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Developmentally Appropriate Patient Education during Transition: A Study of Healthcare Providers' and Parents' Perspective

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Abbreviations

AT: Activity Theory

DAH: Developmentally Appropriate Healthcare.

DAPET: Developmentally Appropriate Patient Education during Transition

FG: Focus Group

HP: Healthcare Providers

Abstract

Introduction Patient education is recommended to improve the transition from pediatric to adult care for young people with chronic conditions. But a consensus has not been reached regarding a particular model. Our study aims to understand how to prepare the implementation a *Developmentally Appropriate Patient Education during Transition* (DAPET), which would revolve around the young people's psychosocial development.

Method Three focus groups were organized with healthcare providers (HP) and two focus groups took place with the parents of young people with chronic conditions. We relied on Activity Theory to explore practices and to identify obstacles, as well as recognize which resources were available to implement a DAPET.

Results HP agreed on the need to engage in an educational approach centered on the psychosocial development of young people during transition. However, our study highlights the following obstacles: a lack of competencies in adolescent and young adult medicine and a lack of available resources to meet these goals. Furthermore, the parents wanted to redefine their role with HP in order to apprehend the transition to adult care and to allow their children to develop self-management skills.

Conclusion HP and parents considered the implementation of a DAPET to be acceptable and even advisable. However, this program's feasibility was questioned due to the perceived shortfalls of the hospital system as it currently stands and the ways in which an educational approach would be applied. An environment that facilitates the HP's educational initiatives and encourages the participation of parents would therefore be required.

Keywords: Transition, Pediatric, Young People, Patient Education, Chronic Condition.

Young people, who are defined by the World Health Organization (WHO, 2001) as ranging from 10 to 24 years of age experience a specific period of biopsychosocial development marked by physiological, cognitive, psychological and social transformations. While their healthcare needs are different from those of children and adults, they nevertheless share the same health services (Payne, 2013; Sawyer et al., 2012). This is why the scientific community has been paying more attention to the idea of making these healthcare services more appropriate to this particular period of life. The term *Developmentally Appropriate Healthcare* (DAH) for young people is used to qualify healthcare services in which consultations answer the young people's subjective experience of the illness and are adapted to their level of development. An educational approach is also used to help young people become progressively autonomous in the daily management of their illness (McDonagh et al., 2018). For young people with chronic conditions, both pediatric and adult services are concerned, and this includes the in-between transition period.

Transition consists in setting up a coordinated plan to accompany and prepare young people to move from one healthcare service to another, while also preserving their health and their personal development (Blum et al., 1993). DAH approach does not simply revolve around ensuring a secured passage from pediatric to adult care (this is called a *transfer*). Instead, it ensures that the needs of young people are continuously met at all stages of development in the pediatric and adult care, *despite* the change from one service to another. Instead of using an exclusively organizational approach, a life-course approach is therefore favored (Farre et al., 2016; Sawyer et al., 2012) in accordance with international recommendations (McDonagh, 2007).

However, recent reviews of the literature on the assessment of transition approaches have shown that practices tended to focus on transfer rather than on the developmental transition of young people (Clemente et al., 2017). Similarly, studies on the needs of young people during transition have mainly centered on organizational issues and give little consideration to the psychosocial skills needed to learn to live with a chronic illness (Morsa et al., 2017). Psychosocial skills are defined as a person's capacity to maintain their mental well-being through adaptive and positive behaviors to deal with others, with one's own culture and one's environment effectively (WHO, 2003). Unlike self-care skills which are understood as the self-management of medical and treatment-related issues (Modi et al., 2012).

Patient education is meant for young people to acquire the skills they need to live as well as possible with a chronic illness. It is a key part of the recommended approach when facilitating the transition of young people (Johnson et al., 2019; Nutt et al., 2016; White et al.,

2018). However, studies have shown that patient education practices with young people tended to revolve more around self-care skills than psychosocial skills (Sattoe et al., 2015) even when the latter skills were central to the young people's development and were determining factors in the success of their treatment and in the risk of medical complications (Ferro and Boyle, 2013). Focusing exclusively on self-care skills in patient education could also be counter-productive, since some young people could view this educational program as insisting that they become adults and manage their illness alone when they are not ready for such level of responsibility (Fonte et al., 2019). This could potentially lead them to disengage with the healthcare system. The number of missing patients is, in fact, higher during this period (Campbell, 2016). These figures tend to show that patient education during the transition is not *developmentally appropriate* enough, both in terms of the content and the pedagogical means that are made available.

