choose their future occupation.
- (8) Patients will need to understand the details of the treatment they will receive and independently manage their health by themselves. Patients and healthcare providers should have good understanding about the status of transition readiness through the use of transition readiness assessment.
- (9) Pediatricians should have each patient prepare a medical summary to facilitate his/her self-management, and utilize the transition summary at the time of transfer to adult medical care services.
- (10) Adult care physicians should endeavor to understand the special characteristics of pediatric CKD patients and to provide adequate medical care for CKD patients in adolescence and young adulthood.

### Necessary support by medical societies/associations

- Regarding continued provision of medical care from pediatric to adult health-care services, identify financial problems and request the administration to provide adequate support.
- (2) Conduct surveys on patients in transition process and discuss problems.
- (3) Develop educational programs on transition medicine for health-care providers.
- (4) Investigate qualification requirements for transition coordinators and human resources for transition support, for the purpose of making programs successful, and request administrative personnel to provide adequate support regarding these issues.



#### Statement

# Transfer from pediatric to adult care

 Ensure that the transfer from pediatric to adult care does not cause disruption to advanced and high-quality medical care.

The consensus policy statement issued by AAP/AAFP/ACP-ASIM in 2002 indicated that transition in medical care to adolescence and young adulthood is special medicine performed during a time of life in which children reach adulthood, and that during this transition period, advanced and high-quality medical care must not be disrupted [5].

- (2) Transfer patients from pediatric to adult care after they have achieved sufficient psychological and social development as well as relevant education. Avoid the transfer as far as possible if the patient's symptom(s) or psychological status is unstable.
- (3) Transfer from pediatric to adult care should occur only after preparation and assessment have been made. It is important to develop transition programs.

In the consensus statement announced by ISN/IPNA, it is stated that transfer from pediatric to adult nephrology services should occur only after preparation and assessment have been performed and that the transfer should take place when patients have completed school education, have attained sufficient social and psychological development, and are stable in terms of symptoms and psychological status [7]. The social development refers to a process in which individuals are establishing adequate relations with their families and those outside the families, and are becoming adapted to living in groups. In adolescence and young adulthood, some individuals may sometimes be isolated, because their social engagement is not going well; this requires special attention.

Got transition [an organization established by the US Maternal and Child Health Bureau (MCHB) and the "National Alliance to Advance Adolescent Health", an NPO] in collaboration with AAP/AAFP/ACP-ASIM has developed the six core elements [10]. It was reported that in accordance with the six core elements, systematic transition of health-care has been possible on both sides, in pediatrics and internal medicine [11]. The six core elements consist of the following:

 Transition policy: develop a document describing the approach of the practice to transition (transition policy), share the policy with the patient and his/her family, and

- start the transition at age of 12–14. Educate all staff about the practice's approach to transition.
- 2. Transition tracking and monitoring: establish criteria for identifying transitioning patients, and enter their data into a registry.
- 3. Transition readiness: use a transition readiness assessment tool (checklist) beginning at age of 14. Develop goals on self-care with the patient and his/her family.
- 4. Transition planning: develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical (transition) summary, and emergency care plan. Plan with youth and parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each.
- 5. Transfer of care: transfer the patient to adult care when his/her condition is stable. Upon transfer, prepare documents necessary for the transition (readiness assessment, medical summary, emergency care plan, etc.). On the side of adult care services, complete preparations by team members, and at the time of first medical examination, update the medical summary and the emergency care plan.
- 6. Transfer completion: contact patient and parent/caregiver 3–6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process. Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed. Build ongoing and collaborative partnerships with adult care providers.

### **Transition programs**

(1) Transition programs should be started as early as possible.

The consensus statement issued by AAP/AAFP/ACP-ASIM in 2002 provided proposals to prepare a transition plan by age of 14 [5]. The consensus statement announced by ISN/IPNA in 2011 made proposals to introduce to the concept of transition at age of 12–14 and to proceed with transition gradually in accordance with the stage of development and intellectual abilities [7]. The six core elements propose that a document be developed describing the approach to transition (transition policy) that it be shared with the patient and his/her family, and that the transition be started at age of 12–14 [10]. It is necessary to start a transition program by age of 15 at latest.

(2) Physicians who are familiar with transition programs should be made available on both sides, for pediatric



and adult care. A team consisting of nurses, psychological specialists, social workers, and other relevant persons should be organized. Measures to support the transition, e.g., establishment of a transitional outpatient clinic, should be formulated.

