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de médecine sociale et préventive



1st European Transition Symposium

Friday, September 14th 2018
Lausanne

Unil
UNIL | Université de Lausanne



Program
Friday, September 14th



8:00
Welcome & coffee

8:15
Welcome address

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Dr Christina Akre
Prof. Umberto Simeoni

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Keynote session 1

« La suite-necker »:

an innovative transition care program
for teenagers and young adults with
rare or chronic diseases

Nizar Mahlaoui



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Christina Akre

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Conclusion

Even though transition from pediatric to adult care is currently a hot topic, when about one year ago we decided to launch the first European Symposium on Transition, we did not know what to expect. In our worst nightmare, we thought that it might interest so few that we could hold it in a taxicab...

Then we started to receive emails from a little bit everywhere. Moreover, this interest translated into 30 abstracts from 10 countries and about 50 participants registered to date. The oral presentations include a broad thematic spectrum (from description and evaluation of programs, research results or clinical work to policy development) and illustrate the interest that transition arouses among health professionals.

Furthermore, what most participants have told us they are thrilled with is having the opportunity to meet and network with other professionals working in their field of interest. These contacts should facilitate creating common grounds in the development of transition programs that work.

Transition is not just moving patients around. Transition is helping young people and their families safely navigate the usually complicated health system, improving their health and quality of life, and, above all, become socially integrated adults.

We are sure that this is just the beginning of more symposia to come.

Joan-Carles Surís & Christina Akre
Organizing Committee

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«LA SUITE-NECKER»: an innovative transition care program for teenagers and young adults with rare or chronic diseases

A rare (or "orphan") disease is a chronic inherited disease affecting less than 1/2000 inhabitant. There are more than 8,000 rare disease and overall, it is estimated that there are 4 millions patient in France (amongst 30 millions in Europe). Often times, these diseases are complex and need high level of multidisciplinary medical management.

Necker-Enfants maladies hospital is a highly specialized hospital; especially in rare diseases since more than 4000 patients aged 13-25 years accounting for 4000 rare diseases are seen every year in one of the 40 national reference centers located at Necker Hospital.

Life expectancy has improved over decades. Thus, transfer to adult care of adolescents and young adults with rare or chronic diseases treated in our hospital has become a major topic since a few years.

In fact, it is a challenge for patients and their family but also for the medical team.

Along with the patients themselves, patients associations, the Necker healthcare community (doctors including surgeons and psychiatrists, nurses, psychologists, social workers and board of Directors) and adult hospitals in Paris (12 million inhabitants), a large program to tackle issues related with Transition Care (2015-2020) was designed with the following aims:

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1. Building stronger partnerships between Necker and close adult hospitals where patients are taken care upon transfer.
2. Improve the transitional care from Necker's end.
3. Address unmet needs for the cohort of adolescents and young adults followed at Necker Hospital, within a newly designed and built space, called "La Suite-Necker", along with the dedicated website and mobile app.

The goals are:

- Take care of themselves
- Work on their self-esteem
- Prepare their future
- Plan their life with the disease
- Learn how become an independent adult.

This space is open to any AYA followed at Necker for a chronic disease. Their parents are welcome upon the first time and should let their child alone for any of the one-on-one appointment, should it be medical (gynecology-andrology) or non-medical (body image, socio-aesthetics, adapted physical exercise, relaxation, shiatsu, yoga) ; or any of the group activities (patient therapeutic education programs or dedicated workshops) usually with a qualified reception, health prevention and promotion for an easier transfer from pediatric department to an adult department.

Introduction to the space itself and these resources is made by the coordinator of this space (social worker with a training in adolescent care). Resources can also be offered to inpatients if need be.

La Suite-Necker is the first project of its kind, hence experimental and has welcome more than 200 patients since Oct 2016.

Many pediatric hospitals in France have showed interest in our project and are about to design a project in relation to their needs.

In July 2018, the Georges-Pompidou European Hospital (Paris) opened the Marina Picasso Space for young adults transitioning from a pediatric hospital (mostly from Necker Hospital) with many more collaborative projects to come.

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Cohort study of 130 patients with juvenile idiopathic arthritis during transition from pediatric to adult care

BACKGROUND AND PURPOSE

Juvenile idiopathic arthritis (JIA) is the most common chronic inflammatory arthritis in children. The International League of Associations for Rheumatology 2001 (ILAR) classification includes 7 subgroups: systemic JIA, polyarticular JIA, oligoarticular JIA, enthesitis related arthritis (ERA), psoriatic arthritis and undifferentiated arthritis. Most JIA persist into adulthood. Therefore, a transition from paediatric to adult care is a necessary step. However difference in classification criteria in paediatric and adult rheumatology can cause significant difficulty for adult rheumatologists. The aim of this study was to determine the characteristics of JIA seen during the transition period and to compare paediatric classification criteria to those of adults.

METHODS

A retrospective bi-centre study included patients with JIA according to ILAR classification seen at transition consultation. JIA classification criteria were compared to ACR/EULAR 2010 criteria for rheumatoid arthritis (RA) and ASAS criteria for spondyloarthritis.

RESULTS: 130 patients were included: 18 systemic JIA, 32 polyarticular JIA, 26 oligoarticular JIA, 45 ERA and 9 psoriatic arthritis. The median age of transition was 19 years old. Nine cases of uveitis were observed among patients with oligoarticular JIA and 7 with ERA. 12% of patients displayed erosions or carpalis, mainly in psoriatic arthritis and polyarticular JIA patients. 27% of patients with ERA displayed sacroiliitis. In comparison with adult rheumatism, 37% of patients with polyarticular JIA fulfilled criteria for RA. 75% with ERA and 100% with psoriatic arthritis fulfilled criteria for spondyloarthritis.

CONCLUSIONS

Comparison of JIA criteria to adult rheumatism criteria showed that polyarticular JIA with positive rheumatoid factor fulfilled criteria for RA. However, oligoarticular JIA and polyarticular JIA without rheumatoid factor did not fulfill any adult rheumatism criteria and seem to be paediatric entities. Finally, most patients with ERA and psoriatic arthritis fulfilled the ASAS criteria for spondyloarthritis.

