Pediatric Endocrinology Transition Clinic Profile at the University of Santo Tomas Hospital Outpatient Department – Clinical Division (USTH OPD-CD)

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Abstract

Introducation: Structured and well-coordinated transition from pediatric to adult medical care is an integral part of continuous disease management of maturing adolescents. However, the evaluation of the degree of efficiency of transition process is usually taken for granted. The objective of this study is to characterize the pediatric endocrinology transition clinic profiles at the University of Santo Tomas Out-patient Department-Clinical Division (USTH OPD-CD).

Methods: A descriptive observational study that reviewed the pediatric endocrinology database containing the data of patients who attended the clinic from January 2012 to July 2014 was conducted along with a month-long immersion of the investigator. Patients aged 15 to 19 years old who attended the pediatric endocrinology clinic were included in the study. Variables of interest included were the patients' demographic data, clinical information, follow-up care, physician-patient interaction, and manner of transitioning patients by their healthcare provider.

Results: Twenty patients were included in the analysis. Majority of the patients were female (n=17, 85%) while three (15%) were male. Although all patients had controlled disease, only twenty percent were compliant with follow-up. The most common condition was Graves' disease (45%). Transfer to adult clinic was advised in a 19-year-old patient with type 1 diabetes mellitus, and the process was merely verbal. There was no information whether the patient who was advised this transfer complied. In terms of physician-patient interaction, it was noted that physician readily listened to their patients, after which the former was able to give education and counselling to their patients in order to empower them to have informed decisions. In general, the manner of transitioning patients was done in a purely verbal manner.

Conclusion: There is a need to modify the system of transitional care at the USTH OPD-CD primarily in terms of structured and formal collaboration between pediatric and adult services to ensure the continuity of care, and adequacy of disease management. Preparing patients prior to their target age of transition is imperative. Taking measures to improve the patients' compliance with their follow-up and attain the full cooperation of the family is also necessary. Regular evaluation of the transition program is essential.

Keywords: pediatric endocrinology, transition clinic, outpatient department

Introduction

There should be a continuity of medical care in patients with childhood-onset chronic disease. In this case, an organized, consistent, and smooth process of transition from pediatric to adult medical care must always be ensured.[1,2] Good transition has been defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems.[3,4] Six factors have been identified to fulfill in order to have an efficient transition program. These include a policy on timing of transfer, preparation period and education programme, coordinated transfer process, interested and capable adult service, administrative support, and primary care involvement.[3,4] Coordination of transition process is not only required from health care professionals. There should also be collaboration of patients and families with their health care providers.[1,2,5,6] However, obstacles to attaining an effective transition include the dearth of empirical evidence on the best approaches to the transition process, fundamental differences in health care delivery between pediatric and adult health care providers, lack of well-defined criteria for determination of transition readiness, the changing social and demographic characteristics of young adults that may influence their utilization of health care, differences in learning styles between individuals in this transition period compared with both younger children and adults beyond the period of emerging adulthood and deficiencies in training of health care professionals in care delivery for emerging

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adults.[7] Aside from these, there are multiple psychosocial adjustments during the post adolescent period of emerging adulthood that can be confounded by financial stressors.[7] This is particularly true in our setting.

There have been several unexplored questions about basic mechanisms during transition from child to adult healthcare systems.[8] The most fundamental question is how to find effective strategies that can engage the adult care, so that young people can be successfully integrated in a coherent care system.[8] Failure to transfer to an adult service may produce a delay in the acquisition of normal developmental tasks.[9] In addition to this, evaluation of effectiveness of transition process has received less attention. Therefore, the general objective of this study is to characterize the pediatric endocrinology transition clinic profiles at the USTH OPD-CD. Other objectives to describe the process of transitioning patients, and formulate a recommendation to improve the transition program.

Methods

Study Design and Setting

This is a descriptive observational study that reviewed the pediatric endocrinology database owned by the USTH section of endocrinology, diabetes, and metabolism containing the data of patients who attended the pediatric endocrinology transition clinic from January 2012 to July 2014. Information recorded in this document included the following: date of consultation, patients' name, age, gender, address, contact number, hospital registration number, diagnosis, treatment modality, follow-up date, and name and signature of pediatric resident and endocrine fellow who saw the patient. Immersion of the investigator in the said clinic for one month was also done to observe the process of transition and healthcare provider-patient interaction.

