

Factors Influencing the Transition from Pediatric to Adult Care: A Scoping Review of the Literature to Conceptualize a Relevant Education Program

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Abstract

Objective: To give a comprehensive overview of the factors that influence the transition from pediatric services to adult care, and to conceptualize a relevant education program. **Method** An evaluation grid was used to analyze the literature and classify factors depending on whether they were related to the patients, to the health care organization, to health care personnel, to the interaction between medical staff and patient, or to the illness and its treatment. **Results** We based our analysis on a selection of 20 publications. The following factors were identified and classified in an integrative framework: self-management skills, trust in adult care, the feeling of self-efficacy, social support, the patient's gender and social position, the trust between child carers and adult carers, interdisciplinary cooperation, and the medical staff's consideration of the patient's projects. **Conclusions and practice implications** The current analysis makes it possible to formulate educational aims and to design a way of integrating them to a transition plan. However, the collected studies mainly focus on knowledge of the illness, on treatment, and on the health care system. Psychosocial dimensions at play at the time of the transition – such as identity development – are not sufficiently explored in the research.

1. Introduction

Nearly 10% of adolescents in industrialized societies grow up with a chronic illness [1]. The phenomenon is spreading and is expected to increase in the coming years [2]. Given existing knowledge, almost 90% of young people with long-term health conditions (all chronic illnesses combined) live to an adult age and must be transferred from pediatric services to adult care [3]. Despite an increase in publications since the early 2000s, proposals to support patients remain limited [4, 5] and many institutions have not yet established transition policies [6]. However, when transitions are inadequately managed, young people with long-term health conditions can suffer from a diminished adherence to treatment [7], an interruption in their medical follow-up [8], the emergence of medical complications [9] or general health deterioration [7, 10]. The transition's major challenge lies in determining how to prevent such difficulties.

A transition is a *process* that is organized and coordinated to go from pediatric care to the adult health system. It conveys the idea of a formalized plan that optimizes the young person's health and promotes his or her autonomy and personal development [11, 12]. A transition is therefore different from a transfer, the latter being considered as a one-time event. Adolescence is a process in itself, a developmental transition which is marked by increased self-identity [13]. It takes place between the ages of 10 and 19 years, according to the WHO [14]. An illness can disrupt adolescence by diminishing a young person's well-being and quality of life. Thus, a transition can be viewed as successful when it results in the youth's adherence to treatment, his or her continued medical follow-up, the prevention of any medical complications, and the maintenance of a globally satisfactory health condition and autonomy.

According to the literature, patient education can support the transition. Patient education is a process which enables patients to acquire and retain skills and abilities that help them maintain a healthy lifestyle given their illness [15]. The need for patient integration is now undisputed [6, 16, 17]. But the specific skills that the young person is meant to acquire have not yet been defined, and the definition of a relevant education for transition is still unclear [2, 16].

In order to design an adequate patient education program, one must identify the factors that influence health behavior in given circumstances (in this case, the context of transition) [18]. Fegran et al. [19], Pai and Ostendorf [20] and Lugasi et al. [21] published literature reviews which provide answers (as shown in Table 1). However, the results of these studies only offer a rough outline and therefore cannot help to model the transition's educational aims and the ways in which these are to be implemented.

As Fegran et al. pointed out [19], the literature on transition did not examine the specific needs of young people with health conditions in much detail, while the points of view of carers and parents had been prioritized. Based on this observation, it seems difficult to devise a transition education program that would meet the expectations, preoccupations and priorities of the young people involved. It is interesting to add that the three literature reviews cited above only took into account articles that had been published up to 2009. However, publications on transition have soared since then. For instance, on the PubMed data base, 257 works were published between 2000 and 2009 compared to 421 from 2010 to 2016. It would be worth examining these recent publications (by summarizing the results and identifying potential flaws). Such a new set of data could be added to the previous results and be included in the discussion surrounding the conceptualization of a patient education for transition.