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Transition program in pediatric cardiology

BACKGROUND

Our center covers an area of 2 Mio inhabitants and all CHD patients are followed at our clinic. For several years our clinic has been conducting transfer consultations in common with the GUCH cardiologists. As the number of our adolescent patients increases, we have decided to create a transition program targeting their specific needs. Our first step was to evaluate their needs in education and support as well as the actual response to them. Our goal is to help them acquire autonomy regarding their health.

METHODS

Patients with CHD from our clinic between 14 and 18 years old and their parents received each a questionnaire targeting the importance and the actual response to their needs in relation with transition. At the same time we began a program of thematic workshops for these patients.

RESULTS

We sent 187 questionnaires to adolescents and their parents (374 questionnaires in total). We received 136 answers, 61 adolescents (32%) and 75 parents (40%). The adolescents and their parents show a good degree of satisfaction regarding communication with the professionals. Our patients declare knowing their cardiopathy but are unclear with the related restrictions and the signs that should alert them. They have little information regarding their future and their degree of autonomy is insufficient. However the need of autonomy seems to be more important for the parents than the adolescents. Only 14 adolescents participated in the workshops. 75% of them would be ready to attend further workshops.

CONCLUSION

The answers to the questionnaire show the need for a personalized program for adolescents with CHD which includes education on their actual health, healthy lifestyle and prevention as well as their future perspective. The workshops answer certain needs, but they need to be completed with individual interviews and patient education.

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KidsETransplant: a serious game to prepare the transition of children with liver disease or after liver transplantation

BACKGROUND

Transition from pediatric to adult care is problematic for all chronic diseases in children. In solid organ transplantation it has been associated with graft loss and patient death. Common challenges for patients are lack of understanding of their illness, lack of sense of responsibility and erratic therapeutic observance. KidsETransplant is a unique electronic platform designed to assist children in developing these skills.

METHODS

KidsETransplant combines the child's electronic medical records with 3D serious gaming. Patients consulting in our clinic from 1/2014 to 10/2014 were included in this study. Two semi-structured interviews were conducted to measure the impact of KidsETransplant: one before, and one after 1 year of use.

RESULTS

Sixty-nine patients having received a liver transplant were included. Usage by parents accounted for 82% of all usage, while only 7% by patients themselves. One year after KidsETransplant implementation, 68% of families used it, mainly at home (84%), but also at the pediatrician's office (8%) or when travelling (8%). The main reason for using it was for checking lab results.

CONCLUSION

KidsETransplant is appreciated by children and their family, and used to consult lab results and facilitate communication with caregivers. It contributes to a fundamental cultural change in the relationship between health professionals and children suffering from chronic illness by encouraging education and self-management.

Inartis Foundation, Lynx-for-Hope, Fondation PrimEnfance, Glencore International, Carigest, Fondation Privée des HUG

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Polyarticular juvenile onset arthritis at transition period: screening of antinuclear antibodies may be useful!

Adolescent patients affected with chronic juvenile inflammatory arthritis (JIA) need to be supported through the transition process from pediatric to adult care. Follow up focuses on clinical status and treatment adjustments. If JIA is not under remission, immunological status and antinuclear autoantibodies (ANA) should be checked.

CASE REPORTS

Case 1: a 14-year-old girl was diagnosed for rheumatoid factor negative polyarticular JIA and maintained under remission with methotrexate and etanercept. At the age of 17 years she presented with severe Raynaud's phenomenon and received iloprost. At the age of 19 years, at transition, she presented with a polyarticular relapse, and she fulfilled the criteria for mixed connective tissue disease (MCTD) with ANA 1280, negative anti dsDNA, and high level of anti-U1RNP antibodies. Etanercept was discontinued and tocilizumab was initiated. Articular outcome was favourable with 2 years follow-up and corticosteroids were tapered.

Case 2: a 16-year-old boy was diagnosed for polyarticular juvenile inflammatory rheumatism. Rheumatoid factor and ACPA were negative. One year later, he was referred at the transition clinic with IPP arthritis on both hands. ANA were 320, Farr>98. Diagnosis of systemic lupus was established and hydroxychloroquine was started. After 1 year of follow-up, symptoms are controlled.

DISCUSSION

at transition, when some young patients are confronted to flares or evolutive juvenile onset arthritis, diagnosis of polyarticular seronegative arthritis should be reconsidered. Patients may have psoriatic arthritis, systemic lupus, rhus, overlap syndrome, MCTD. These conditions require specific treatments different from those for polyarticular JIA. Adequate assessment of autoantibody profiles is required at transition for appropriate management of inflammatory rheumatisms.

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Juvenile onset arthritis at transition: check for nail psoriasis!

Young patients with polyarticular arthritis, enthesitis, dactylitis are diagnosed psoriatic arthritis when typical nail alterations are identified at transition clinic.

CASE REPORTS

Case 1: a 15-year-old girl was referred to the pediatric clinic because of left MTP1 arthritis. Laboratory tests were negative: rheumatoid factor (RF), anticitrullinated protein antibodies (ACPA), antinuclear antibodies(ANA), HLA-B27. Two years later at transition, she was examined for bilateral MTP1 arthritis. Hyperkeratosis of toes-nails indicated nails-psoriasis that was confirmed by biopsy. Naproxen was effective on arthritis symptoms.

Case 2: a 18-year-old boy was admitted with a 6-months history of dactylitis of 2 toes. Psoriatic nails were identified. Results revealed elevated CRP 78 mg/L; other tests were negative such as RF, ACPA, ANA, HLA-B27 and HLA-Cw6. Methotrexate was effective and lasting improvement is maintained after 2 years.

DISCUSSION

nail findings may indicate psoriasis. Different nail alterations can be observed: leukonychia, onycholysis, hyperkeratosis. Juvenile inflammatory rheumatism without RF, ACPA, ANA but with nail psoriasis should be considered as psoriatic arthritis. Topical nail therapy may be tried but is rarely sufficiently effective. When quality of life is severely impacted by nail psoriasis and psoriatic arthritis, systemic treatment includes methotrexate and biologics (anti-TNF, anti-IL12/23, anti-IL17).

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Transition training for staff in paediatric palliative care

BACKGROUND

LauraLynn is Ireland's first Children's Hospice based in Dublin. More children with life-limiting conditions are surviving into adulthood and transfer of care from paediatric to adult services is complicated by the complex needs of these young people. A process known as Parallel Planning keeps the focus on quality of life while acknowledging the possibility of an early death. The wishes of the young person and their family are central to this process and planning continues in times of uncertainty.