The policy statement issued by AAP/AAFP/ACP-ASIM proposed that all young people with special health-care needs should have an identified health-care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health-care planning [5]. The consensus statement by ISN/IPNA made recommendations to identify lead clinicians (transition champions) on the pediatric and adult care sides, and to designate transition coordinators such as nurses and social workers, so as to formulate an organization responsible for the process from preparations for transition to transfer to adult care services through a transition clinic. The ISN/IPNA statement also provided recommendations to transfer from pediatric to adult nephrology services only after efforts to assess and prepare the adolescent/young adult have occurred and take place during a period without crises, and to be offered the opportunity of an informal visit to the nominated adult service before transfer occurs [7]. The position paper announced by SAM in 2003 indicated that patients and their families should have transition coordinators who are responsible for transition programs and support their transition to adult health care [12]. It is advisable, whenever possible, to designate specialists (psychiatrists, psychological specialists, nurses, etc.) who are familiar with psychological status of children suffering from diseases.

(3) Patients, their families, and health-care providers should always consider, from the start of a transition program, that a patient should be independent in the future. The patient him/herself should be at the center of the program, independent from his/her family, to participate in decision making.

Reiss et al. [13] describe in their article entitled "Health-Care Transition: Destination Unknown" that early development of a transition plan is a key to success of transition. They also recommend, for the purpose of facilitating transition, that discussion with patients should be held in early stages regarding their future, and that patients should be informed of changes that will occur in the future as early as possible. They argue that, in transition programs, it is important that patients themselves can describe their own health status and that patients can voluntarily visit hospitals to receive medical examination and perform self-management when taking drugs. A program helping the patient to understand his/her disease in early stages is necessary.

(4) Health-care providers and patients' families should not be overprotective and/or exert too much control over their children only because they worry about disease aggravation, so that before transfer to adult care services, patients can become able to adequately live their lives on their own and receive medical care.

Higashino et al. [14] pointed out that one factor disturbing transition is excessive parental control over patients; severe rating of disease and underestimation of a child's abilities also disturb transition, which may lead to a situation in which the patient does not work, stays home, and lives his/ her life under the protection of his/her parents. They also have described that pediatricians themselves have strong mental relationships with patients and their families and are prone to maintain the present status, and thus constitute the maximum opposing force against transition. Honda [16] stated that "pediatricians have to instruct parents not to be overprotective or over-meddling, and pediatricians themselves have to prevent themselves from being overprotective unconsciously". The Guidebook of the Transition Care for Adolescent Nurses also indicates that overprotection of children, mother-child attachment, familial malfunction, and other relevant factors constitute problems in transition [4]. It is important for pediatric health-care providers and families to encourage patients to voluntarily consult health-care providers about their own issues, including psychological problems.

(5) Health-care providers should take time to discuss with patients the changes that are expected to occur in the future (e.g., explanation on adult medical care) and the patients' future, before transfer to adult care, so as to share information.

Watson et al. [15] described some of the differences between pediatric and adult units in their review in 2005. Reiss et al. [13] also stated in their review that discussion should be held with patients and their family about their future and that patients should be given information about adult care services and insurance, and be made aware that they themselves will live their lives in the adult medical world. Some patients may harbor concerns about education and employment, since they had needed to receive treatment for their disease and will not be able to achieve the academic career they should have obtained. Health-care providers need to discuss with patients' employment types that are commensurate with their abilities and aptitudes.

(6) Health-care providers should provide, as appropriate, patients with information about health insurance and medical expenses.



In the consensus statement by ISN/IPNA, it is proposed to resolve financial problems as preparation for transition [7]. Reiss et al. [13] pointed out in their review that problems with the scope of health insurance coverage constitute structural difficulties disturbing transition. It is important to identify problems with health insurance and medical expenses in the preparatory phase for transition and to provide patients with relevant information, to endeavor to identify solutions.

(7) Support to help patients develop independent living skills should include support to help them receive adequate education and to choose their future occupation.

The support to help patients develop independent behaviors should include support to help them receive education appropriate for their abilities and to choose their future occupation accordingly. The report entitled "Guidebook of Health-Care Transition of Adult Patients with Childhood-Onset Chronic Diseases for Pediatricians" demonstrated that the rates of advancement to universities of the patients with chronic disease were less than 40% and the presence of disease was caused problems at the time of employment in 56.3% of patients, which highlights the importance of providing opportunities to receive education and expand employment possibilities [9]. One of the six core elements set as the objectives in transition support programs is an employment type suitable for the patient's own physical capacities (educational and occupational planning) [9]. Families and health-care providers should support patients while being careful not to disturb their independence.