The hypothesis which consists in saying that healthcare providers (HP) lack training in adolescent medicine (McDonagh et al., 2006; Wright et al., 2015) partly explains the gap between the recommendations and the actual practices. This gap can also be explained by the absence of a recognized model for patient education focusing on the developmental transition. In a recent study involving young people living with a variety of chronic illnesses, Morsa et al. (2018) suggested a model for a *Developmentally Appropriate Patient Education during Transition* (DAPET). According to this model (**Figure 1**), transition is described as a learning period which can be supported by patient education interventions that are tailored to the singular needs of each young person. The following principles are formulated: **(1)** During this transition phase, **experiential learning** is the favored method for young people, therefore educational strategies must support this type of learning to allow young people to acquire the necessary knowledge to manage their daily health-related issues. **(2)** The acquisition of targeted **skills to cope with interdependence** as well as possible (in social life and in the healthcare system) **and of functional autonomy skills** should be included in the patient education interventions. **(3)** The acquisition of such skills could also be facilitated by learning from **peer educators**. **(4)** In addition, **parents** are the main resource to help young people become more autonomous when managing self-care procedures; they should therefore be involved in this capacity. **(5)** Finally, the implementation of a **double-contact period** (between the pediatric and adult care) provides a safer learning environment for the young patient during the transition and young people should be given time to discover and “experiment” with the new adult service in order to understand it and use it effectively.

We aimed to study the conditions for the implementation of a DAPET in healthcare practices. The changes in the roles played by professional caregivers and parents when faced with the development of young people has not been well documented (Farre et al., 2015). Our study therefore aimed to examine the conditions of a DAPET's implementation for its main instigators: the HP (who could lead educational sessions for patients) and the parents (involved in delegating self-care skills). Through a comprehensive exploration of the activity of HP and parents, we attempted to identify the obstacles and the resources needed to implement a DAPET according to the principles cited above, and therefore determine its perceived acceptability and feasibility.

Method

Focus group

We chose the focus group technique to study the conditions for the implementation of a DAPET, the latter of which is recommended in the field of health for intervention implementation (Litt, 2003). Focus groups make it possible to study the opinions, attitudes and motivations of people who share a common characteristic (Green and Thorogood, 2014). In this way, we aimed to understand more clearly the point of view of HP and parents in regard to the implementation of a DAPET, and to see how such a program could fit in with their roles.

Sampling

We set up focus groups composed of HP as well as focus groups composed of parents. For the focus groups made up of HP, the study's inclusion criteria consisted in participants being (1) HP, (2) who worked in a service that cared for patients with a chronic condition and (3) who were in contact with young people (10-24 years of age) through their professional practice in pediatric services or in adult care. The HP were recruited in three French hospitals: one hospital was located in Paris, one in the Paris suburbs, and one in the Hauts-de-France region. These three hospitals were chosen because a variety of environments could be explored (the three hospitals are respectively based in a city, the suburbs of a city and the countryside, three areas with three different sociological patient characteristics). Although the setting was not directly analyzed, we explored the HP' point of view in their different environments in order to identify the invariable factors. These factors therefore could not be narrowed down to any specific and limited context. Each focus group was composed of HP from the same hospital in

an effort to explore different points of view within a same context. The consistency of our sample was therefore maximized while its diversity also increased. In each hospital, a doctor supported us when proceeding with the recruitment of participants. He sent invitations to colleagues from his hospital who met the inclusion criteria asking them to participate in the focus groups.

For the focus groups composed of parents, the study's inclusion criteria consisted in participants being the parents of young people (10-24 years of age) who lived with a chronic condition. In order to maximize the heterogeneity of the situations, we intentionally chose to recruit the parents of young people who suffered from prevalent diseases as well as the parents of young people who suffered from rare diseases. A doctor supported us in recruiting parents who met the inclusion criteria by sending personal invitations to them. A pediatric diabetologist from the Occitanie hospital invited the parents of young diabetics who were cared for in his service to participate in the focus group. A pediatric hepatologist from a Parisian teaching hospital invited us to participate in an information day for the parents of young transplant patients from his service to help us create a focus group. The recruitment of parents was therefore subject to opportunity: we approached several doctors from various teaching hospitals in France to help us recruit parents and these two doctors responded positively to our request.