A Transition Care Pathway, based on international best practice, is being implemented at LauraLynn using the Quality Improvement Cycle. A crucial starting point was to educate staff across the organisation ensuring a common understanding of the term 'Transition' and its implementation.

METHODS

A slide presentation describing the LauraLynn Transition Care Pathway was designed and presented to small groups by the Transition Lead between October 2017 and May 2018. A total of 83 people have undergone training to date including medical, nursing and care staff, allied health professionals, the management executive, education and administration staff. A survey to ascertain the response to training was conducted during April and May 2018.

RESULTS

The response rate was just over 30% (N=33). 32 people reported the training was useful. All found the training format clear and rated their knowledge of Transition as Good or Excellent following training. The themes deemed most important were Starting Early; Planning; and Clear Process.

CONCLUSION

Training staff across the organisation has proved a successful strategy. The format used allowed training to occur at times that suited staff, this is particularly important where workload varies during the day and staff work shifts. Training sessions provided a valuable opportunity to explore staff concerns, opinions and suggestions.

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No reason to be complacent: first results of a mixed- methods controlled evaluation study into transition programmes in dutch diabetes care

BACKGROUND

The need to improve transitional care is widely acknowledged, but uncertainty remains about interventions effectively supporting young people during their transition and transfer to adult care. The evaluation of multifactorial transition programmes is complex. This study, part of a national quality improvement initiative to advance transitional care in diabetes, aimed to map the added value of transition clinics among other interventions.

METHODS

Mixed-methods, retrospective controlled design consisting of interviews with professionals, observations of consultations, chart reviews of patients transferred 2-4 years before data-collection and questionnaires among those included in the chart reviews. Qualitative data-analysis focused on structure, content, barriers and facilitators of transition programmes. Quantitative outcomes involve within-groups (over the four years) and between groups (intervention-control) comparisons. Outcomes include no-show, experiences and satisfaction with care, clinical parameters, healthcare use and self-management.

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RESULTS

Fourteen centres participated; 50 consultations were observed; 40 professionals interviewed. Data from 321 patient charts were collected; 165 responded to the questionnaire. Large differences existed in the amount of attention paid to transition, often limited to joint clinics around transfer. Organisational barriers included lack of funding of transition clinics while professionals were highly motivated to improve collaboration. Clinical outcomes were alarming with only 20% of patients reaching targeted Hb1Ac-scores (no difference between child/adult care); 10% not showing up for their first consultation in adult care. Youths' transfer experiences showed room for improvement and the need to involve young people.

CONCLUSION

Transition programmes need to focus on both organisational and self-management challenges.

This research was financially supported by FNO and the Dutch Diabetes Fund.

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Medical care of unaccompanied minors at the geneva university hospitals: a qualitative study to explore the challenges of their transition to majority

BACKGROUND AND PURPOSE

The number of unaccompanied minors has increased in Switzerland in 2015, prompting medical teams to improve management of these young people and their transition towards adult medical care. The aim of our project was to assess how the Geneva University Hospitals' Adolescents and Young Adults Program (primary care center for this population) prepared for this transition.

METHODS

Semi-structured interviews were conducted with 6 health professionals all working with unaccompanied minors in order to explore what preparations took place for minors reaching the age of majority and their proposals to improve the transition of care.

RESULTS

Health professionals are challenged when their patients reach majority by difficulties with network coordination, school integration and unadapted foster homes. The process of transition is described as an area of uncertainty. The need of continuity in health care is recognized, but the topic of the legal age and its consequences is rarely addressed in consultation and caregivers question the adequacy of their role in addressing this issue. This research also identified that there were no clearly structured medical transition program between the Youth Health Unit and the Adult Migrant Health Program. Participants underlined the emotional consequences for these young people (feelings of anger, depressive mood) and worried about their impact on the most vulnerable.

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DISCUSSION/CONCLUSION

The transition of care for young migrants is challenging for health professionals. An integrative and transversal understanding of this transition is needed by further exploring how the community responds to this transition and the impact on unaccompanied minors' mental health. Health professionals need to address this transition during their consultation, before the age of 18 as part of the medical follow up. This study has also lead to structure an experimental transition procedure with the Adult Migrant Health Program involving a dedicated nurse.

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Developing and standardising adolescent transition services in epilepsy care in Ireland- a coordinated, systematic approach

BACKGROUND

Young people (YP) with chronic conditions such as epilepsy face many challenges including changes to their healthcare provision. The lack of developmentally appropriate healthcare at this stage can have a significantly negative impact often leading to a deterioration in health and result in YP falling through the «care gap». Transition is a gradual integrated process which has a shared responsibility between paediatric and adult services. An Epilepsy Transition Coordinator post was created to improve the preparation and engagement of YP with epilepsy for transition from paediatric to adult services and to develop a standardised evidence based approach to transition.

METHODS

A needs analysis of existing services was conducted. The views of YP and families were elicited through involvement with ongoing research studies at Temple Street Children's University Hospital (Crowley et al 2017) and via the Epilepsy Partnership in Care (EPIC) study. System based issues and clinicians views were identified through engagement with epilepsy teams at paediatric and adult sites nationally.

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RESULTS

Eight key objectives were identified:

1. Agreed transition pathway for YP with epilepsy that is sustainable
2. Improve access to services at paediatric and adult sites.
3. Development of a transition registry to track and monitor YP
4. Standardised referral process and transfer documentation.
5. Development of information resources and transition interventions for paediatric, adult and community settings.
6. Development of staff education and support.
7. Electronic Patient Record development and integration.
8. Engage with national clinical programmes to develop national guidelines

CONCLUSION

The role of the transition coordinator has enabled transition services to grow in a consistent and systematic way. Hopefully this will continue to improve the journey of YP across the care gap.

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The pass'âge: a multipurpose dedicated space to improve transition

BACKGROUND

Adolescence is a critical period of mutation during the life and the underlying changes may be challenging in the context of chronic diseases. Young patients are facing to the necessity for independence acquisition, are integrating the disease and the treatment and built their identity and future.

In Lyon, France, the pediatric hospital has developed a specific connected workspace inside the outpatient unit to facilitate actions in transitional cares.

METHOD

A focus group including young patients has been built in order to delineate the specific need of adolescents with chronic diseases. A online questionnaires were sent online to determine the ongoing projects and integrate all physicians (pediatric and adult practitioners). From the beginning, the project was collaborative and integrative inside the pediatric hospital and has benefit from private fundings.