The pediatric endocrinology transition clinic was established in 2007 and is located in the outpatient department of USTH clinical division. The clinic is visited by budget-restricted patients with childhood-onset endocrine disorders who are to be transitioned to adult care in the near future. It is attended by a senior pediatric resident and assigned senior endocrinology fellow-in-training on a weekly basis for two hours. The patients (old and new) are seen initially by the senior pediatric resident together with the senior endocrinology fellow-in-training. Subsequently, the patient is presented to the pediatric endocrinologist senior consultant to discuss and provide plans for the patient. Transitioning patients were done in a verbal manner, with the physician telling the patient and his/her mother about transfer to adult care. This transition advise was noted in the pediatric follow-up form as well as in the pediatric endocrinology database. No formal transition form to contain the details of transition was accomplished. In addition, no means were available in order to determine whether the patient complied with transition. Grandrounds of notable cases are also facilitated. The study was approved by the Institutional Review Board of the said hospital.

Inclusion Criteria

Patients, aged 15 to 19 years old who attended the pediatric endocrinology clinic from January 2012 to July 2014 were included in the study.

Exclusion Criteria

Patients with insufficient data for analysis were excluded in the study.

Study Variables

Variables of interest included the patients' gender, age, diagnosis, compliance with follow-up, degree of control of disease as indicated by its notation in the database and absence of admission to hospital, whether the patient is undergoing transition preparation, number and outcome of transition, healthcare provider-patient interaction and manner of transitioning patients by their healthcare provider.

Statistical Analysis

Descriptive statistics namely frequency, percentage, and mean was used to summarize the data. All data were encoded and analyzed using the Microsoft Excel for Mac 2011 (Version 14.6.5).

Results

Twenty patients were included in the study. Majority of the patients seen were female (n=17, 85%) while three (15%) were male. Figure 1 shows the proportion of patients who attended the clinic according to age. The mean age of the study population was 16.7 years old. The age distribution in descending order of frequency were the following: 18 years old (n=6, 30%), 15 years old (n=5, 25%), 16 years old (n=4, 20%), 17 years old (n=4, 20%), and 19 years old (n=1, 5%).

Figure 2 shows the proportion of the different conditions encountered. The most common condition seen is Graves' disease (n=8, 45%). Other conditions include type 1 DM (n=3, 15%), multinodular goiter (n=3, 15%), papillary thyroid cancer (n=1), type 2 DM (n=1), polycystic ovary syndrome (n=1), Cushing's disease (n=1), congenital hypothyroidism (n=1), and pineal gland germinoma (n=1).

Figure 3 shows the consultation outcome of patients seen in the pediatric endocrinology clinic. A great proportion of patients are lost to follow-up (n=15, 75%). Four patients (20%) are not yet transitioned and remains in pediatric care.

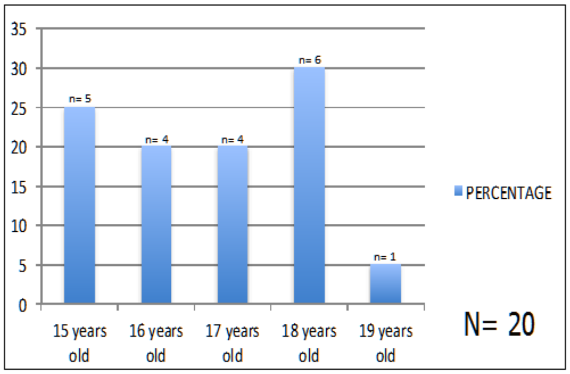

FIGURE 1. Proportion of patients seen at the clinic from 2012 to 2014 grouped according to age

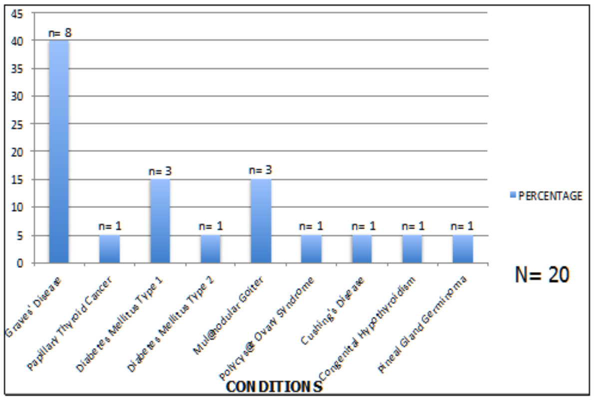

FIGURE 2. Proportion of the different conditions encountered in the clinic from 2012 to 2014