Procedure

The main investigator (MM) co-led the sessions with another researcher for the focus groups composed of HP. The parents' focus groups were led by one of the hospital's HP¹ while the main investigator took notes. This difference is due to organizational matters. The focus groups took place between June 2017 and October 2018. We used a semi-structured interview guide (**Tables 1 and 2**) to lead the sessions. In terms of interview techniques, different kinds of probes were used to help participants elaborate further on certain topics. They were, for example, asked to reword or to clarify certain statements, or asked to elaborate on their feelings. Or the investigator listened to the conversations in silence and made sure to refocus the discussions when necessary.

The participants had been fully briefed on the topics to be discussed in the focus groups through an informational letter that had been included in their invitation to participate.

¹ These were the HP of the children whose parents were taking part in the focus groups. It was therefore specified orally and in writing that anything mentioned during the focus groups would not influence in any way the care given to their children and that the discussion would be used to help improve the HP' practices.

The HP' focus groups took place in the hospitals in which the participants worked. The parents' focus groups took place in the hospitals in which their children were monitored.

Focus groups lasted between 45 minutes and 1.5 hours (with an average duration of 1.16 hours). They were audio-recorded and transcribed verbatim.

Data analysis framework

We conducted a thematic analysis. The thematic analysis allowed us to study the themes identified within the interviews both through deductive (i.e. theory-driven) and inductive (i.e. data-driven) means (Zarotti et al., 2019). Since a gap between recommendations and practices had been identified, we found it useful to rely on a theory that would allow us to understand the actual activity of the individuals, in conjunction with their environment. We used Engeström's activity theory (AT) (Engeström et al., 1999) as a framework for the deductive analysis of the verbatims. AT consists of a systemic model of activity. In it, individuals are viewed as protagonists who are socio-culturally rooted in their environment. Engeström's model (**Figure 2**) is useful to understand the ways in which a large number of factors work together to affect an activity: in this precise case, it was the implementation of a DAPET according to the criteria that Morsa et al. (2018) had formulated. To obtain a *result*, certain *objects* must be produced (experiences, knowledge and physical products, for example). Human activity is carried out through *artefacts* (tools, documents, recipes, etc.). Activity is also ensured by an organization or a *community*. Furthermore, the community can impose *rules* that have an effect on the activity. The subject works in the framework of the community to reach the object. An activity is also usually composed of a *division of labor*.

Since AT is often used to implement training or health interventions (Gedera, 2016), it is relevant when studying the conditions for the implementation of a patient educational model. The point is not so much to observe the activity for its own sake, but to study the discourses on the activity by the people involved, as well as to explore the levers and obstacles that must be taken into account when an innovation (DAPET) is introduced to the activity. Over the course of our analysis, we paid close attention to new categories of analysis that we had not originally taken into account in our analytical framework and that could potentially emerge as important.

One researcher in health education who was exterior to the study (CD) discussed and agreed on the analysis made by the main investigator (MM) and on whether the themes and codes that had been identified corresponded to the verbatims.

Ethics

The study was approved by the Ethics Evaluation Board for Health Research (n°201713), the Advisory Committee on the Treatment of Information in the field of Research (n°16-311) and the National Commission on Computer Technology and Freedom (n°1984766v0) in France.

The anonymous nature of the data was guaranteed.

Results

Three focus groups were conducted with HP and two focus groups were conducted with parents.

A total of 26 HP from the three hospitals cited above participated in the focus groups. Groups were composed of HP from pediatric and adult care. A variety of medical fields and professional types were represented (**Table 3**). Despite the fact that a similar recruitment approach was used for all three groups, only one focus group represented a good balance between pediatric HP and adult HP (HP' FG 3). The two other focus groups were almost exclusively composed of HP from pediatric services. Participants in the study hypothesized that HP from the adult services of the hospitals under study were perhaps less interested in the transition. We must however note that these two focus groups took place in the pediatric services in a building that is separate from the adult services. On the other hand, the HP' FG 3 took place in a location common to both pediatric and adult services.

A total of 22 parents participated in the focus groups. One focus group was composed of the parents of young people between 10 and 24 years of age with type 1 diabetes and the other group was composed of the parents of young transplant patients. A prevalent disease (diabetes) and a rare disease (transplant) were therefore represented (**Table 4**).

The content analysis allowed us to examine the relations between the different points of the Engeström model (Engeström et al., 1999). The potential tensions in the implementation of a DAPET were also analyzed. Five themes of tensions inspired by the Engeström model were identified as well as an emerging theme and 14 associated codes (**Table 5**).