(8) Patients will need to understand the details of the treatment they will receive and independently manage their health by themselves. Patients and health-care providers should have good understanding about the status of transition readiness through the use of transition readiness assessment tools.

In the consensus statement by ISN/IPNA, it is recommended to use tools including, but not limited to, a transition medical passport, a self-administered transition, readiness survey, the TRxANSITION Scale (TRxANSITION) and other relevant tools to aid in acquisition of disease self-management skills [7]. Two systematic reviews published in 2014 demonstrated the validity and reliability of the Transition Readiness Assessment Questionnaire (TRAQ) and TRxANSITION Scale (TRxANSITION) as comprehensive tools, which have been described in published reports to aid in transition readiness assessment [17, 18]. In the six core elements also, it is recommended to use readiness assessment and develop goals on self-care through joint

cooperation with the patient and his/her family, and in addition, to evaluate the readiness assessment at regular intervals to confirm achievement of objectives [10]. In the report entitled "Guidebook of Health-Care Transition of Adult Patients with Childhood-Onset Chronic Diseases for Pediatricians", it is recommended to use readiness assessment tools for the purpose of determining to what extent patients manage their health by themselves [9].

(9) Pediatricians should have each patient prepare a medical summary to facilitate his/her self-management, and utilize the transition summary at the time of transfer to adult medical care services.

In the policy statement issued by AAP/AAFP/ACP-ASIM, it is recommended to prepare and maintain an upto-date medical summary that is portable and accessible, which is critical for successful health-care transition [5]. In the consensus statement by ISN/IPNA also, it is recommended that as preparation for transition, patients have a comprehensive written and verbal summary of all the multidisciplinary aspects of the young person's care; this should include medical, nursing, dietary, social, and educational information [7]. Patients are instructed to have a transition summary, as a "health handbook", so that they may individually utilize it for their self-management. In the six core elements, it is recommended to prepare a medical summary and other relevant information at the time of transfer to adult care and to update the medical summary at the first visit at the adult health-care service facility [10].

(10) Adult care physicians should endeavor to understand the special characteristics of pediatric CKD patients and to provide adequate medical care for CKD patients in adolescence and young adulthood.

Higashino et al. [14] pointed out the following facts as transition-disturbing factors on the side of health-care providers: adult care physicians lack understanding about pediatric diseases and about proper handling of adolescent and young adult patients. Ishizaki et al. [19] conducted a questionnaire survey and reported that a factor disturbing transition is the absence of specialists in adult health-care units. What is important in transition is to understand the characteristics of patients with childhood-onset CKD due to CAKUT, multiple anomalies, or other relevant causes that are rarely observed in adults. For the purpose of promoting this understanding, our research team has developed the above guidelines on medical care for CKD in adolescent and young adult patients.

Those concerned on the side of adult health-care services will understand their patients and organize a transition team consisting of psychological specialists, social workers, and



other relevant personnel to work in collaboration with pediatric units. It is recommended to re-check transition readiness assessments, review entries stated in medical summaries, modify the emergency care plans, and take other relevant actions. Even after patients have received care at adult health-care units, they need to concurrently receive medical care at pediatric units and transition clinics for a certain period of time (for at least 6 months after transfer to adult care services).

# Necessary support by medical societies/associations

 Regarding continued provision of medical care from pediatric to adult health-care services, identify financial problems and request the administrative personnel to provide adequate support.

The statement by SAM in 2003, the consensus statement by AAP/AAFP/ACP-ASIM, and the consensus statement by ISN/IPNA highlight that the continuity of the health insurance system from pediatric to adult care services should be ensured [5, 7, 11]. In not a small number of cases, financial problems cause nonadherence. It is important that patients themselves understand the scope of health insurance coverage, and in addition, medical expenses covered by the National Health Insurance for intractable diseases are ensured. The report entitled "Guidebook of Health-Care Transition of Adult Patients with Childhood-Onset Chronic Diseases for Pediatricians" reported cases in which patients encountered employment-related problems (e.g., having a disease is a disadvantage when working), medical expenses are great, and some patients are not motivated to continue medical care, since provision of medical benefits for specified pediatric chronic diseases is discontinued at age of 20 [<del>9</del>].

(2) Conduct surveys on patients in transition process and discuss problems.