RESULTS

Patients and physicians have pointed the importance of therapeutic education programs and a joint consultation (adult and pediatric sector) prior to being transferred to the adult sector.

Adolescents and young adults seem interested in adapted physical activity program, focused therapeutic sessions (addictions, relaxation, professional future, dietetics..) and a discussion group between both of them.

Thematic rooms including sport space, disease education centre and a transitional room have been created.

CONCLUSION

This new workspace is a promising area at the interface of hospital and outpatient ward, between adult and pediatric unit. Connectivity and innovation have been particularly promoted. Regular assessments will be done to determine the efficacy of this program to keep young patients involved in their care.

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An overview of rare diseases transition networks in france in 2017

BACKGROUND

The missions of the 23 french rare diseases networks called “filières” created in 2014, are to facilitate the orientation of patients, to create data bases, to diffuse guidelines, to coordinate research works, education and training of caregivers.

Since 2016, the NeuroSphinx network has been designated by the French Health Ministry as pilot of the “inter-filières teenagers-adults transition group”. Out of 23 networks, 2 were not concerned by this topic.

PURPOSE

To conduct an overview of major actions and tools in transition developed by the filières in France.

METHODS

A survey was carried out on 21 filières and conducted between november to december 2017. Its aim goals were to list the major actions in transition in organizing networks, research works, therapeutic education of patients, recommendations and concerned patients associations.

The medical specialties considered as transversal for transition were identified.

RESULTS

All the 21 networks responded to the survey. Tools to facilitate the transition (transition booklet, mapping of specialists...) were developed by 15/21. Specific recommendations were performed by 2/21 and 18/21 have ongoing projects. Were defined as transversal specialties: general and internal medicine, gynecology, psychology.

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DISCUSSION/CONCLUSION

France is leader in the organization of rare diseases management. However, transition is still late and many projects are just emerging.

NeuroSphinx has identified 3 main areas to work on in priority:

- Formalization of a national network of caregivers for adults follow up.
- Elaboration of recommendations of essential and transversal skills to be acquired during adolescence before transfert.
- Creation of a «transition and rare diseases» website, listing all actions in transition in the country (places, tools, research, etc.).

The first major action of NeuroSphinx transition group is to organize a caregivers conference on June the 1st, 2018: «Adolescence and Rare Diseases: what are the common perspectives?» to specify the priority actions.

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Building a transition programme for young people with chronic conditions

BACKGROUND

Transition from paediatric to adult health care settings is a challenge for all adolescents/young adults (AYA) with chronic conditions (CC). Of the 5000 patients at Robert-Debré University Hospital, 500 pass each year to adult health care services located in the Paris area but also all over France.

METHODS

A hospital-wide survey was conducted in 2015 to evaluate the situation regarding transition. Some units had already incorporated the subject in their patient education programmes; others had not yet tackled the issue. In order to respond to the various needs of each unit, a multi-disciplinary steering committee including 10 patient associations was put into place to elaborate a hospital-wide transition programme, now called AD'VENIR. Despite the perceived interest of hospital administration, financing for the programme had to be obtained from exterior sources.

RESULTS

Funding was obtained from a private foundation to build a dedicated transition space and from the MOH in a call for projects on patient empowerment to hire a coordination team. AD'VENIR's main objective is to help prepare AYA with CCs for transition by facilitating the acquisition of skills and knowledge necessary for adulthood. Programming includes individual consultations and group workshops on numerous issues related to becoming an adult with a CC: patient rights, vocational counselling, sexuality and relationships, relaxation... A parent support group will begin soon and a dedicated website is in development.

CONCLUSION

AD'VENIR's programming is appreciated by AYA who have benefited, as well as by their parents and HCPs. However, engagement has proven challenging. With a dedicated space built, the website launched, communication broadened and more HCPs on board, the expectation is that the hospital-wide transition programme can improve the transition process for AYA, their parents and HCPs.

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Co@ch: an app-based intervention to support parents of adolescents with chronic illness during transition

OBJECTIVE

To describe a transition support tool for parents of adolescents/young adults (AYA) living with a chronic condition (CC), in order to facilitate transition.

METHODS

We developed a Mobile Application called CO@CH for parents of AYAs with a CC aged 12-24 years old preparing for or going through transition from pediatric to adult care. On CO@CH, parents use their smartphones to create visual narratives to talk about what it is like to care for a child with a CC and share them with others by uploading them on the App. The App is monitored: the project manager checks all the incoming videos for accuracy and assigns a title and keywords to each before posting them on the APP in order for all participants to watch. CO@CH aims at acting as a platform for parents to share a caring experience, to connect and to crowdsource challenges, problem-solving and strategies, struggles, and successes. Parents of AYAs suffering from a chronic condition in different pediatric and adult clinics at the Lausanne University Hospital are invited to take part in CO@CH.

RESULTS

A total of 63 parents (6 fathers) of AYAs with a CC were invited so far to participate. To date, of the 63, 15 parents dropped out and 6 were excluded as they did not answer. Therefore, 42 participants are involved in the project so far.

CONCLUSIONS

This intervention is part of a wider endeavor to ameliorate vulnerable families' experience of going through transitional years during adolescence on a medical and psychosocial point of view. If proven effective, CO@CH can become, in the longer term, an ongoing peer support resource for these parents.

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Ten steps transition to adult services: an innovative pathway for improving transition to adult services for young people including those with multiple complex long term conditions

AIMS

To develop a pathway supporting all transition to adult services from simple to multiple complex long term conditions.

METHODS

Development: Pathway informed by literature review, interviews with adult specialists and GPs, workshops, experiences of professionals and of young people themselves: further refined through face to face and online consultation, and a one day workshop.

