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Current referral practices and adolescent transition to Adult clinic: Setting an agenda

John C
Ocheke IE
Okpe ES
Ige OO
Yilgwan C
Ejeliogu E

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John C (✉)
Department of Paediatrics,
University of Jos,
Jos, Nigeria
Email: cchibunkem@yahoo.com

Ocheke IE, Okpe ES, Ige OO
Yilgwan C, Ejeliogu E
Department of Paediatrics,
Jos University Teaching Hospital,
Jos, Nigeria

Abstract*:* *Background:* The goal of adolescent transition from child to adult care services is to provide uninterrupted, coordinated and developmentally appropriate health care as transfers are made from paediatric to adult clinics. Adolescent transition practices are available but not in Nigeria.
This study was carried out to determine current practice of patient referral and adolescent transition practice.
Methodology: The study was a cross sectional studies among paediatricians attending the annual paediatric conference, using a self-administered questionnaire.
Result: A total of 80 respondents, 33 consultants and 47 paediatric residents were involved. Females were 41 (51.2%) and 39 (48.8%) were males. Mean duration of practice was 12.5±0.75 (range 2-20years). Most respondents practice in urban centre, 91.2%; in public hospitals (96.2%) and many attend to adolescents (80%). Most practice intra-departmental referral (96%) done through verbal communication (46.4%); referral notes (92.8%); or through clinical conference (21.9%). Feedbacks were occasional (76.7%) or maybe verbally given (61.4%). Inter-departmental referral/transfer was through use of referral notes (96.8%), or involved one-on-one discussion (81.0%). Most referred patients are managed independently (64.2%), or may involve clinical conference (30.8%) and grand rounds (31.2%).
Adolescent referral is through referral notes (92.3%) with formal discharge (81.6%). Discussions before transfer with the adolescent, and the relatives, occur frequently (91.6% & 92%). Discussions with the receiving physician, adolescents and caregivers occurs much less (37.8%). No written referral policies were available (86.1%) and no existing policy with adolescents transfer was available (66.2%). Mean age of transfer was 16.8±1.8years (range 12-20years); this was determined by hospital (72.9%) or department (71.9%). Informed consent usually requested before transfer(90.7%). Most respondents, (97%), see refused transfer or returning clients. Possible reasons for refusal of transfer are fear (90%); difficulty with new treatment relationship (89.1%); and physician attitude (61.7%).
Conclusion: Little or no guidelines exist and a robust adolescent transition protocol is required.

Introduction

Transition has been defined as the "purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care."[1] The goal of transition is to provide health care that is uninterrupted, coordinated, and developmentally appropriate and psychologically sound before and throughout the transfer of youth into the adult system[2]. For young people, poor adherence with treatment and disaffection with the healthcare system and providers can be particularly problematic for those with serious chronic diseases. The fate of older adolescent patients in paediatric clinics is either one of transfer to adult services, long term retention in the paediatric clinic, or discharge from medical supervision, either voluntarily or by neglect[3].
Most patients need an efficient and gradual transition from paediatric to adult services. Change from paediatric to adult healthcare systems is difficult not only for those with chronic disease but even for normal young

people.[4]
As management capabilities improve, more adolescents with chronic illnesses are surviving longer and ultimately transiting to adult care.[5]
While paediatric care is family focused, relies on developmentally appropriate care with significant parental involvement in decision-making and care provided with in a multidisciplinary team, adult care is patient focused and investigational, requiring autonomous, independent consumer skills without many interdisciplinary resources.[6]

A concerted effort therefore, must be made by the paediatrician based on prevailing circumstance to offer the most beneficial and appropriate method to the transiting adolescent. Transition must be individualised, designed according to the illness the child is being managed for and should include close collaboration with the adult physician.[7]

Adult health care differs significantly from paediatric care in the type and level of support, decision-making, consent processes and family involvement. These factors may play a role in the decrease follow- up visits by adolescent patients after transfer to the adult care system. Some authors believe that this decline is, in part, attributed to the lack of transition planning and insufficient coordination with adult services[8]

Some countries and paediatric associations have made deliberate effort at defining and putting in place measures to ease transition. In 2002, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) issued a joint statement that defined specific steps for ensuring an effective transition. These include having a primary care provider with responsibility for transition planning, incorporating the necessary knowledge and skills to provide developmentally appropriate health care transition services, maintaining an up-to-date portable medical summary, creating a written health care transition plan by age 14, implementing recommended preventive service guidelines, and ensuring continuous health insurance coverage.[9]
A transition programme can only succeed with the active participation and interest of the staff in the adult clinic, which face the challenge of matching the level of family support and rapid staff response that are features of most paediatric services. The paediatrician would be the anchor man in such a process.