In May 2010, Honda et al. [20] performed a questionnaire survey among councilors of the Japanese Society for Pediatric Nephrology (49 medical institutions) about how they view transitional programs for nephrotic syndrome. Only one institution had a transition program, and more than half of the medical institutions studied conducted transitions without prior discussion with adult care physicians. However, since treatment methods including steroids for nephrotic syndrome are different between adult and pediatric patients, many problems have occurred in conjunction with the transition, and these problems associated with transition are not sufficiently recognized in Japan. Hattori et al. [3] pointed out financial problems in reference to their finding that approximately 20% of patients aged 20 years or older were unemployed. They also found that approximately 30% of patients visited adult care units, without authorized referral by pediatric care units, because of aggravation of symptoms or recurrence, or for urinary screening and other relevant reasons. What is required is to identify the actual status on transition patients, to discuss problems with transition, and to recognize the importance of transition programs.

(3) Provide educational programs on transition for health-care providers.

Hattori et al. [3] reported that only three pediatric institutions (3%) of the responding 101 and one adult institution (0.9%) of the responding 107 had transition coordinators. In the consensus statement by ISN/IPNA, it is recommended to have physicians who lead transition programs (transition champions) available at transition clinics both in pediatric and adult care services, and to formulate an organization consisting of transition coordinators, such as nurses and social workers, and psychological teams, so as to provide support from the preparation for transition to transfer to adult care services [7].

McManus et al. [21] provided education regarding the six core elements to health-care providers at both pediatric and adult care units, and reported that their knowledge about transition was enhanced after the education. They described the following advantages, among others: the health-care providers became able to understand patients more easily; and they began to activate communication between pediatric and adult care units. The reality is that an increasing number of pediatric CKD patients require transition, whereas only a small number of health-care providers are engaged in transition medicine and they lack knowledge about transition. It is urgently necessary to expand educational programs on transition for health-care providers.

(4) Investigate qualification requirements for transition coordinators and human resources for transition support, for the purpose of making programs successful, and request administrative personnel to provide adequate support regarding these issues.

Supporting patients who feel anxious about transition in achieving a smooth transition to adult care units requires a multidisciplinary approach involving physicians, nurses, psychological specialists, social workers, and other relevant personnel, and takes a long time in terms of medical care. That is why the financial support of administrative agencies is necessary for practical implementation of transition support. A surveillance on transition performed once every



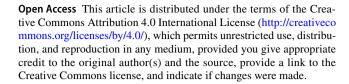
4–5 years in the US, since 2001 has revealed that between the 2005–2006 surveillance and the 2009–2010 surveillance, the number of transition programs implemented for patients requiring transition support had not increased at all, which indicated that financial incentive is necessary for promoting transition [21].

In addition, transition coordinators who play roles to facilitate relations between pediatric and adult care units as well as between patients and hospitals are inevitable, and having transition coordinators is considered a key to successful transition [11]. It is required to identify knowledge and technologies necessary for transition, to develop qualification requirements for acquired staff, and to foster transition coordinators.

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## **Compliance with ethical standards**

Conflict of interest Hirokazu Okada has received honoraria from Kyowa Hakko Kirin Co., Ltd., Alexion Pharmaceuticals, Inc., and subsidies from Takeda Pharmaceutical Co., Ltd., Chugai Pharmaceutical Co., Ltd., Torii Pharmaceutical Co., Ltd., Kyowa Hakko Kirin Co., Ltd., Pfizer Japan Inc., Boehringer Ingelheim GmbH, Astellas Pharma Inc., Otsuka Pharmaceutical Co., Ltd., MSD K.K., Shionogi & Co., Ltd., Novartis Pharma K.K., Sumitomo Dainippon Co., Ltd., Mitsubishi Tanabe Pharma Co., and Daiichi Sankyo Co., Ltd. Masayuki Iwano has received honoraria from Otsuka Pharmaceutical Co., Ltd., and subsidies from Takeda Pharmaceutical Co., Ltd., Chugai Pharmaceutical Co., Ltd., Kyowa Hakko Kirin Co., Ltd., Pfizer Japan Inc., Astellas Pharma Inc., Otsuka Pharmaceutical Co., Ltd., Novartis Pharma K.K., Baxter Ltd., Sumitomo Dainippon Co., Ltd., Eli Lilly Japan K.K., and Mitsubishi Tanabe Pharma Co. Mayumi Sako has received consulting fees from Astellas Pharma Inc. and Zenyaku Kogyo Co., Ltd. Takao Masaki has received honoraria from Kyowa Hakko Kirin Co., Ltd. and subsidies from Takeda Pharmaceutical Co., Ltd., Chugai Pharmaceutical Co., Ltd., Torii Pharmaceutical Co., Ltd., Kyowa Hakko Kirin Co., Ltd., Otsuka Pharmaceutical Co., Ltd., JMS Co., Ltd., Mitsubishi Tanabe Pharma Co., Daiichi Sankyo Co., Ltd., Bayer Yakuhin Ltd., Baxter Ltd., Kaneka Medix Co., TERUMO CORPORATION, and Mochida Pharmaceutical Co., Ltd. Shuichi Ito has received honoraria from Alexion Pharmaceuticals, Inc. and Genzyme Japan K.K., and subsidies from Pfizer Japan Inc., Astellas Pharma Inc.