Implementation:

- Face to face meetings, online consultation, newsletter, workshop, conferences, staff training
- Executive led transition team: specialty transition leads
- Identifying all patients of transition age accessing the hospital in the last 2 years
- Identifying and learning from incidents and near misses
- Phased implementation, including baseline audit, specialty by specialty
- Engagement with adult sector

Evaluation

- Professionals survey and specialty by specialty audit against 10 Steps Pathway Standards before and 3 years after initiation of the programme

RESULTS

The 10 Steps Transition Pathway and resources including:

- What good looks like – young person's guide for what to expect
- Empowering young people, supporting parents
- Role of Lead Consultant, Keyworker and GP
- Planning for emergencies including self-management, GP and hospital admission
- Transition Exception Register – actively supporting and monitoring young people remaining in children's services
- Transition Policy for children's and adult services with auditable standards
- Transition integrated into electronic patient records
- Multidisciplinary transition training
- Website

Successful implementation including:

- Engagement with over 250 professionals
- Improvements in professionals awareness, engagement and whole organizational approach to transition
- Monitoring transition status for young people of transition age
- Identification of professionals' understanding and learning needs regarding transition
- Engagement with commissioners and adult services to develop appropriate pathways including for young people with complex neurodisability

CONCLUSIONS

The 10 Steps Transition Pathway supports transition to adult services for all young people including those with the most complex needs. Implementation of the 10 Steps Pathway has the potential to ensure safe effective person-centred transition for all young people.

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Transition website - a new tool for health professionals, young people and their parents

BACKGROUND

Several international guidelines regarding transitional care exist. However, planning and implementation of feasible programs are still lacking in Denmark, and there have been no nationwide place to find tools or material about transition. The aim of this project was to develop a website on transitional care to make it more manageable for health professionals to plan and implement transition programs and to establish an easy way to get evidence and experiences of others. Furthermore, the website was aimed to support young people and their parents during transition and gather all needed information about the transition process.

METHODS

We developed the website www.transitionsforløb.dk on basis of international recommendations as well as guidelines from a PhD dissertation on transition, dealing with the practical planning of transition including concrete tips about communicating with young people and how to include identity related topics in the conversation. The website was launched in March 2018.

RESULTS

www.transitionsforløb.dk was developed for three target groups: Health Professionals, young people and parents. The pages aimed at health professionals involved information material and letters for download, advice on communication (specific techniques and suggestions on questions to young people), inspirational cases, checklists, leaflets and tips for planning. The pages aimed at young people involved descriptions of the transition process, how it takes place as well as audio files, where other young people tell about their experiences of transition. The pages aimed at parents involved support to their child and description of transition.

CONCLUSION

The website has been well received and it has been featured in more media. We expect it to be a useful tool in implementing transition programs for young people in the Danish hospitals during the coming years.

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www.
dessinemoiunmouton
.org

Transition should include out-of-hospital support

As we know, when young people with chronic illness should be transferred from pediatric to adult care, nearly 30% of them do not transition. This interruption results in the halting of their medication regimen and intake.

In France, Dessine-Moi Un Mouton is a unique center that works to compliment hospital care. Our organization has 20 years of experience on this subject. In 2000, the organization started a service dedicated to adolescents from ages 14-25 to help them live a more wholesome life with their illness, and see a brighter future.

Many years of experience have helped us develop some principles:

- an adolescent with chronic illness often lives with no hope for the future, which prevents them from transitioning to adult care. To restore their hope, we must include psychological care in conjunction with medical care.
- Transitions should include familial and romantic relations, as well as education and/or professional path guidance.
- Therapeutic activities should not impose subjects of discussion. They should instead create spaces that allow adolescents to be themselves and to speak on subjects that they want to discuss within the framework of support, which could take place for 3-4 years during their transition.

In conclusion, these adolescents with chronic illness indeed require a very particular care:

- Transition should not only be medical, but should also improve adolescents' overall quality of life
- Outside complimentary organizations from hospital are necessary for overall treatment
- Transition should include peer relations
- Each adolescent should have a personalized health path
- Transition should take into account their life story and personal circumstances
- Their transition should integrate physical bodily changes and the psychological impact of these changes in relation to their self-image and relationships to others

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What is the impact of a structured healthcare pathway dedicated to patients in transition on their long-term follow-up?

Management of patients presenting a chronic endocrine or metabolic disease during transition period is a challenge for multiple reasons. The department of Adult Endocrinology and Reproductive Medicine in Pitié Salpêtrière Hospital, Paris has been involved in the management of such patients for many years. However, in our own experience, 81% of patients are still followed-up after 1 year, 71% after 3 years and only 49% after 5 years.

Based on such experience, we decided to set up a structured healthcare pathway dedicated to patients in transition. We built up this program with the Department of Nutrition, the Department of Diabetology and the Department of Endocrinology and Metabolism, all located in the same building in Pitié Salpêtrière Hospital. We associated to this program among others nurses, dietiticians, psychologists and more recently a coordinator dedicated to this healthcare pathway.

Since september 2016, 273 patients have been included at a mean age of 19 yrs. These patients were mostly referred from Children Hospitals located in Paris and managing children with endocrine disorders. The most frequent chronic diseases were brain tumours (15%), obesity (14%), DSD (11%), Diabetes (10%) and Pituitary deficiencies (9%). Among this population we studied the follow-up of patients included between September 2016 and February 2017 and analyzed their management after one year, by the end of march 2018. Seventy-nine patients were followed-up during this one-year period; seventy-four patients (93.6%) have been currently managed in in-door or out-door clinics. Even if this appears as a very important number of patients, we have to notice that such result depends on the strong involvement of the educative team dedicated to this pathway.

In conclusion, this structured healthcare pathway appears potentially helpful for the management of young adults during transition period.

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Transition for patients with type 1 diabetes with a dedicated transition nurse

BACKGROUND

Transition in diabetology is associated with loss to follow-up and adverse health outcomes. Promoting optimal continuity of care might decrease acute complications and hospitalizations. In the Canton of Vaud, a nurse-led, structured transition program for patients with type 1 diabetes has been developed since 2011.

PURPOSE

To describe outcomes of a transition program for patients with type 1 diabetes mellitus

METHODS

To enhance care for young adults with T1DM in the canton (state/province) of Vaud Switzerland, a structured transition program was developed to ease the transfer of patient care for young adults with T1DM from pediatric to adult care. This program provided nurse-led (the "transition nurse") consultations to coach and guide patients during this process. Data from the Swiss federal office for statistics were used to determine the number of hospitalization for diabetes in Switzerland.

RESULTS

In the first 6 years of the program, 150 patients (46% male) have successfully transitioned from pediatric to adult care, 33% to a tertiary center, and 67% to community-based practices. The number of nurse visits ranged from 1-32visits/patient. Consultations were well accepted and responsive to patient needs and desires. 2 years after the initiation of the transition program, the incidence of hospitalizations for diabetic decompensation declined from 4.5 to 1.7 (number per 10'000 inhabitants) among 15-19 year old type 1 diabetes patients.