This is why, as we faced such a large number of recent publications, we aimed to supplement previous data. First, we added data taken from journals issued since 2010, and second, we modelled this new set of data by using an analytical framework that classifies the various factors influencing the transition process. Such modelling gives an overview of the factors that influence the transition in order to conceptualize a relevant education program. More specifically, we attempted to elucidate a certain number of points left unanswered in previously cited articles: which of the patients' educational needs are known at the time of the transition, and which dimensions have yet to be explored? Which operational educational aims can be defined to foster the transition? Which conditions (organizational or based on the environment) must be taken into account to implement an education program for the transition

process?

2. Method

A scoping review of the literature was carried out between February and September 2016 using the PubMed, PsycInfo, ScienceDirect and ERIC databases, and the following key words: Transition; Transition care; Transition Health Care/programs; Adolescence; Chronic illness/disease/disability; Young adult; Pediatric; Transfer, Special health care needs.

A scoping review is a type of literature search recommended by Arksey and O'Malley "to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available" and identify gaps in the existing literature. It is especially recommended to study areas that are complex or that have not been comprehensively reviewed [22]. This type of review differs from systematic reviews, the latter being most useful when answering narrow questions and assessing precise data from the literature (for measures of effectiveness, for example) [23, 24]. Since the study of influencing factors is wide-ranging, a scoping review is more appropriate. The intention here is indeed to summarize and share research findings, as well as determine whether the particular educational needs of adolescents are sufficiently taken into account when deciding on the specific skills and knowledge to include when creating an educational program that is integrated to the transition plan. Our study includes 4 key steps: 1) identifying studies, 2) selecting studies, 3) classifying data, 4) analyzing data.

We included publications that hadn't been considered in the three reviews of literature cited above by choosing works published during or after 2010, and if they related to (1) an assessment of the needs of young people (11-25 years) with long-term health conditions during their transition from pediatric services to adult care (2) or an assessment of the satisfaction and/or the factors influencing the experience of transferring from a "children's" unit to an "adult's" unit among young people with long-term health conditions, parents and/or health care providers.

The categorization of factors influencing health behavior as suggested by Deccache [18] was used as an interpretive framework for the analysis. It consists in an integrated theoretical framework that classifies factors influencing health behavior in 5 categories:

- Factors related to patients (psychosocial, cognitive, social, demographic...);
- Factors related to the organization of health care (communication, health model, type of management...);
- Factors related to health professionals (training, know-how, psycho-affective...);
- Factors related to the illness and the treatment (severity, complexity, cost...);
- Factors related to the interaction between health professionals and patients (and their relatives).

Each factor identified in the literature and influencing the transition was, therefore, categorized according to this interpretative framework. The framework was used to assess the level of educational action (meaning factors that could be modified through learning) within the transition plan, which took into account all of the other factors. With this approach, the factors influencing the transition were included in one single framework, thus giving an overview of the factors at play in any given situation.

Two researchers (MM and CD) reviewed the headings and summaries of all of the selected articles. A third researcher was consulted when a divergence in analysis arose.

615 articles were collected in total.

After reading the headings and summaries of each article, the following types of works were excluded: position papers, inventories on the issue of transition or recommendations without specific assessment mechanisms, reviews of literature, articles assessing the effects of transfers (or of a specific transition mechanism) on the health (biomedical measurements) of young people with long-term health conditions, articles testing the validity of a measurement scale, and articles out of the scope of our research. These works didn't assess the educational needs of young people with chronic health conditions, nor did they evaluate the factors influencing the youth's health behavior during the transition period. They were therefore not relevant in the

context of our study. Finally, articles written in languages other than English or French were also excluded from the study.

23 articles were eligible based on the selection criteria. Three of these papers were not used, as they did not deal directly with factors influencing the transition or with needs in this field (one study focused on factors predicting the age of patients at the time of transfer, another was a descriptive analysis of the transition process, and the third was an epidemiological survey of the transition). In the end, 20 articles were selected for our research, according to the defined criteria. Fig.1 uses the PRISMA convention to show the selection stages [25].