Theme 1: An organizational prism in regard to the object (Subject/object)

The HP who were interviewed all agreed on the idea of offering an educational approach to young people to teach them how to grow up with a chronic illness. They also observed the importance of taking psychosocial skills into consideration during this period. They

mentioned that their role consisted in acting on psychosocial aspects and not merely on strict medical issues. Finally, they highlighted that it would be appropriate for young people to be encouraged to participate in their own transition arrangements: co-deciding on which educational workshops to attend, among the many on offer, reflecting on how spaces can be furnished to make them more pleasant, co-deciding on the right time to move to adult care, having other young people come in to share their experiences, etc. Irrespective of the HP' given field, the object was therefore judged as being acceptable.

HP' FG 3: "The transition period is first and foremost a period of developmental transition. We must adapt our practices: talk about the future, talk about training, housing, etc. And we must offer fun initiatives to spark young people's interest"

We did, however, observe that HP had a tendency to think about the object, and transition in general, in organizational rather than in developmental terms. Discussions revolved around issues such as: the ways and relevance of designating more specialized caregivers to assist young people in the transition process, how information should be transmitted from pediatric to adult care, or whether a specific space should be dedicated to transition. The object's feasibility was questioned during these exchanges. HP also mentioned their need to be trained in adolescent medicine in order to better support young people in their transition process.

Theme 2: The lack of resources (Tools/ object)

HP called for resources to tailor an educational approach that would correspond to the young person's developmental level. In order to address the importance of psychosocial skills with young people, they would like to have access to pedagogical tools or to become proficient in certain pedagogical techniques (for example: role play, group discussion, audio and visual activities). They had similar expectations regarding the assessment of a young person's level of development in order to personalize the educational initiative according to each person's needs. A space dedicated to transition was also mentioned as a potential resource. Furthermore, formalized guidelines, shared by all services in the institution, would help HP adopt such an approach. Without these tools, some initiatives still exist, but they depend on people acting as resources, and they have a limited effect. For example, support groups that are co-organized by young adults and HP may be offered in the services of certain medical specialties, but such an initiative may not have a precise pedagogical objective, nor

are its modalities shared with other services from other specialties in an effort to generalize its implementation.

HP' FG 2: "We are aware that young people don't all have the same needs during this period. So we personalize as much as we can. For example, we might not sign someone up for an information day after having talked to the young person and the parents and realizing that they don't need it. But we would need tools to personalize our offer in a more relevant and systematic way."

Theme 3: A diverse set of practices (Rules / division of labor)

A variety of practices as well as different patient profiles were mentioned in the various medical specialty services. Transition is generally thought through and organized by a particular service rather than by the institution as a whole. The common developmental needs of all young people with chronic illnesses are therefore not recognized since the medical specialty is the main source of focus. Services therefore organize transition processes according to medical specialties, and the various arrangements on offer can widely differ from one service to another. In one given institution, a specialized department could, for example, offer a single transition consultation as its only arrangement while another service could plan on educational workshops and joint consultations. Services from different specialties do not have a shared model despite the fact that the young people themselves have expressed common needs. Best practices rarely transfer from one service to another.

HP' FG 1: "The planning of transition activities depends on the patient cohort. It's easier to rally staff with a smaller cohort (such as for cystic fibrosis, for example). For certain pathologies such as epilepsy, the diagnosis isn't always perinatal, it can happen during adolescence. Fast transitions can therefore be complicated, since the patient will not have been seen much by the pediatric service. In such cases, the transition takes place later, giving enough time to establish a relationship."

Theme 4: Defining the role of the parents (Subject / community)

The role of parents during transition has not been clearly defined. This observation was made both by the HP and the parents. HP tended to say that parents sometimes acted as

obstacles: they were either too present, protective and maternal, and consequently prevented a young person from gaining autonomy, or they were not involved enough in their child's treatment and health, therefore preventing the young people from adhering to treatment. Parents, on the other hand, expressed a need to redefine their role during the transition and, in particular, when their child moved to adult care: should the parents still be present during consultations? When should they move aside and fade away from the consultation? How can they contribute to help their child gain more autonomy when managing his/her overall health? To help and reassure their children, parents were also eager to receive more practical information on the change from one service to another, such as the new doctor's contact information, the date of the passage to adult care, new consultation modalities, etc.

P' FG 1: "During my son's first adult consultation, the doctor did not welcome me in the consultation room. It was very strange, I didn't know what to do. I didn't know what I could be useful for. And I'm realizing that, in the pediatric service, we never discussed what my role would be when monitoring my son's health once in the adult service."

