The individualized, accompanied transition program “TraiN” for adolescent kidney patients – a local initiative

Abstract: Since the transition from pediatric and adolescent to adult care often proceeds unaccompanied and unplanned, young patients with chronic kidney disease may experience health risks and non-adherence after the transfer. The psychosocial team at the Department of Pediatric Nephrology at the University Hospital of Cologne has therefore developed its local transition program “TraiN” for patients with chronic kidney disease aged 13 years and older. It combines structure and flexibility through predefined content modules that can be individually adapted to the patients, offering continuity and sustainability through a transition contact person. In addition, the family members are offered regular psychological consultations. The timing of the transfer is chosen individually depending on the level of psychosocial and medical transition readiness. The aim of “TraiN” is to strengthen the patients’ transition competence and the responsibility for their disease management and to provide them and their families the best possible support during the transition in order to prevent possible health risks. In the near future, a scientific evaluation will be conducted aiming to determine whether “TraiN” can support young people in their independence and self-reliant disease management.

Keywords: adolescence; patient education; pediatric nephrology; transition.

Background

The transition from pediatric to adult care is very challenging for adolescents suffering from a chronic renal disease. Not only do they need to deal with growing up, age-specific developmental tasks and the associated detachment from their parents [1], but they are also required to take responsibility for their disease. They are supposed to become experts in their own disease, arrange doctor appointments independently and coordinate their treatment [2]. Kidney diseases also present special challenges depending on the severity of the disease – some of the young patients have to follow strict dietary rules, stick to a long dialysis schedule, adhere to medication regulations or need to deal with the consequences of their disease (scars after operations, reduced growth or side effects of the medication) [3].

Generally, in Germany, the transfer itself is scheduled for the age of 18 years. However, it often proceeds without any planning or guidance. This can lead to discontinuation of therapy, medical complications and adherence problems [2, 4, 5], the risk of which is increased in adolescence [6]. In transplant patients, a loss of transplant occurs significantly more frequent in patients aged 17–24 than in younger or older patients [7], regardless of the age at transplantation [8]. In addition, 40% of transplanted adolescents report a graft loss within 36 months after transfer to adult care, presumably due to lack of (drug-) adherence, insufficient care during transition or psychosocial stress [7, 9].

These findings highlight the need for support during the transition. A successful transition is based on early planning, the involvement and willingness on the part of young patients, and their parents. If the transition process
takes into account age and state of physical and mental health of patients, as well as their cognitive status and all requirements relevant to the transition, it holds the potential to prevent health risks and impairments [10]. The Consensus Statement of the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA) provide transition standards that include individualized transition plans, a transition key worker and collaboration between pediatric and adult care [11]. According to them, important components of a successful transfer are the beginning of transition at the age of 12–14, the inclusion of the family and the promotion of self-management skills.

The psychosocial team of the Department of Pediatric Nephrology at the University Hospital of Cologne, in a first step, attempted to support their affected patients before the transfer by means of annual 1.5-day transition training courses based on the German “ModuS” transition training, a modular training program with generic as well as disease-specific modules for various chronic diseases [12]. However, the team noticed insufficient encouragement and low numbers of participants, which demonstrates the difficulty of reaching all young patients who are in need of a transition training course. Furthermore, the limited time available and the lack of opportunity for individual adaptation is a big challenge for both the psychosocial team and the young people, with the risk of the training having no long-term effect on the transition competence [13, 14].

**Content and project description**

For this reason, the psychosocial team of the Department of Pediatric Nephrology at the University Hospital of Cologne developed a local transition program called “TraiN – Transition in Nephrology” in order to provide an early individual support to adolescent patients aged 13 years and older during their transition. “TraiN” is aimed primarily at patients with chronic kidney disease from stage three onwards. A psychological research assistant was hired as permanent contact person for the patients and their transition. This is due to the increasing emphasis on the importance of mentoring for young people in transition in scientific literature [15, 16]. In regular one-on-one interviews, 17 modules are step wisely worked through together. For this purpose, among other things, patients practice their own doctor’s consultations or conversations about their disease with friends or family. Questions and ambiguities are worked out together and, if necessary, clarified again in additional discussions with a treating doctor. In cooperation with the social worker of the department, the patients discuss social aspects. Accompanying parental meetings with the responsible psychologist are offered to discuss possibilities of support, solutions for conflicts and changes in medical responsibilities. This offer is supposed to enable parents to take adequate responsibility and let go of their child and, finally, facilitate transition for both the young people and the entire family.