3. Results

3.1. Study types

Table 2 describes the methodologies used in the included papers.

Among the 20 articles selected, 11 came from the United States, 3 from Switzerland, 2 from the Netherlands, 1 from Canada, 1 from Hong-Kong, 1 from Japan and 1 from France.

Nine studies related to patients suffering from various chronic illnesses (more than 3 distinct illnesses in the sample). Other studies dealt with a specific illness: 2 focused on HIV, 1 on chronic endocrine disorders, 1 on type 1 diabetes, 1 on asthma, 1 on sickle-cell anemia, 1 on neurological disorders, 1 on multiple sclerosis, 1 on lupus erythematosus, 1 on chronic renal disease and 1 on chronic bladder disorder.

Young people with long-term health conditions were most often consulted (in 15 articles), mainly by way of surveys and questionnaires. Eleven articles used quantitative methods, while 4 papers used qualitative methods. Seven studies were prospective, 6 were retrospective and 2 were both prospective and retrospective.

Most of the articles analyzed had a weak level of evidence, according to the frame of reference put forward by the *Centre for Evidence Based Medicine* [26]. The researchers used either quantitative methods by *case series* (level of evidence of 4 out of 5; 1 being the strongest level) or qualitative methods.

3.2. Categorizing the factors influencing the transition

Table 3 is an article-by-article summary of the factors influencing the transition in all of the studied papers. We divided these factors into 5 types of categories, in accordance with the model offered by Deccache [18], as explained in the method.

3.2.1. Factors relating to young people with long-term health conditions

A lack of information on the part of the adolescents about the transition process was seen as a determining factor [27, 28, 29, 30]. Likewise, adolescents sought more information on their illness [31] and on aspects of life in general [32], as well as on emotional and sexual matters [31, 32, 33]. Acquiring autonomy to manage their treatment seemed essential, suggesting new skills in treatment management. However, some young people with long-term health conditions played down the idea that it was important to stay connected with the care system as an adult [34] (**cognitive factors**). Other determining factors included a lack or loss of confidence in new care structures provided by adult services [35], young people feeling uncertainty regarding when a transition process was starting and/or feeling abandoned [36], all the more so due to an oftentimes strong attachment to pediatric units and care teams [28, 30, 31, 33, 35]. Transfers also implied emotional adjustment for young people [37], as they didn't always feel capable of assuming more responsibility in the management of their illness and its treatment [38] or as they were not mature enough to do so [39]. Young people were torn between contradictory needs of independence and dependence when managing this new phase [34] (**psychosocial factors**). Parental fears could also impair young people at the time of transition, as situations became more stressful or as parents put pressure on their children over their health [40]. However, the youth's need for social support was very high at this time [41]. Transferring skills from the parents to the child to manage the illness and the treatment must be done progressively [41] (**social factors**). Age [32, 38, 42], gender [38, 42] and the social position of the home [35, 39, 42] could also influence a transfer's success. It seems that girls respond better than boys to the demands of autonomy related to the transition, and that the older the

adolescents are, the better they are at dealing with the transition. The correlation between the social level of the home and the success of the transition also appeared to be positive (**sociodemographic factors**). Finally, the young people's disability levels determined their capacity to move from one unit to the other. A study carried out among youth with multiple sclerosis showed that patients with deteriorated cognitive capacities experienced a harder transition phase than others [43] (**medical factor**).

3.2.2. Factors related to the health care organization

The study has shown that one of the major obstacles to a successful transition was the lack of clearly defined recommendations to tackle the transition process, or a lack of institutional policy in this regard [36]. Similarly, health care providers were not helped in their work when a consensus around the definition of a successful transition and the measures to put in place had not been reached, as well as when there were no available assessment tools [44]. In addition, cultural differences in the children's units and the adults' units, coupled with a lack of communication, could also be obstacles in the transition [42]. Suris and Akre [45] brought together a group of experts to formulate a series of recommendations on planning the transition process, which included: the coordination between units, early planning in adolescence, discussing self-management of the illness and the treatment early with patients and their families, and including patients in the planning of the process. Moreover, an interdisciplinary approach seemed fundamental [34], as was an educational approach [32]. Another determining factor consisted in the importance of making adult care geographically accessible so that young patients could get there relatively easily [35]. Finally, a pediatric specialist could be appointed to monitor the transition phase for young people with long-term health conditions [35].