Similarly, parents are the main sources for young people to acquire self-care skills. They identify as such. For this reason, they expect to be included in the transition process so that the young person's autonomy can coincide with his/her arrival in adult care. This is why some parents find their participation in educational workshops to be essential once the child is diagnosed. These workshops allow them to have the skills they need to manage the young person's illness and treatments and to teach him/her to progressively become more autonomous.

Theme 5: The absence of institutional policies (Rules / object)

The lack of rules emanating from the healthcare establishment when coordinating the transition can lead HP to limit their actions in this regard: mainly because they are afraid of making mistakes or because dedicated timeframes for such activities are neither planned nor recognized. Institutional recognition would allow all components of transition to be recognized, including the activities that support the young people's development.

HP' FG 3: "It would be good for us to have a space that would be specifically dedicated to the transition. It would help to formalize the process and to make planning easier by bringing the staff and resources together."

Discussion

In an attempt to understand the gap between the experts' recommendations and the actual practices of HP during transition, and in order to find ways to fill this gap, we chose to study the conditions for the implementation of a DAPET, starting with the proposal of a model.

We first noted that professional caregivers lacked the resources to support and accompany young people in their psychosocial development. According to AT, this is an essential factor needed to implement an activity. This lack may explain why HP in pediatric and adult care services find it difficult to maintain a *developmentally appropriate* practice. Our analysis shows that training alone is not enough if it is not accompanied by an access to resources that make practices easier, and by the support of the institution. Several HP in the focus groups had been trained in patient education but they had not managed to organize educational activities dedicated to developmental transition. They argued that they did not know which personalized content they should start using with young people or how to proceed from a pedagogical standpoint. In a recent study, Akre et al. (2018) did make a list of biopsychosocial themes to broach with young people during the transition, along with a list of the appropriate ages for each topic. Such resources could be made more available in hospital services to improve the developmental orientation of transition arrangements. The sharing of resource does, in fact, have an impact. Britto et al. (2014) showed that an educational tool for the management of asthma had been adapted for young people living with other chronic illnesses and that the healthcare offer had improved as a result.

We note that, while HP believed that gearing their practice towards supporting the psychosocial development of the young people in their wards was essential, they still talked about organizational ways to reach their goals rather than discussing communicational or pedagogical strategies. And yet, they perceive their role as dealing with relational aspects and the patient's education. These results can, in part, be explained by the ways in which the institution organizes the healthcare it provides. Most healthcare services are currently leveraged to treat acute diseases and reduce hospital stays for chronic conditions (Adams and Woods, 2016). The planning and coordination of services for young people with chronic illnesses are therefore largely planned by the HP themselves instead of the institution. The healthcare system therefore seems to condition HP into tackling the issue from an

organizational standpoint without providing them with the appropriate strategies. Studies have indeed shown that a majority of young people had not received adequate information or preparation when moving from pediatric to adult services (McManus et al., 2013; Wong et al., 2010). The institutions must therefore define clear organizational strategies, which would then allow HP to focus more intently on their pedagogical role during transition.

The gathered evidence therefore shows that, for the healthcare activity to be truly transformed, caregivers should be able to offer an educational approach in an “enabling environment”. The enabling environment designates an environment which supports one’s *power of action* even more than one’s *knowledge of action* (Falzon, 2005). The institution should therefore be more systematic in the ways in which it implements the organizational conditions that can allow HP to activate their potential educational skills: making time and space for transition, setting up task forces or best practice exchanges on patient education during the transition, providing access to training programs, etc. HP in pediatric and adult care could therefore improve their grasp on educational activities that are geared toward the transition. In recent works, Williams and Iverson (2018) described a tried and tested method to develop a transition policy within an institution. The first step resides in exploring the current transition practices that take place in the healthcare services. On this basis, a “Transition Council” composed of HP from the institution is in charge of formulating the key principles. These are then reviewed in consensus conferences with human resource services and services guaranteeing the quality of care. Finally, once the transition policy is approved, communication and training campaigns contribute to making its implementation effective.

Young people and parents could also be members of the Transition Council. Parents do indeed constitute a resource for HP when it comes to educating young people to manage their illness and its treatments. Parents are the ones who care for their child and help them become progressively more autonomous (Heath et al., 2017; Rivard and Deslandes, 2012). Finally, certain services offer workshops in which young adults come to share how they experienced their transition with young people in pediatric services. Through this type of peer learning, young people can project themselves more easily thanks to the words of their peers, and this could alleviate their feeling of living alone with an illness on a day-to-day basis (Klodnick et al., 2015). The peer-educator has been recognized as making positive contributions, especially in the realm of emotional support, understanding the healthcare system and sharing information (Gopalan et al., 2017; Pomey et al., 2015).