DISCUSSION

The model including a dedicated transition nurse providing individualized coaching, therapeutic education during transition and serving as a navigator role, seems successful in ensuring that patients attend initial visits to adult-oriented community-based practices as well as tertiary care centers. This model is well accepted and seems to lower hospitalizations for acute complications.

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Implementing and evaluating a patient navigator service in alberta, canada for youth with chronic conditions transitioning to adult care

BACKGROUND

Clinical practice guidelines for transition to adult care recommend use of patient navigators to coordinate patient entry into the adult health system. Access to navigators may decrease disease-specific adverse events and non-compliance. Additionally, no study to date has evaluated the effectiveness of intervention across multiple chronic disease settings.

METHODS

The navigator service has been implemented across multiple chronic disease settings. Using a pragmatic randomized control design, intervention will be compared to usual care for reducing emergency room visits and improving overall care satisfaction among adolescents aged 16-21.

The navigator intervention, provided by experienced social workers within the health system, was defined as follows: 1) Preparation - educate families about the multifaceted nature of transition, focusing on readiness for transfer. 2) Self-management - use strategies such as motivational interviewing to facilitate development of self-management in patients. 3) Systems broker - facilitate system collaboration to address needs of complex patients, encourage use of primary care/medical home, and develop self-navigation skills. 4) Navigating psychosocial services - address social determinants of health and modifiable barriers to service access within multiple systems.

Sources of support:
Maternal, Newborn,
Child and Youth Strategic
Clinical Network;
Alberta Health Services;
Alberta Children's Hospital;
Canadian Institutes
of Health Research

Intervention was developed after extensive stakeholder consultation and interviews with patients and families. Navigators will also use standardized assessments (e.g. SSHADESS) to achieve treatment goals.
RESULTS: We expect navigator intervention will improve overall care experience and decrease ED/urgent care use among transitioning youth.

CONCLUSION

The program will provide an essential service to youth in Alberta with chronic health conditions. It will also provide data to guide service providers and policy makers regarding optimal transition care.

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Transition from child and adolescent mental health services and adult health health services in europe: lessons from the milestone project

BACKGROUND & PURPOSE

Disruption of care during transition from Child and Adolescent Mental Health (CAMHS) to adult mental health services (AMHS) represents a major challenge for society. The MILESTONE project proposes an EU-wide study of transition from CAMHS to AMHS in 8 countries, to strengthen transitional care across eight different healthcare systems.

METHODS

The project includes, among many other activities, an online mapping survey and a cohort study with a nested cluster randomised controlled trial. The mapping survey was directed at expert(s) in each of the 28 EU countries to collect data about CAMHS organization, characteristics and actual national transition policies/practice. In the cohort/cRCT study CAMHS have been randomised to provide either (i) Managed Transition or (ii) usual care for young people reaching the transition boundary (TB) at the age of 18 years. Data have been gathered by young people reaching the TB, one parent/carer and clinicians for each recruited young person. Need of care, as measured by Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA), is the primary outcome measure. Secondary outcomes include mental health, social and adult functioning outcomes, quality adjusted life years and health and social care resource utilisation.

→

RESULTS

With a 100% response rate, the mapping survey highlights considerable country differences in the characteristics and activities of CAMHS, as funding sources and user access, with a lack of written policies for managing the CAMHS-AMHS interface. Over 1,000 young people and 900 parents/carers have been recruited for the cohort study. Three of the four follow-up assessments have been completed and data collection will end by 31st December 2018.

DISCUSSION

This project provides important data of the processes influencing transition at the service interface across differing healthcare models in Europe and longitudinal outcomes for young people leaving CAMHS, solutions for improving transitional care in a cost-effective manner.

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Experiences with transitional care for young people with diabetes type 1: a quick scan among young people and their healthcare professionals

BACKGROUND

For young people with diabetes type 1 (DM1), balancing between developmental milestones and disease-related adaptive tasks may be complicated. They are at risk for poorer glycemic control and need tailored support to successfully take up self-management during transition to adulthood and make the transfer from pediatric to adult care. Loss to follow-up is a serious problem in DM1 which could cause severe acute and chronic complications. The research aimed to gain insight into young people's and professionals' experiences with current transitional care provision for DM1 in the Netherlands.

METHODS

A national, cross-sectional questionnaire study was conducted among young people with DM1 (12-25 years; n=384) and healthcare professionals (pediatric and adult care; n=156). Patient-related outcomes such as empowerment, transfer experiences, coping with DM1 in everyday life and topics discussed during consultations were collected in young people. Professionals reported on transitional care interventions and attitudes.

RESULTS

Young people rarely meet their adult providers prior to transfer; information about and preparation for changes when moving to adult services is often unsatisfactory. They also indicated that they were insufficiently involved in the process. Little attention was paid to non-medical aspects during consultations while impact of DM1 on daily functioning was high. Professionals recognized these shortcomings. Essential interventions such as transition clinics and self-management plans were not structurally provided. Professionals felt that transitional care needs higher priority both in pediatric and adult care.

CONCLUSION

To realize a smooth transfer to adult care for DM1 patients, more attention for transitional care is needed. Professionals need training and access to practical interventions that support and empower young people.

This research was financially supported by FNO and the Dutch Diabetes Fund and made possible by the support of patient organisations (DVN and Stichting Eendiabetes) and the professional organisations EADV, NVK, and NIV.

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Parents to chronically ill adolescent are ambivalent towards confidential youth consultations

BACKGROUND

Youth consultations between adolescents and healthcare professionals without the parents are a recommended part of transitional care. However, parents play an important role in the adolescents' health and treatment course as parental monitoring and support enhance adolescents' adherence to treatment. The conflicting needs for the parents i.e. to be involved and at the same time withdraw result in a clinical dilemma. Furthermore, several studies have found a striking ambivalence in the parents' attitudes as they at the same time support confidentiality and are worried of consultations where healthcare professionals spend time alone with their child. The aim of this study was to explore the underlying reasons behind the parents' ambivalence to youth consultations.

METHODS

We conducted three semi-structured focus group interviews among parents (n = 12) to chronically ill adolescents (median age 14.5, range 12-19 years) with a wide range of diagnosis. One father and 11 mothers with an average age of 48 years participated. Transcriptions were analyzed using the template analysis method in accordance to King.