The young people participating in the program receive their own transition folder, in which worksheets and information material are collected. This serves as orientation and learning aids for knowledge transfer and motivation. Moreover, it contains a checklist to tick off the already completed modules in order to keep an overview of the transition progress. “TraiN” is divided into 17 modules (for an overview see Table 1), addressing aspects of the adolescents’ disease, their self-esteem and the development of independence. Beyond that, it deals with future questions, career aspirations and, finally, change to the new doctor in adult care.

Each module contains a short introduction and, if necessary, an information page for explanation as well as practical exercises, which are worked out together with the patient. During implementation, content and focus of the interviews are adapted to the participants’ personal life circumstances and can be modified individually. Various methods are used during the transition process, including relaxation exercises as a strategy for successful stress management, case studies to learn how to deal with conflicting situations or the Circle of Resources, which is used to visualize the social relationships around the patients and their disease (see Figure 1). The topics and exercises are based on the “ModuS” transition training program and were designed in a way that, in addition to growing up with the disease, personal development and disease-unspecific issues such as dealing with money management are addressed as well. Parts of the materials have been kindly provided by the “ModuS”-responsibles.

The modules can be divided into different phases for different age groups. This facilitates orientation on development tasks and structuring of the interviews, the modules’ prioritization and order however depend on the patients and their individual needs. Thereby, the patients’ individual stage of knowledge and development are always considered. In **phase 1 (13 years)**, focus is on the patients’ own knowledge of the disease and therapy. Other topics are personal responsibility, resources, social contacts and appropriate stress management. **Phase 2 (14 years)** covers aspects of physical change, sexuality and autonomy. In **phase 3 (15 years)**, career aspirations and application and additional issues such as personal goals,
Table 1: The 17 modules of the transition program "TraiN" and the related topics that are being worked on.

| Phase          | Module                        | Topics                                                                 | Methods                                      |
|----------------|-------------------------------|------------------------------------------------------------------------|----------------------------------------------|
| One (13 years) | My disease                    | – Introduction to transition                                          | – Medication plan                            |
|                |                               | – Comprehensive overview of disease, therapy, restrictions – understanding the disease, providing a basis for adherence | – Circle of responsibility I                 |
|                |                               | – Assumption of responsibility with future prospects and goals         | – Confidence barometer I                      |
|                | My network of resources       | – Network of resources and social contacts                             | – Three-sentence summary                      |
|                |                               | – Whom do I talk to about my disease? How is the best way doing this?  | – Circle of Resources                         |
|                | My stress management          | – Personal limits in stressful situations                              | – Relaxation exercise (e.g. fantasy journey, progressive muscle relaxation) |
|                |                               | – Coping strategies against stress, e.g. sports, leisure habits        |                                              |
|                |                               | – Activation of personal resources                                     | – Stair exercise                              |
| Two (14 years) | My needs and wishes           | – Personal needs and wishes – creating values and norms, role models   | – Pyramid of needs                            |
|                |                               | – Creating alternate solutions to dissatisfied needs due to the disease |                                              |
|                | "Who am I?"                   | – Self-concept, self-esteem, self-confidence (finding identity, own values and norms, role models, …) | – Self-esteem exercises (Who am I?, mirror exercise …) |
|                |                               | – Existential fears, individual strengths                               | – Coats of arms                               |
|                | "I can do this myself."       | – Efforts towards autonomy                                             | – Circular questions                          |
|                |                               | – Strategies to facilitate independence                                  | – Letter to the parents                        |
|                |                               | – Parental relationship: unspoken feelings of guilt, independence, giving up control, taking responsibility, adaptability | – Case studies                                |
|                | Partnership & sexuality       | – Preparation for the next medical consultation                          |                                              |
|                |                               | – Coping with the disease in relationships with peers and in romantic relationships | – Painting a body portrait                    |
|                |                               | – Physical changes – That’s what I like about my body                    | – Case studies                                |
|                |                               | – Open questions concerning the future                                  |                                              |
| Three (15 years)| My health insurance           | – Insurances, rights and disability pass                                | – Informational material                      |
|                |                               | – Working with and asking the social worker                             | – Calling your own health insurances’ hotline |
|                | My future                     | – Career aspirations                                                     | – Informational material on studies, training, application and Co. |
|                |                               | – Applications                                                           | – Checklist for your application              |
|                |                               | – Professional role models                                               | – Practicing a job interview                  |
|                |                               | – Money management                                                       |                                              |
|                |                               | – Advantages and limitations of the disease concerning work             |                                              |
|                | My interests                   | – Interests and leisure activities                                       |                                              |
|                |                               | – Hobbies and disease                                                    |                                              |
|                | My vacation                   | – Independent planning of trips and excursions                           |                                              |
|                |                               | – Emergency contacts and emergency plan                                 |                                              |
| Four (16 years)| My goals                      | – Personal goals and obstacles                                           | – Learning from the experience of others      |
|                |                               | – Role modes                                                             | – Verbalization of concrete goals             |
|                |                               | – Making your own decisions                                              | – Circle of Resources II                      |
|                |                               | – Expression of wishes                                                   | – Confidence barometer II                     |
|                | "I relax!"                    | – Obstacles and difficulties caused by the disease                       | – Circular questions                          |
|                |                               | – Relaxation methods                                                     |                                              |
|                |                               | – Current stress and worries                                             |                                              |
|                |                               | – Future stress or frustrations                                           |                                              |
|                |                               | – Interrelation of thoughts and feelings                                  |                                              |
money management and leisure activity opportunities are discussed. **Phase 4 (16 years)** emphasizes making one’s own decisions and practicing independent disease management by arranging doctor appointments. The patients’ resource network, responsibility for disease management and personal goals are discussed again. The last phase (**Phase 5; 17 years onwards**) is about emergency contacts, moving out and the transfer to the new doctor. For this purpose, the patients practice a doctor’s interview and they record the most important conditions of the handover. In addition, they are encouraged to reflect on the new daily routine including the current medication as well as new responsibilities. After completion of the transfer, the transition contact person schedules a final interview, which also includes the patients’ feedback on the transition process.