Limitations

We referred to AT for the deductive thematic analysis of the focus group verbatims. Our study did, however, limit itself to the discourses on the activities of the people involved in the process. It did not intend to be a thorough analysis of the activity of all participants (complete with observations, the analysis of tools, the analysis of internal regulations, etc.). Furthermore, the chosen mode of recruitment may have introduced biases. Parents and HP were probably already involved and interested in the topic of transition. The information we obtained from these groups may have therefore been influenced by this factor. Similarly, we made the deliberate choice of only interrogating HP and parents, our argument being that they are the main people involved in helping a young person gain more autonomy during transition. This sample should allow us to complete our previous study (Morsa et al., 2018) which explored the point of view of the young people. Furthermore, our results were focused on hospital activity, but HP outside of hospitals can also be instrumental in the education of young people during transition. Our study did not examine the activity of these actors. We also note that we only interviewed the parents of children with two different illnesses. We therefore cannot claim to have explored the experience of parents of children with chronic illnesses fully.

Conclusions

HP, whether in pediatric or in adult care, were hoping for resources that could help them support the psychosocial development of young people and their illness in tangible ways. This is a necessary condition for the sustainable and shared implementation of a DAPET. The managers of the healthcare establishments also have a part to play. Defining transition policies with all those involved could help alleviate HP from having to manage organizational issues. They could, instead, focus on their roles as HP-educators. The participation of parents, when it is possible for them, should be encouraged by these organizational policies.

Table 1. Interview Guide for the Healthcare Providers' Focus Groups

- How do you view the idea that healthcare providers can help young people develop interdependency skills (asserting oneself in the social space, using healthcare services) and not only skills related to functional autonomy (self-care skills)?
- How should one adjust to the young people's level of development to allow him/her to gain the appropriate skills?
- What role should the parents be given during this period?
- How should sensitive or intimate questions be approached with young people?
- How could peer-educators be integrated to the transition processes?
- Which steps should be taken to optimize the continuity of care and the continuity of patient education between pediatric and adult care?
- How should a young person be trained to use a new healthcare service?

Table 2. Interview Guide for the Parents' Focus Groups

- Based on your experience, what essential elements are needed to experience an optimal transition?
- How do you view the idea that healthcare providers can help young people develop interdependency skills (asserting oneself in the social space, using healthcare services) and not only skills related to functional autonomy (self-care skills)?
- What role should the parents be given during this period?
- How should sensitive or intimate questions be approached with young people?
- How do you proceed to make young people more autonomous during this period?

Table 3. The Characteristics of the Healthcare Providers' Focus Groups (HP' FG)

| HP' FG | Number of Participants | Job Titles | Healthcare Service |
|---------------|-------------------------------|---|---------------------------------|
| 1 | 10 | 5 doctors 5 nurses | 9 pediatrics 1 adult service |
| 2 | 6 | 3 doctors 1 nurse 1 psychologist 1 social worker | 5 pediatrics 1 adult service |
| 3 | 10 | 8 doctors 1 nurse 1 psychologist | 6 pediatrics 4 adult service |

Table 4. The Characteristics of the Parents' Focus Groups (P' FG)

| P'FG | Number of Participants | Chronic condition |
|-------------|-------------------------------|--------------------------|
| 1 | 12 | Type 1 Diabetes |
| 2 | 10 | Transplant |

Table 5. Themes and Codes

| Themes | Codes |
|--|---|
| Theme 1: An organizational prism in regard to the object (<i>Subject/object</i>) | The perceived need to adapt practices to young people's psychosocial development; The organizational aspects are given as the first solution; A need for training; Coherence with the perceived role. |
| Theme 2: The lack of resources (<i>Tools/ object</i>) | A need for additional tools, techniques, and resources; Non-formalized initiatives; Personalizing the young people's educational process; Organizational solutions are implemented |
| Theme 3: A diverse set of practices (<i>Rules / division of labor</i>) | Practices are divided according to services; A lack of common institutional rules |
| Theme 4: Defining the role of the parents (<i>Subject / community</i>) | The parents perceive their role as unclear; The parents are perceived as potential barriers by the healthcare providers; Parents express a need for more information about adult care; Parents express a need for more education on managing young people's care. |
| Theme 5: The absence of institutional policies (<i>Rules / object</i>) | The lack of a common institutional project for patient education during transition |

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