RESULTS

The preliminary results show that the parents perceive themselves as an octopus with numerous roles represented in four themes: 'a life with chronic illness', 'responsibility', 'protection' and 'apprenticeship'. The parents' attitudes were influenced by their many roles and their perception of the adolescent's competences as well as their experience with the healthcare system.

CONCLUSION

Trust is essential before the parents feel safe to hand over their roles to the adolescent and healthcare professionals. A major challenge for the healthcare professionals is therefore to create a trustworthy relationship through continuity and balancing of expectations.

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Transition is about parents too

OBJECTIVE

To assess differences in the transition easiness between youths and their parents

METHODS

Data were drawn from a pilot study carried out among rheumatology and diabetology post-transition patients (N=68) and their parents (N=72) seen in Lyon and Lausanne. Samples were divided according to whether they considered that the transfer to adult care had been easy (patients, N=55; parents, N=45) or not and compared on having discussed about transition, feeling at ease with the adult provider, feeling accompanied during transfer, youth being ready for transfer, coordination between teams, transferring at the right moment and socioeconomic status. Parents were also asked whether they were ready for transfer themselves. Variables significant at the bivariate level were included in a logistic regression. Results are given as adjusted odds ratio (aOR).

RESULTS

At the multivariate level, patients finding transfer easy were significantly more likely to feel ready (aOR: 69.8) and to rate the coordination between teams as good (aOR: 14.2). Parents also indicated feeling their child ready (aOR: 8.8) and the coordination between teams (aOR: 10.1) as linked to an easy transfer. When parental readiness was included, only their readiness (aOR: 6.9) and coordination between teams (aOR: 9.8) remained significant.

CONCLUSION

Feeling ready for transfer is an important asset to find transition easy, especially for parents. Additionally, a good coordination between teams seems to be a necessary requisite. Health providers should have in mind that when transition is made easier for parents, the chances that the process runs more smoothly are enhanced.

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Adolescents with epilepsy and their ability to fulfil their development needs

BACKGROUND

Epilepsy is one of the most frequently encountered neurological disorders among young people. It is estimated that it affects about 1% of school age population. The purpose of the study is to analyse the needs of adolescents with epilepsy as seen from the perspective of the teenagers themselves, their parents and teachers.

METHODS

The results of three research projects conducted in Poland in 2013-2016 have been presented. The first project was carried out in 2013 among 76 patients of the Neurology Clinic and their parents. The DISABKIDS (DCGM-37) questionnaire was used. The differences in the HRQL of adolescents with epilepsy in two perspectives, the teenager and the parent were analyzed. The second research project consisted in conducting interviews with adolescents with epilepsy and their parents. The third project, entitled «Let's overcome the barriers together!» was conducted as part of the ERASMUS+ project. The study was carried out in 2016 among a group of 724 Polish teachers. The purpose was to evaluate the teachers' competence to work with students with epilepsy.

RESULTS

The results showed that parents had a significantly lower assessment of most of the studied aspects of the HRQL than the adolescents themselves. According to the adolescents one of the most important limitations is the overprotective attitude of parents, the need to conceal their condition and uncertainty of plans concerning the choice of profession and starting a family. The parents emphasized the need for changes in school, which would result in improving the psycho-social functioning. Among teachers who taught aoven students with epilepsy 32% declared that it was a difficult experience for them.

CONCLUSION

The burdens associated with epilepsy make it impossible for adolescents to fulfil their development needs. Support for adolescents with epilepsy entering into adulthood requires actions addressed at the adolescents themselves, their parents and teachers.

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How the cystic fibrosis (CF) french care centers manage the transition for adolescents to adult cf care center? What the SAFETIM* app study tells us

BACKGROUND

The French CF registry shows that the proportion of adult patients has reached 55% since 2016. The transition to adult care centers is one of the main workstream of the 'muco CFTR' branch. SAFETIM-APP is the first national study to provide both presentation and analysis of professional practices within the French CF care centers.

METHODS

Between February 2015 and December 2016, self-administered questionnaires were sent to all French CF centers. These questionnaires asked about the modalities of transition in the CF center, the strengths and areas for improvement as well as the best criteria perceived by the teams for an ideal transition program. A qualitative analysis of the procedures, then a quantitative analysis of the criteria retained by the CF center were matched with the results from the literature about transition.

RESULTS

Three quarters of the 46 CF centers have answered, one third of the transition processes have been evaluated. Between three and six events were described in the systematic follow-up, starting around 15 years old. Transition may take from one to four years.

According to the teams' point of view, some quality criteria can be compared with the literature data, but others differ, such as initiating the transition as soon as possible, developing improved communication between the teams, taking into account each patient's adolescence and specificities, developing a therapeutic education program, involving both the teenager and his or her parents in the process, to offer a special support for parents and to develop a long-term process with reliable indicators in order to assess practices.

CONCLUSION

SAFETIM APP shows that, in the French CF centers, the transition stage is taken into account, but it necessarily could include more quality, more communication, and more resources to develop the acquisition of new skills for patients.

This study was supported by Vertex (r) laboratory (cost of sending questionnaires, collecting data base)

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Needs assessment of youth with developmental disabilities and their families enrolled in a transition clinic program in a tertiary institution, 2015-2018

BACKGROUND

There is a recognized gap for Youth with Developmental Disabilities in their transition to adult care, thus the Transition Clinic for Youth with Developmental Disabilities was established. This is the first of its kind in the country and a needs assessment was seen as crucial.

METHODS

This was a descriptive study done at the developmental clinic of a tertiary institution in the Philippines. Caregivers of Youth with Developmental Disabilities and key informants involved in the Transition Clinic for YDDs were interviewed. Frequency and distribution were used to describe nominal variables. Mode, mean and standard deviation were used to describe interval or ratio variables. Microsoft Excel was used to summarize all descriptive statistics.

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RESULTS

There were a total of 40 respondents (35 caregivers and 5 key informants).

The reported needs of the YDDs and their families were grouped into the following themes: (1) vocational, (2) financial, (3) medical, (4) educational, (5) environmental, (6) social, and (7) support, and (8) service needs. Of all these, the most vital need perceived is vocational-related since this is seen as a instrument to enable the YDDs to be as independent as possible.

Identified barriers affecting the transition process were as follows: (1) patient's condition and maladaptive behaviors; (2) cultural beliefs, (3) family factors, (4) community barriers, (5) lack of accessibility to services/ resources, and (6) lack of coordination.