Young people who require continuing healthcare into adulthood have generally been transferred from paediatric services at a time of great change in their lives, both physical and emotional. While in some climes, effective transfer policies have been put in place with transition processes beginning as early as 13years. There is no known documented report of transition care services in any Nigerian hospital or institution.
It is therefore the objective of this paper to review the current practice of patient referral and adolescent transition care and set a template for the development of transition to adult care policies and programme as we pay greater emphasis on adolescent medicine in Nigeria.

Methodology

The study was cross sectional and descriptive among paediatric consultants and residents. A self-administered semi structured questionnaire was used in data collection. Information collected included age, sex, years of practice, place of practice, subspecialty and designation. Current practice of referral and adolescent transition care was assessed using YES or NO question format and a few fill in the blanks.

Study Area and Population

Study area was Nigeria paediatric care practice. All consenting paediatric consultants and resident doctors in Nigerian hospitals as well as visiting paediatrician from other countries attending Paediatric Association of Nigerian Conference (PANCONF) 2014 formed the study population.

Sample size

All consecutively returned forms from participants at the 2014 PAN AGSM in Calabar Cross River state were included.

Data collection and analysis

Data collected was entered into excel sheet and analysed using Stata 12SE statistical software. Frequency distribution tables were generated for the entries.
A p value of <0.05 was considered statistically significant.

Result

General characteristics

Eighty questionnaires were filled and returned out of 200 sent out. Of these 33 (41.2%) were consultants and 47 (51.8%) were paediatric residents. There were 41 (51.2%) females and 39 (48.8%) males. Mean duration of practice was 12.5±0.75years with a range of 2-20 years. Consultants have mean years of practice of 16.9±6.0years while the residents have 9.4±5. 2 years. Most of the respondents, 91.2% (73/80), practice in urban setting. The rest have their practice in rural/ suburban places. Of the respondents, 96.2% (77/80) are in public practice while 3.8% (3/80) are in private practice.

Out of the 80 respondents, 61.2% (49/80) work in Teaching Hospitals, 26.2% (21/80) in specialist hospitals, 6.2% (5/80) general hospital and the remaining work in private hospitals, federal agencies and non-governmental organisation.

Over 80% of the respondents see adolescent patients in their practice. Percentage of adolescents seen range from 2-70% of patients seen. Nearly all (98.8%) have co-managed patients with other specialities and subspecialties.

Patient referral practices

Intra-departmental patient referral and feedback
Most respondents, 96%, are involved in patient referral within the department. Patient referral is done either by verbal communication with the desired subspecialty in 46.4% (26/56), relayed information to caregivers 55.8% (30/56), written note to the new team, 92.8% while 21.9% of respondents will have a clinical conference with the new team.
Feedback during such referral is received verbally in 61.4%. Significant numbers of responders (76.7%) says feedback maybe occasional.

Inter-departmental referral and co-management

Most respondents (96.8%) stated referral was done through written notes. One on one discussion takes place significantly (81.0%) during referral. Referred patient are however managed independently in 64.2% of cases while regular clinical conference occurs in 30.8% of clinical scenario and ground rounds occur in about 31.2% of cases.

Transition to adult clinic
Adolescent referral to adult clinic

Written notes are utilized during transfer to adult clinic by 92.3% (48/52) of respondents and formal discharge from originating department occurs greatly, 81.6% (40/49). Formal/informal discussion with patient relatives occurs frequently 92% (47/51). In the same vein, 91.6% (44/48) of respondents will discuss with the adolescents and his caregivers before referral. Only 37.8% of physicians will engage all parties (caregivers, patient and receiving clinicians) in a discussion before referral and 50% of the attending clinicians may discuss with only the adolescent. A few (11.9%, 5/42) may make no formal input before referral.