## References

- Ishikura K, Yoshikawa N, Nakazato H, Sasaki S, Nakanishi K, Matsuyama T, Ito S, Hamasaki Y, Yata N, Ando T, Iijima K, Honda M. Morbidity in children with frequently relapsing nephrosis: 10-year follow-up of a randomized controlled trial. Pediatr Nephrol. 2015;30(3):459–68.
- Wühl E, van Stralen KJ, Verrina E, Bjerre A, Wanner C, Heaf JG, Zurriaga O, Hoitsma A, Niaudet P, Palsson R, Ravani P, Jager KJ, Schaefer F. Timing and outcome of renal replacement therapy in patients with congenital malformations of the kidney and urinary tract. Clin J Am Soc Nephrol. 2013;8(1):67–74.
- Hattori M, Iwano M, Sako M, Honda M, Okada H, Akioka Y, Ashida A, Kawasaki Y, Kiyomoto H, Terada Y, Hirano D, Fujieda M, Fujimoto S, Masaki T, Maruyama S, Matsuo S. Transition of adolescent and young adult patients with childhood-onset chronic kidney disease from pediatric to adult renal services: a nationwide survey in Japan. Clin Exp Nephrol. 2016;20(6):918–25.
- Ishizaki Y, Maru M. The Japanese Society of Adolescent Nursing: guidebook of the transition care for adolescent nurses and medical staffs. 2nd ed. Tokyo: Division of International Nursing Development, Tokyo Medical and Dental University, 2012.
- 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;110:1304–6.
- Blum RW, Garrel D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, Slap GB. Transition from child-centered to adult healthcare systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993;14:570–6.
- Watson AR, Harden P, Ferris M, Kerr PG, Mahan J, Ramzy MF. Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA). Pediatr Nephrol. 2011;26:1753–7.
- Yokoya S, Ochiai R, Kobayashi N, Komamatsu H, Mashiko T, Mizuguchi M, Minami M, Yao A. Statement of health care transition of patients with childhood-onset chronic diseases. J Jap Pediatr Soc. 2014;118(1):98–116.
- Ishizaki Y, Maru M. Guidebook of health care transition of adult patients with childhood-onset chronic diseases for pediatricians. Tokyo: Research Committee on the Investigation and Refined Policy to Support Social, Medical and Educational Life of Children with Chronic Diseases. 2012.
- Six Core Elements of Health Care Transition 2.0 Transitioning Youth to an Adult Health Care Provider. http://www.gottransit ion.org/providers/leaving.cfm 2016-0114
- McManus M, White P, Barbour A, Downing B, Hawkins K, Quion N, Tuchman L, Cooley WC, McAllister JW. Pediatric to adult transition: a quality improvement model for primary care. J Adolesc Health. 2015;56:73–8.
- 12. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with



- chronic conditions: position paper of the society for adolescent medicine. J Adolesc Health. 2003;33:309–11.
- Reiss J, Gibson R. Health care transition: destinations unknown. Pediatrics. 2002;110:1307–14.
- Higashino H. Longitudinal support for patients with childhoodonset chronic diseases: to fill the gap between child and adult health care systems. Shoninaika. 2006;38(5):962–8.
- Watson AR. Problems and pitfalls of transition from pediatric to adult renal care. Pediatr Nephrol. 2005;20(2):113–7.
- Honda M. Health care transition for pediatric CKD patients. J Jpn Soc Pediatr Ren Fail. 2013;33:5–9.
- Schwartz LA, Daniel LC, Brumley LD, Barakat LP, Wesley KM, Tuchman LK. Measures of readiness to transition to adult health care for youth with chronic physical health conditions: a systematic review and recommendations for measurement testing and development. J Pediatr Psychol. 2014;39:588–601.
- Zhang LF, Ho JS, Kennedy SE. A systematic review of the psychometric properties of transition readiness assessment tools in