In regular interdisciplinary meetings, the pediatric team consisting of psychologist, social worker, nephrologist, nurses, nutritionist and the transition contact person, discusses the transition progress of the participating patients.

**Discussion and outlook**

In Germany, so far only a few transition programs exist, including the Berlin Transition Program for chronically ill young people, which is applied to various diseases and combines transition discussions, the transfer itself and accompanying case management. However, the program only lasts two years and is aimed at young people aged 16 and older [17]. Elements of the program such as case conferences or joint consultation hours are rarely realized due to the high amount of time involved [18].

The program “endlich erwachsen”, developed by the Kuratorium für Dialyse und Nierentransplantation e.V. (KfH) and the Hannover Medical School, consists of a seven-day opening seminar and twice-yearly weekend workshops over a period of three years. It aims at adolescents with kidney failure between 16 and 21 years of age [19]. A survey of graft survival rates in 160 training participants showed that 90% of grafts were functional three years after the opening seminar; compared to a nontrained group, long-term renal function appeared improved 15 years after transplantation [20]. However, there was a lack of a clinical control group to validate the results. In addition, conducting weekend training sessions rather than regular one-on-one meetings bears disadvantages already discussed, such as a lack of adaptability to patients’ needs.

The transition program “Ready Steady Go”, developed in the UK, offers patients from 11 years support in working out their independent transition with the involvement of their caregivers [21]. By means of questionnaire packages, topics to be worked on at each stage of development are defined. Although participants, caregivers and health care professionals have reported positively about the program, there is no analysis of its effectiveness. In addition, concerns have been expressed that due to the non-specificity of the program, some non-relevant questions are included in the questionnaires [21].

The generic “ModuS” transition training has been evaluated on 14 different health disorders. The participants...
of the 1.5-day “ModuS” transition training reported significant improvements in transition knowledge, transition competence and patient activation compared to non-participants [12, 22]. Even 24 months later, online surveys of participants showed that the short-term effects of transition training remained stable in the long term compared to the control group without training [22]. Nevertheless, the parents requested a more extensive program at the beginning of adolescence [12].

Another two-day generic transition-training course designed at the Universities of Greifswald and Luebeck showed significant improvements in the participants’ transition competence and self-efficacy six months later compared to non-participants [13]. However, the results implied conclusions about disease-specific outcomes, but the sample did not include participants with chronic kidney disease. Furthermore, the workshop showed no significant effects on quality of life and patient activation.

The Zurich standardized multilevel transition program for kidney disease consists of an early start and a fixed transfer time point depending on psychosocial development level, self-management skills and adherence assessment [23]. A retrospective cohort study with a control group showed, among other things, a beneficial effect of
participation in the transition program for the transplant outcome three years after the transfer [23]. Unlike “TraiN”, however, the transition is not accompanied by a designated contact person, but by a nephrologist and a nurse.

Different models of transition can be described [24]: direct transition from pediatric to adult care is indicated for diseases where the transfer changes little in terms of responsibilities; in sequential transition, patients are made experts in their own disease, i.e. via “young adult” clinics [25]; developmental and professional transition models explicitly address specific conditions such as learning disabilities or rare diseases. Transition can therefore be handled in various ways; the transfer itself can be made to a practicing adult nephrologist or to the adult nephrology unit of the center, combined with regular transition appointments in the clinic or through one-off intensive training.