x-axis: conditions encountered
y-axis: percentage

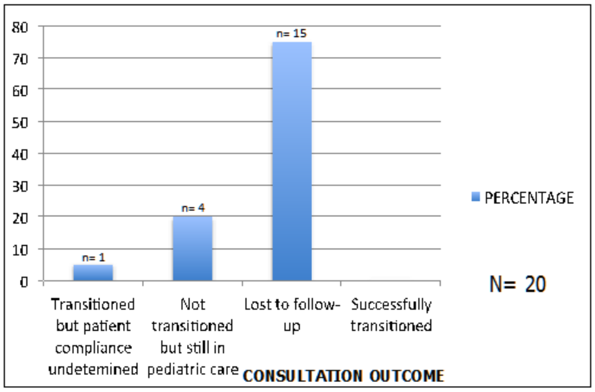

FIGURE 3. Consultation outcome of patients seen in the clinic from 2012 to 2014

x-axis: consultation outcome
y-axis: percentage

During this period, one patient who was 19-years old with type 1 DM was verbally advised transition into adult care and this was also documented in the database. However the compliance of this patient to the advise was unknown. For the other age groups, no data was found whether they were advised transition into adult care. No data was found on successfully transitioned patients. In addition, there was also no evidence regarding the provision of preparation period for transition for the remaining age groups. Despite these findings, all patients were noted to have controlled disease as indicated in the database.

There was no information whether the patient who was advised this transfer complied. In terms of physician-patient interaction, it was noted that physician readily listened to their patients, after which the former was able to give education and counselling to their patients in order to empower them to have informed decisions. In general, the manner of transitioning patients was done in a purely verbal manner.

Discussion

Transfer to adult clinic was advised in one patient with type 1 diabetes mellitus, and the process was merely verbal. There was no information whether the patient who was advised this transfer complied. These results suggest that modification of transitional care is necessary. This is to promote efficient transfer and endorsement of the patient from child to adult medical care.

A well-timed transition from child- to adult-oriented health care is specific to each person and ideally occurs between the ages of 18 and 21 years old.[6] Setting a target age of transition for a particular patient is very important for both patient and health care provider in preparing for transition.[3,4] A target age of 18 years or school-leaving age is best.[3,4,10] The finding of the study showed that one 19-year-old patient had been advised transition to adult care. Probably because that particular patient manifested the capability of being independent when it comes to taking care of oneself as assessed by the health care provider. Whether the patient actually went to adult care must be determined and this must be documented in the database. This is not only to ensure continuity of care, but also to assess the effectiveness of transition process. There was no data showing that 18-year old patients were advised transition. There is a probability that patients from this age group were verbally advised but not documented in the database. Another possibility is that these patients would be advised transition on the next visit, however they were lost to follow-up, as shown by the high proportion of patients who were non-compliant with follow-up. A data on whether or not the patient is undergoing preparation for transition or actual transition should be documented in the database. Some clinics use cut-off varying from 15 to 20 years.[3,4] Earlier, at 15 or 16 years, many with chronic illness will not have completed their growth or pubertal development, and adult service are unlikely to pay attention to growth and development.[3,4] It is appropriate that these remaining age groups be prepared for transition at a later age by educating them. Discussion regarding complications and preparations for transition must take place before the actual transition to adult care systems.[5] In addition, the timing of transition should depend on the developmental readiness and health status of the adolescent.[10] Transition should not occur before the young person is able to manage his or her illness largely independent of parents and staff, and can function in an adult clinic.[10] This can be done by educating the patient and allowing him/her to take responsibility for medication.[10] A structured assessment of their transition readiness must be assessed. This may take in the form of validated rating scales, checklists, questionnaires, and parental interview.

The most common condition seen in the clinic was Graves' disease. This is in contrast to the finding that type 1 diabetes mellitus as the most common chronic endocrine disease in children.[11] This finding may be partially due to the analysis of a particular subset of pediatric population. Another possible reason is the small sample size of the study. All patients were documented to have controlled disease, and this is the reflection of good quality of medical care provided by the physicians, and compliance of the parents and patients with treatment. However, the degree of disease control may wane with non-follow-up of the disease. This also puts patients at risk for developing complications.

As noted, a great proportion of the patients did not comply with follow-up. Financial issues might be one of the underlying reasons for this non-compliance. Other possibilities include change of residence that is farther from the clinic, consult with another clinic, decrease of guidance from the parents, patient demise, non-satisfaction, lack of time to go to the clinic due to major school events such as graduation or exams or acquisition of job, absence of signs and symptoms, lack of understanding of the need to move from a service that has served them for many years and simply the lack of desire to comply with follow-up as a result of psychosocial adjustment typically experienced by the adolescent.[7] Transitioning older teens and young adults are at high risk for disengagement from health care and, in turn, the emergence of complications that may go undetected without appropriate follow-up.[7] Teens and young adults require assistance with transition because they are a vulnerable population at risk for loss to follow-up care and poor health outcomes.[7] Facilitating consistent follow-up care may be in the form of strictly and accurately recording the patients' residential address, email address, contact numbers, and sending them reminders in the form of emails, text messages or phone calls. Always emphasizing to the parents and patients the importance of carefully monitoring their disease should also be done. With enough resources, getting a coordinator or care ambassador or patient navigator is beneficial especially to health care providers who may be busy enough to remind the patients.[7] Another strategy is to assist the young adult with scheduling the first appointment within three to four months of the final pediatric visit.[7]