Transfer policy and standard operating procedures

Among the physician respondents 86.1% (62/72), there is no written policy on patient transfer. Of those with written policy 90% are in teaching hospitals.
For adolescent referrals, there are no written policy (66.2%) for referral and no standard operating procedures (SOP). Most agree on the relevance of SOP (98.6%).
The relevance of SOP agreed to by respondents is as shown in table 1. Most agree on its usefulness.

Table 1: Relevance of SOP

Relevance of SOP	Agree (%)	Disagree (%)	Total (%)
Minimize lost to follow up	69 (97.2)	2 (2.8)	71 (100)
Ensures continuity of care	73 (98.6)	1 (1.4)	74 (100)
Addresses psychosocial challenges	65 (97.0)	2 (3.0)	67 (100)
Affords all inclusive care	67 (97.1)	2 (2.9)	69 (100)
Window of opportunity for further input	61 (93.8)	4 (6.2)	65 (100)

Age at referral to adult clinic and reason for choice

Mean age at transfer to adult clinic was 16.8±1.8years, range 12-20years. Male physicians refer at slightly later age than female physicians 17.2±1.8years and 16.5±2.0years respectively, p=0.12.
The age at transfer is determined by the either hospital practice (72.9%) or departmental policy (71.9%). This is shown in Table 2

Table 2: Determinant of age of transfer to adult clinic

Determinant of transfer	Yes (%)	No (%)	Total (%)
Hospital policy	43 (72.9)	16 (27.1)	59 (100)
Departmental policy	41 (71.9)	16 (28.1)	57 (100)
WHO/UNICEF	26 (49.2)	28 (51.8)	54 (100)
Body size	4 (8.3)	44 (91.7)	48 (100)
Inadequate manpower	4 (8.7)	46 (91.3)	50 (100)
Infrastructural need	10 (21.3)	47 (78.7)	57 (100)

Informed consent prior to referral and refusal of referrals

Most (90.7%, 59/65) will request consent from the adolescent before referral. A few (29.2%, 14/48) will make do with parental consent. Consent may not be sought for by 21.7% (10/46) of respondents while 26.8% (11/41) of respondents may take a unilateral decision to refer.
Most respondents (97% 53/57) have seen adolescents who refused referral to adult clinic or returned after referral. The reasons for this are as shown in the table 3 below.

Table 3: Reasons for refusal of referral to adult clinic

Reasons given	Yes (%)	No (%)	Total (%)
Fear of the unknown	47 (90)	3 (10)	50 (100)
Adult Physician attitude	29 (61.7)	18 (38.3)	47 (100)
Uncertain of level of care	42 (85.7)	7 (14.3)	49 (100)
Inadequate preparation	23 (54.8)	19 (45.2)	42 (100)
Inability to start new care relationship	41 (89.1)	5 (10.9)	46 (100)
Inconvenient appointment days	15 (38.5)	24 (61.5)	39 (100)

Discussion

This study highlights the current practice of paediatricians with patient referral both within and outside the department. It also highlights the current mode of adolescent to adult care transition practice.
Practically all respondents do intra-departmental refer

ral, a practice that engenders better patient management, allowing experts to bring to bear their experience and skills in the management of the index patient. Ringberg *et al,*[10] noted that referring a patient to secondary care in order not to overlook anything is a common and legitimate reason for referral. High referrers report that about one-third of their referrals were carried out to avoid overlooking anything, compared with only 11.9% among low referrers. The results revealed a reduced tolerance for uncertainty among high referrers. This is in keeping with best practices in patient management.