3.2.3. Factors related to health care personnel

Adult care providers didn't always know as much about pediatric illnesses as care providers in pediatric units, especially when they worked in general practice units that were not

specialized in caring for people with certain specific illnesses. The attention given to youth patients could also be less acute than that provided by the pediatric staff. Finally, it emerged that health care providers in pediatric units could sometimes lack confidence when providing adult care [36].

3.2.4. Factors related to the interaction between adolescents, parents and medical personnel

Sound communication between the two parties (the adolescent/parents and the medical personnel) is of the utmost importance, and the young person's projects and level of independence must be taken into consideration [34]. There should at least be a discussion between the medical care provider and the patient about the transition [43]. Finally, the quality of the new relationship with the "adult" medical carers may influence the young patient's behavior.

3.2.5. Factors related to the illness and the treatment.

Factors related to the illness and the treatment were not raised in the selected articles. However, according to the Deccache model [18] used for our analysis, factors such as the treatment's complexity level (the number of different types of medication to ingest, the frequency of administration, the change in lifestyle that the medication and/or the illness dictates), any side effects or indeed the illness's degree of severity can influence the health behavior of individuals.

4. Discussion

The scoping review method allowed us to gather scientific data by using an analytical framework to conceptualize an educational program for the transition. Based on the systematic review conducted by Crownley et al. [2], we knew that the education of patients encouraged the transition process. The systematic review method, which uses a precise question to assess

research studies, was called upon for questions related to the process's efficiency [23]. But to conceptualize an educational process, for which little information was available, a broader – but nonetheless indispensable – question had to be answered, namely which factors influenced the transition. This is why we chose the scoping review, which allowed us to summarize the research results and to identify their flaws.

A new categorization of influencing factors at play during the transition from pediatric to adult care has been put forward in our review of the literature. The integrative framework which we propose (**Figure II**) shows the factors that influence the transition process and the transition's success (the adolescent's adherence to treatment, the medical follow-up, the prevention of any medical complications, the maintenance of satisfactory health and autonomy). It also contributes to help decide on the level of action needed (educational, relational, organizational, medical or environmental). It confirms and completes the results of the three previous literature reviews on the influencing factors of transition [19, 20, 21].

First, thanks to the present study, we can now list the aims of educational programs as follows: to increase the level of knowledge concerning the transition, to improve knowledge and skills in self-managing the illness and its treatment, to improve knowledge and skills in health and lifestyle (emotional and sexual life, use of drugs, etc.), to encourage a feeling of self-efficacy, to build trust in adult health care and to reduce the (emotional) attachment to the pediatric unit if there is a resistance to change. Reaching these aims could empower young patients and prevent potential difficulties related to the transition. This constitutes new insight, since previous studies presented factors influencing the transition without clearly identifying how some of these factors could be modified through educational action, as is suggested here with our choice of an analytical framework. Furthermore, the feelings of self-efficacy and trust in adult healthcare had not been clearly identified in previous reviews of the literature.

Second, sociodemographic variables (gender and social background) and the young patient's environment (the quality of the relationship with the medical staff, the support from family and friends and the accessibility to adult care) seem to be determining factors during the transition.

Such elements had not been highlighted much in previous works focusing on the factors influencing transition. If some factors cannot be solved through an educational intervention, they should nevertheless be taken into consideration when preparing the transition process so that this process may fit with the young person's sociodemographic and environmental reality, and thus act on any health inequalities. Incidentally, in the context of transitions for young people with cancer, the illness's level of severity was taken into account by Schwartz et al. [46], who validated the relevance of "socio-ecological" measures for patients, parents and health care providers. The coordination between units, the adult unit's investment and the transition plan's formalization also appear as required conditions to support an educational intervention in the transition.