Another finding was the lack of a structured and coordinated program in terms of the actual process of transition from pediatric to adult service. A clear-cut and effective transition program is important because there are fundamental differences in the approach and delivery of care between pediatric and adult patients.[7] This also ensures patients' compliance with regards to transition advice leading to uninterrupted management of their chronic disease. In adult care, focus is more on the autonomously functioning individual patient, who can be informed or counseled but then is expected to make his or her own choices about behavior or treatments.[7] Professional meetings appeared to be of vital importance to enable the building of bridges between pediatric and adult care.[8] The collaboration between pediatric and adult medical care in order to create a smooth transition between the links in the chain of care for adolescents during the vulnerable phase of life must be emphasized.[8] Regular evaluation of the program's effectiveness, identifying its strengths and weaknesses, formulating a model of a more effective process provide a room for improvement of the program. Support from peers and family is indispensable as well as care providers' attitudes and strategies.[8]

According to Ishizaki et al, the prevalence of some kinds of chronic illnesses in childhood is increasing.[1] These adolescent patients are still developing socially, and they often lack social experiences because of their childhood disease and have difficulties in adapting to both adult social life within their community and adult healthcare systems.[1] Therefore, programs are really required to ensure a seamless transition of medical care in childhood and adolescence to that in adulthood and to help children grow socially and become independent, working adults.[1] Indeed, there is a need for a proper endorsement of the patients between the pediatric and adult service. The provision of a transition form which contains the patient's medical data is one way facilitate this kind of endorsement. The prospective adult medical care provider must have enough interaction with the patient in transition. This paves the way to familiarity, comfort, and trust in both parties.

As mentioned above, there are six core elements of a successful transition program.[3,4] The policy on timing of transfer involves the determination of a target transfer age depending on his developmental readiness.[3,4] According to Viner, transition should not occur until young people have largely completed the developmental tasks of adolescence.[3,4] A preparation period and education program involves the identification of a necessary skill set to enable the young person to function in adult clinic.[3,4] The preferable period is in early adolescence.[3,4] A series of educational interventions should tackle their understanding of disease, rationale of therapy, source of symptoms, recognizing deterioration, seeking help from health professionals.[3,4] Leaflets and material about the transition program and details of adult service should be provided.[3,4] Making the patient familiar with adult program can be facilitated by provision of its outline, and visit to adult clinic a year before the actual transition.[3,4] A joint pediatric-adult clinic is useful to introduce adolescents to adult physicians.[3,4] A coordinated transfer process requires a coordinator since pediatricians may rarely have time to undertake this role.[3,4] An interested and capable adult service is also required for the success of the program.[3,4] The development of a close and frequent clinical and academic links between the services can ensure that the collaboration is beneficial to both services, and that patients are not lost to follow-up.[3,4] Institutional and administrative support must be assured at both ends of the transfer chain.[3,4] This can be in the form of secretarial support to ensure the efficient organization of appointments and the transfer of medical records.[3,4] Transition planning must involve primary care providers who may provide the only medical continuity for young people and their families during the time of discontinuities.[3,4]

Currently, a paucity of data exist on the most effective and practical method of transition.[5,7,12] With a relatively few model practices exemplifying high-quality transition supports, training providers in the principles of health care transition remains challenging.[6] Further studies are needed to provide evidence-based transitional care programs that take both medical and psychosocial aspects of care into consideration.[5] Randomized control trials evaluating models of transition from pediatric to adult care may be performed.[12] Due to small sample size, conduction of researches in a multicenter manner is appropriate. Structured interviews and questionnaire surveys among health care providers, and nurses about their perceptions of the transition process are helpful.[1,8] Finally, assessing the health-related quality of life of the patients in preparation for transition, and in actual transition is as beneficial.

Conclusion

This study is able to identify the major problems in the transition clinic. There is a need to modify the system of transitional care at the USTH OPD-CD primarily in terms of structured and formal collaboration between pediatric and adult services to ensure the continuity of care, and adequacy of disease management. Preparing patients prior to their target age of transition is imperative. Taking measures to improve the patients' compliance with their follow-up and attain the full cooperation of the family is also necessary. Once a structured program is adopted, evaluation of its effectiveness in a regular manner must be executed.

The authors recommend formulation of structured and formal endorsement from pediatric to adult care. This can be done by a.) strengthening the joint pediatric-adult endocrine transition clinic, b.) utilisation of basic, follow-up, and transition forms, c.) putting up a registry which includes the patients' complete address, and contact numbers, d.) quarterly audit, e.) quarterly grand rounds (c/o pediatrics but with participation of adult endocrinology), and f.) evaluation of effectivity of revised transition clinic program in the form of another research and assessment of the patients' health-related quality of life in the form of surveys.

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