- adolescents with chronic disease. BMC Pediatr 2014;14:4. https://doi.org/10.1186/1471-2431-14-4.
- 19. Ishizaki Y, Maru M, Higashino H, Katsumoto S, Egawa K, Yanagimoto Y, Nagahama T. The transition of adult patients with childhood-onset chronic diseases from pediatric to adult health-care systems: a survey of the perceptions of Japanese pediatricians and child health nurses. Biopsychosoc Med. 2012;6:8.
- Honda M, Iijima K, Ishikura K, Kaneko K. The problem of transition from pediatric to adult healthcare in patients with steroid-sensitive nephrotic syndrome (SSNS): a survey of the experts. Clin Exp Nephrol. 2014;18(6):939–43.
- McManus MA, Pollack LR, Cooley WC, McAllister JW, Lotstein D, Strickland B, Mann MY. Current status of transition preparation among youth with special needs in the United States. Pediatrics. 2013;131:1090–7.

## **Affiliations**

Wataru Kubota<sup>1</sup> · Masataka Honda<sup>1</sup> · Hirokazu Okada<sup>2</sup> · Motoshi Hattori<sup>3</sup> · Masayuki Iwano<sup>4</sup> · Yuko Akioka<sup>5</sup> · Akira Ashida<sup>6</sup> · Yukihiko Kawasaki<sup>7</sup> · Hideyasu Kiyomoto<sup>8</sup> · Mayumi Sako<sup>9</sup> · Yoshio Terada<sup>10</sup> · Daishi Hirano<sup>11</sup> · Mikiya Fujieda<sup>12</sup> · Shouichi Fujimoto<sup>13</sup> · Takao Masaki<sup>14</sup> · Shuichi Ito<sup>15</sup> · Osamu Uemura<sup>16</sup> · Yoshimitsu Gotoh<sup>17</sup> · Yasuhiro Komatsu<sup>18</sup> · Shinichi Nishi<sup>19</sup> · Mitsue Maru<sup>20</sup> · Ichiei Narita<sup>21</sup> · Shoichi Maruyama<sup>22</sup>

- Department of Nephrology, Tokyo Metropolitan Children's Medical Center, 2-8-29 Musashidai Fuchu, Tokyo, Japan 183-8561
- Department of Nephrology, Saitama Medical University, Saitama, Japan
- Department of Pediatric Nephrology, School of Medicine, Tokyo Women's Medical University, Tokyo, Japan
- Department of Nephrology, Faculty of Medical Sciences, University of Fukui, Fukui, Japan
- Department of Pediatrics, Saitama Medical University, Saitama, Japan
- Department of Pediatrics, Osaka Medical College, Takatsuki, Japan
- Department of Pediatrics, Fukushima Medical University School of Medicine, Fukushima, Japan
- Tohoku Medical Megabank Organization, Tohoku University, Sendai, Japan
- Division of Clinical Trials, Department of Clinical Research Promotion, Clinical Research Center, National Center for Child Health and Development, Setagaya-ku, Tokyo, Japan
- Department of Endocrinology, Metabolism and Nephrology, Kochi Medical School, Kochi University, Kochi, Japan
- Department of Pediatrics, Jikei University School of Medicine, Tokyo, Japan

- Department of Pediatrics, Kochi Medical School, Kochi University, Kochi, Japan
- Department of Hemovascular Medicine and Artificial Organs, Faculty of Medicine, University of Miyazaki, Miyazaki, Japan
- Department of Nephrology, Hiroshima University Hospital, Hiroshima, Japan
- Department of Pediatrics, Yokohama City University Hospital, Yokohama, Japan
- 16 Ichinomiya Medical Treatment & Habilitation Center, Ichinomiya, Japan
- Department of Pediatric Nephrology, Japanese Red Cross Nagoya Daini Hospital, Aichi, Japan
- Department of Healthcare Quality and Safety, Gunma University Graduate School of Medicine, Maebashi, Japan
- Division of Nephrology and Kidney Center, Kobe University Graduate School of Medicine, Kobe, Japan
- Faculty of Nursing and Rehabilitation, Konan Women's University, Kobe, Japan
- Division of Clinical Nephrology and Rheumatology, Niigata University Graduate School of Medical and Dental Sciences, Niigata, Japan
- Division of Nephrology, Nagoya University Graduate School of Medicine, Nagoya, Japan