Factors perceived to facilitate the Transition process included: (1) early timing of transition, (2) trainings, (3) communication, (4) additional team members, (5) support groups, and (6) financial assistance.

CONCLUSION

There are still a lot of unmet needs of YDDs in the Transition Clinic. It is imperative to incorporate the findings of this research into the current program so that a model can be developed to best address the needs of our local setting.

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Educating for change: the challenge of transitioning from pediatric to adult care

BACKGROUND

Although patient education is recommended to encourage transition from pediatric to adult care, one particular model has not generated consensus. A recent literature review has shown that organizational questions are often highlighted in the existing research and/or that studies generally fall within the bounds of a bio-medical perspective. The experience perceived by youth during this period has not been explored in depth. Our aim is to design an educational program based on a better understanding of the youth's experience.

METHODS

Seventeen semi-structured interviews took place with teenagers/young adults who were recruited in 3 French hospitals. These interviews served to identify the educational needs of the youth and to define action proposals. The feasibility and acceptability of the proposals were assessed by three focus groups composed of healthcare workers and by one focus group composed of the parents of the transitioning youth.

RESULTS

The interviews conducted with the youth led to the emergence of a series of new roles assumed during the transition and involving learning processes: a social and personal role with an illness, the role of responsible of his health and a new role as patient. During the focus group sessions, healthcare workers expressed their need for support when accompanying youth on a psychosocial level and parents wanted their role to be more clearly defined once their child was in adult care.

CONCLUSION

A shift in perspective takes place when the transition is examined through the words of the adolescents themselves: the passage from the pediatric unit to adult care is no longer seen as being the heart of the process. It is instead a change among other changes, all of which impose themselves on youth during this period. We therefore offer an education for change which answers these overall needs.

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Consensus guidelines on the elements to implement in transition from pediatric to adult care

BACKGROUND

Information from several sources shows the relevance of the generic approach in the field of transition from pediatric to adult care. Our goal was to identify guidelines for a consensual, relevant and feasible transition care program applicable to a wide range of chronic illnesses and health services. Our hypothesis was that developing guidelines with all relevant stakeholders -patients, parents, professionals - involved in transition would allow there facilitated appropriation and broad implementation.

METHODS

A mixed study was carried out in 2 steps: 1) Elaboration of the questionnaire content to identify guidelines based on the analysis of qualitative interviews and a literature review; 2) Selection of the final transition care guidelines using an online Delphi consensus survey conducted at the national level. Professionals, young people and parents participated in each step.

RESULTS

A questionnaire of 108 items was elaborated and then submitted to the 36 participants of the Delphi study. Nineteen guidelines were finally selected: 5 concerned preparation in pediatrics, 7 the active phase of transition and 7 the phase of adult care. It requires: commitment of time from health professionals for patients (n=7), coordination time between pediatric service and adult service (n=5), organization of the health system (n=6), preparation and use of dedicated transition tools (n=1). Two obtained a complete consensus: having a longer consultation for the first appointment with the adult doctor and keeping the same adult doctor throughout follow-up.

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CONCLUSION

We established a consensual set of 19 guidelines for transition programs, whose implementation requires no resources other than those currently available in a majority of health services. It enables professionals treating patients with understudied pathologies to propose minimal and essential practices for transition. Thus, this common core could be adapted according to the special needs of young people and the available resources.

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Are paediatric specialist trainees prepared to manage transition, what are the knowledge gaps and how can training be improved?

BACKGROUND/PURPOSE

Local audit demonstrates 62% missed outpatient opportunities to initiate transition tools and 81% of letters fail to mention transition, possibly reflecting inadequate training. This study aims to investigate the training needs of paediatric trainees preparing to manage transition by identifying knowledge gaps and how training can be improved.

METHODS

Paediatric trainees of mixed seniority (ST1-8) were invited to complete a questionnaire. Open-questions explored what should be included into outpatient consultations to facilitate transition, and how training could be improved. Data was thematically analysed until saturation.

RESULTS

25 participants completed questionnaires (average ST4). Only 20% had knowledge of transition tools. The more senior the trainee, the more confident to manage transition (average=2.4/5) and the earlier age of transition initiation.

8 themes capture what should be incorporated into consultations to facilitate transition (most frequent first): social impact, independence, support networks, future plans, psychological impact, liaison with adult services, disease understanding and risky activities.

8 themes capture recommendations to improve training (most frequent first): transition clinics, patient/clinician forum, teaching, familiarisation with support groups and adult services, transition in usual clinical practice, seeing teenagers alone, curriculum.

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CONCLUSION

Trainees are unfamiliar with transition tools. Trainees are well aware to assess the social impact of disease and promote independence, but less aware to explore disease understanding and risky activities. Nor were they initially familiar with exploring support networks. We propose a simple clinic poster to prompt all 8 themes when consulting teenagers. Attending transition clinics was the top suggestion to improve training. Other suggestions acknowledge the importance of facilitating transition within normal clinical practice and consulting teenagers alone. Teaching sessions should regularly provide a forum to learn from patients directly, include information about adult health services, patient support groups, and transition tools. Incorporating transition into curricula may encourage trainees to develop necessary skills.

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Is Health transition developmentally appropriate?

The need for transitional care has been recognised in the literature for over 30 years and in recent years, the need to recognise adolescence and young adulthood as an important developmental phase within a life course framework has also gained a greater profile. One explanation for why we are still debating transitional care is that we have failed to look at it with a developmental lens. Transition programmes and clinics frequently discussed and researched but it is not always clear as how developmentally appropriate these services are.

Transitional care is advocated to start in early adolescence ie when paediatric care evolves into adolescent care and therefore should be developmentally appropriate by definition.



However, recent research has shown that there can be a variation in what is meant by developmentally appropriate amongst health professionals.

Youth friendliness is another concept well-established in clinical and research arenas and although similarly important, does not always convey the need for adjustment of care as the young person develops through adolescence and young adulthood. There are challenges at a system and organizational level however for developmentally appropriate health transition. In addition to the complexity of AYA development and the health conditions issues around coordination, communication, consistency, consensus and continuity both within and between systems are challenging.

In this talk the audience will be encouraged to consider health transition as a developmental milestone. In addition, the need for consideration of how these principles are enacted at a system and organisational level will be explored.

Organisation

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