The mode of referral observed in this study varies among physicians with some referral been done via verbal communication but significantly via written notes. Traditionally, referring clinicians obtained input from specialists by either sending patients for in-person referrals or through "curbside consultations"—that is, conversations that occurred between the two physicians about patients when they met in the hospital hallway or cafeteria, or by telephone.[11]Curbside consultations is initiated for a variety of reasons, including the perceived reliability of an expert's opinion, urgency, cost, timeliness, accessibility, convenience, fear of malpractice litigation, reassurance, desire for an academic discussion, and autonomy[12]. Referral notes are common practice but may be marred by inadequacies such as inadequate content and lack of timeliness.[13]

There are few clinical conference/inter-departmental meetings taking place during referral as observed in this study. This kind of meetings enable both teams to clearly understand the purpose of the referral, define expectations and clear grey areas/differences if need be. This practice underscores important components of the models of team health care practices especially the coordinated, multidisciplinary and interdisciplinary models[14]. This practices may be occurring in our settings but they are not clearly defined. Work schedule and time maybe a particular hindrance to achieving this mode of communication in patient management. A clinical meeting involving the patient/caregiver and management team will be beneficial for continuity of care.

Many physicians do not understand why a patient is referred but will be able to do so if clear communication takes place.[15]An effective referral requires feedback. This however seems not to be the case as our findings in this study show, with a significant number of physicians stating they do not get feedback or that feedback is only occasionally received. This poor feedback practices is not peculiar to Nigeria as other studies in Saudi Arabia showed. Abdelwahid *et al*[16] noted that 53% of consultants gave incomplete and poor feedback while Jarallah[17] observed that 81% of the feedback were inappropriate. Although a referred patient may no longer return to the primary physician, the outcome of the referral is certainly useful for improved care of patients with similar problems.

Adolescent care services

Over 80% of respondents encounter adolescent patients ranging from 2-70%. Most adolescents are referred in the same process of referral using referral notes and most are formally discharged. The process also involves some discussion with the adolescent but not in all cases of referral. In this study, it was observed that not all parties such as the primary care givers and receiving physicians are involved in a discussion before a referral process begins. Exclusion of the adolescent from referral talk may make it much difficult for the adolescent to form long lasting clinical relationship with his/her new management team.[4]

This study shows that there are no guiding policies or standard operating procedures for adolescent transfer to adult clinic. This is different from what is obtained in other climes where guidelines exist.[18] Most respondents agree on the necessity of such policies or SOP. The SOPs are thought to be an avenue to minimize lost to follow up in adult clinic, ensuring continuity of care, addressing psychosocial challenges and providing for an all-inclusive care processes. It is believed that a well-executed transitions can improve outcomes and patient satisfaction, decrease costs, and ensure that patients understand how, when, and where to seek help.[19]

The necessity of a SOP is further strengthened when the varying age of referral to adult clinic is considered. In the present study, adolescent referral age ranges from 12 -20years with a mean age of 17years. This is close to the 16years age of referral adopted by the Royal Children's hospital, although a consideration is in place for an official cut off age of 19years.[18] The age of transfer in our observation was governed by departmental as well as hospital policies while in few instances infrastructural deficiencies influenced the process. The timing of transfer depends on physical and psychological factors and the developmental readiness of the adolescent[18, 20]and not by undefined criteria. For speciality clinics without transition programmes, transfer of patients often happens in a haphazard and idiosyncratic fashion. Common precipitants for transfer are leaving school, crises such as pregnancy or a suicide attempt.[21]

The problem with poorly planned transfer is the high rate of lost to care and return of transferred patients among others.[22]Most paediatricians have encountered children who refused or returned after transfer. Some of the reasons for this 'failed' transfer include fear, uncertainty, attitude of doctors, difficulty with starting new relationship and poor preparation.[3] While this is the finding in this study; difficulties exist with transferring adolescents with special health care need.[18]

For adolescents with chronic diseases, transition is a very important period requiring not only medical, but also psychological and social support, which should begin on the day of diagnosis. Lack of coordination between paediatric and adult units, resistance of the adolescents and their families, and lack of planning and institutional support as well as receive conflicting advice regarding chronic illness management are some of the hardships that can be encountered during transition.[20, 23]

Conclusion

In conclusion, it is obvious that we have no transition care practice in place and no guidelines to the establishment of such practice. This therefore requires concerted effort by paediatricians to interface with their adult physicians to develop such a framework within the context of existing best practices and institutional capabilities. Various subspecialties in paediatrics managing adolescents with chronic disorders need to take up this challenge and develop working guidelines and documents to make adolescent transition to adult care centres smooth and without burden to the adolescents and his caregivers.

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