The transition program “TraiN” in Cologne is specifically tailored to kidney disease in adolescence. It emphasizes matters of growing up, independence and personal responsibility within the scope of the disease. The need for a separate transition program arose from an increased need for counseling for those affected. This is due to the strong emotional burden caused by chronic kidney disease and the low number of participants and difficult accessibility of previous transition training courses. “TraiN” combines aspects highlighted as transition-relevant by literature: provision of a permanent contact person, individual adaptation to the participants, involvement of the family and an individual transfer time. Because of the patients’ increased risk of transplant loss in the age of 17–24 [8], time of transfer should depend on the individual’s state of health and should not be prescribed by law to the age of 18. “TraiN” provides a time corridor for transfer depending on the patients’ state of development, transition progress and health condition. In case of doubt, the patients may remain in pediatric care beyond their 18th birthday.

Since the start of its implementation in autumn 2019, “TraiN” has been presented to 30 patients with chronic kidney disease aged between 14 and 20 years, 20 of whom are already in the active transition process accompanied by the transition contact person in the Department of Pediatric Nephrology at University Hospital of Cologne. Most of them are at the beginning of their transition process. Two patients had to terminate their participation prematurely due to a change of residence. Some of the participants preferred to work on specific modules (e.g. “Partnership and Sexuality”) in advance, which again underlines the importance of individual adaptability of the program. In addition to structure and individuality, “TraiN” also combines a wide variety of methods and content: role-plays, case studies, relaxation exercises or even imagination exercises are offered. Moreover, the exchange with affected peers such as other adolescents with chronic kidney disease is planned to be realized by means of further modules as well as a consultation hour with transition experts whose transfer has already been successful. Peer support through personal contact with other people with the same disease is of central importance for young people to perceive support and to exchange experiences [26].

At the beginning of participation in “TraiN”, the patients are given basic questionnaire packages about transition knowledge and health-related quality of life to adapt the program to their individual needs. These revealed previous overarching problem areas like a distinct lack of illness knowledge about job applications and social law, which are now dealt with using “TraiN”. Health-related quality of life is particularly affected by pessimism and social exclusion and patients report having difficulties talking about their illness, which highlights the relevance of the modules addressing these identified problem areas. For example, the module “My Network of Resources” helps to identify the ones involved in managing the disease. So far, it can only be assumed that it helps patients to adequately integrate their social environment into their disease management.

Therefore, “TraiN” will soon be evaluated on a scientific basis over a period of two years regarding its effects on the patients’ responsibility concerning the disease, transition knowledge, transition competence, patient activation and health-related quality of life. In addition, the parents’ disease-related responsibility, transition knowledge and quality of life will be examined by using the questionnaire packages already mentioned (see Table 2). They serve to survey the mentioned dependent variables annually for both the adolescents and their parents. Based on previous research, the team expects the transition program to lead to an improvement in transition competence, transition knowledge and patient activation among the participants [12, 14, 22]. In addition, a somatic effect of “TraiN” will be investigated by using patients’ routine blood tests to assess adherence and relating them to patient activation measures.

It will also be interesting to discuss to what extent the parents’ and patients’ judgements overlap regarding autonomy and personal responsibility. The transition phase is central for the development of self-confidence and detachment from the family for the adolescents, because their chronic illness usually binds them emotionally, physically and financially to their caregivers [27]. Hence, parents also need to be supported to let go and to attribute confidence in their children’s self-management skills.
Family support is one of the most telling factors in assessing compliance [28]. The accompanying parental meetings during the patients’ participation in “TraiN” therefore also serve to record the individual needs of parents, focusing the parental strategies that promote patient compliance. The search for autonomy also holds some risks for the parent-child relationship because it can be stressful for both parties. For parents, especially mothers, it is often difficult to maintain a balance between granting autonomy and protecting their chronically ill child [29]. Here, it is important to identify sources of risk at an early stage through regular talks and to address fears, needs and possible solutions on the part of parents and patients.

Through the evaluation of “TraiN”, the transition program can be improved continuously adapting to personal needs of the patients and their families and, if positive outcomes are revealed, progressively become standard in Pediatric Nephrology. With the help of this newly gained knowledge, optimization and further development of medical and psychosocial care in Pediatric Nephrology at the University Hospital of Cologne and beyond can be initiated. The structure of “TraiN” could then be extended to other transplant centers and even to other rare diseases and is particularly relevant where group training is difficult to implement.

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