Based on these elements and given current knowledge, an original educational plan for transition can be conceptualized, one which takes into account the factors that can be modified through learning (cognitive and psycho-social factors) as well as factors that must be considered when organizing and planning the learning process. However, we have noticed that the opinions of young people have rarely been investigated in studies on transition. The information and data taken from the literature review mostly originated from quantitative methods and were mainly focused on biomedical health, on observance and illness, on treatment and on the healthcare system. The literature review pointed to the fact that adolescents were calling for information regarding the transition, on the skills needed to manage their illness and their treatment, and for information on life styles (including risky behavior). However, the review also showed that transition research rarely included the psychosocial development of young patients. The psychosocial factors have been underestimated until now. In a recent review of the literature, Sattoe et al. [47] exposed the same lack in the interventions for young people with chronic conditions. Yet, one of the main tasks of young people living with a chronic illness during the transition period is psychosocial in nature as it involves identity development [48]. During this time, the young person has to include the illness as part of his/her self without it encroaching on his/her identity. This *identity synthesis* is vital [49, 50, 51]. When such a synthesis fails, the

illness then takes up too much space in the definition of self. Phenomena such as severe therapeutic non-adherence [52, 53] or a lowering of self-esteem [52] can, in fact, be observed.

Taking into account the specific developmental process of an adolescent living with a chronic illness is, therefore, essential to optimize transition processes [54]. The transition processes could aim to encourage young people with health conditions to learn the following skills, in reference to the elements discussed:

- skills related to adjusting to the illness, such as constructing one's identity, appropriating the illness, developing a non-negative attitude towards the illness;
- Self-management skills towards the illness and its treatment;
- Lifestyle skills: emotional and sexual life, use of tobacco, alcohol and other drugs, life hygiene (food, sleep, etc.).

It appears to us that educating patients on the transition's psychosocial dimension, and, in particular, on their ability to adjust to the illness, constitutes a precondition for a learning process that should occur simultaneously with the learning process of the other two skills cited. Adolescents may judge issues such as self-image and social image, the demonstration of anxieties or the search for feelings as more "useful" than maintaining good health, according to the Self-determination theory [55]. In this context, self-management skills could focus as a priority on the patients' ability to formulate opinions on the care they receive or the care they would want to receive. This would allow them to become partners in the transition and to adhere more thoroughly to healthcare.

5. Limits

There are several limits to our research. Although all of the selected articles came from peer-reviewed publications and, therefore, boast a good level of scientific validity, their level of evidence remains weak. We must be very careful in making generalizations concerning influencing factors, and should instead view them as hypotheses. We did not proceed to weigh any of these influencing factors. And yet, some of these factors are likely to have more of an

impact than others. They would consequently require essential and/or priority action, while others could act as useful complements. But the integrative framework proposed in this study does not take this into account. Finally, we presented the influencing factors and the requirements stemming from these factors without distinguishing whether they were formulated by patients, parents or medical staff. The level of perceived need varies depending on the source expressing the need. This therefore does not allow us to realistically surmise the expectations of young people with long-term health conditions.

6. Conclusion

The transition from pediatric to adult care for adolescents living with a chronic illness is a major public health challenge. A consensus on international recommendations – which would be based on data and/or scientific information and which would formulate a transition process – has not yet been reached. As a response to such a shortage of guidelines, our research aimed to review literature concerned with educational needs related to transition, and to identify factors influencing transitions. We have thus been able to put forward a new integrative framework, which regroups all of the studied factors under categorizations, making it easier to identify the levels of required actions (contextual, cognitive, psychosocial, etc.). The study has revealed that the best known factors relate to the planning and organization of the transition process. On the other hand, very few factors relating to the transition process's educational content were identified (which specific knowledge and skills?). This is therefore an area of research that has yet to be explored.

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