

Adolescents' experiences during hospitalisation in a paediatric unit

Vivências dos adolescentes durante a hospitalização num serviço de pediatria
Experiencias de adolescentes durante la hospitalización en un servicio de pediatria

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Abstract

Background: Adolescence is a key stage of development characterised by rapid changes and adoption of behaviours with significant health consequences. Given that adolescents were indiscriminately assisted in paediatric or adult units, the extension of paediatric care up to 18-year-olds required the creation of a suitable environment to the specific needs of adolescents.

Objectives: To understand the experiences of adolescents during hospitalisation and identify their needs.

Methodology: Qualitative, descriptive and exploratory study. Data were collected through interviews to 12 adolescents aged between 12 and 17 years who had been hospitalised for more than 72 hours.

Results: Adolescents value the relationship with the professionals and the unit characteristics. They feel confined and miss their usual activities, personal objects, and family. Pain and invasive procedures are the most complicated experiences. They enjoy being in a paediatric unit.

Conclusion: Understanding the experiences of adolescents about their contact with healthcare services contributes to identifying their needs and the best practices for provision of youth services.

Keywords: adolescence; health; hospitalization; experiences; take care.

Resumo

Enquadramento: A adolescência é uma etapa-chave do desenvolvimento, caracterizada por rápidas mudanças e adoção de comportamentos com consequências importantes para a saúde. Atendidos de forma heterogênea em serviços de pediatria ou de adultos, o alargamento da idade de atendimento até aos 18 anos, veio implicar a criação de ambientes adequados às necessidades específicas dos adolescentes.

Objetivos: Conhecer as vivências dos adolescentes durante a hospitalização e identificar as suas necessidades no internamento.

Metodologia: Estudo qualitativo, exploratório e descritivo. O instrumento de coleta de dados foi a entrevista, a 12 adolescentes entre 12 e 17 anos, internados há mais de 72 horas.

Resultados: Os adolescentes valorizam a relação com profissionais e características do serviço. Sentem-se fechados e com falta das suas atividades normais, objetos, família. A dor e os procedimentos invasivos são as vivências mais complicadas. Gostam de estar num serviço de pediatria.

Conclusão: Conhecer a experiência dos adolescentes no contacto com os serviços de saúde fornece contributos para a identificação das suas necessidades e melhores práticas no seu atendimento.

Palavras-chave: adolescência; saúde; hospitalização; vivências; cuidar.

Resumen

Marco: La adolescencia es una etapa clave del desarrollo y se caracteriza por cambios rápidos y adopción de comportamientos con consecuencias importantes para la salud. Se les atiende de forma heterogénea en los servicios pediátricos y de adultos, y la ampliación de la edad de atención en los primeros hasta los 18 años llegó a implicar la creación de entornos adecuados a las necesidades específicas de los adolescentes.

Objetivos: Conocer las experiencias de los adolescentes durante la hospitalización e identificar sus necesidades durante la misma.

Metodología: Estudio cualitativo, exploratorio y descriptivo. El instrumento de recogida de datos fue la entrevista a doce adolescentes entre 12 y 17 años hospitalizados hace más de 72 horas.

Resultados: Los adolescentes valoran la relación con los profesionales y las características del servicio. Se sienten cerrados y sin sus actividades habituales, sus objetos y su familia. El dolor y los procedimientos invasivos son las experiencias más difíciles. Les gusta estar en un servicio de pediatria.

Conclusión: Conocer la experiencia de los adolescentes en contacto con los servicios de salud contribuye a identificar sus necesidades y a que haya mejores prácticas en su atención.

Palabras clave: adolescencia; salud; hospitalización; experiencias; atención.

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Introduction

Adolescence is a stage of development characterised by rapid physiological, cognitive, socio-cultural, and behavioural changes, and the transition to a healthy adult life is one of the major challenges of individuals (Fonseca & Tavares, 2009; Silveira, Santos, & Pereira, 2014).

Despite being considered a stage in which people have a good health, with low morbidity and mortality rates, the number of situations of chronic illness is increasing which, according to the World Health Organization, will be a burden to society and the health system in the next decades (Ministério da Saúde, 2012).

The prevalence of chronic diseases in children and adolescents has increased over the last decades as a result of several factors: better care and accessibility, survival of very preterm infants, and increased survival in various pathologies. In this lifecycle, problems such as obesity, increased use of tobacco, alcohol and other substances, as well as eating and behavioural disorders, are also important (Sawyer, Proimos, & Towns, 2010; Silveira et al., 2014). According to the National Health Plan for 2012-2016, respiratory and digestive diseases are the main reason for hospital admission among children and young people under 18 years of age. External factors such as accidents, HIV, and suicide are the most common causes of death (Ministério da Saúde, 2012).

The provision of care to adolescents in primary care and hospital settings has been given special attention since the 1980s, and, for several years now, this issue has been discussed and measures have been taken to improve care delivery. Examples of these measures are the normative decisions and their practical consequences in the different services (Fonseca & Tavares, 2009).

In the Coimbra Paediatric Hospital, the formal extension of age of admission up to 18 years coincided with the transition to the new hospital. Although there was previously some experience of caring for adolescents with chronic diseases, nurses faced a new reality as a result of this extension and had to acquire knowledge, experience and training to provide better care.

This qualitative study aimed to understand the experiences and needs of adolescents during hospitalisation in the inpatient ward, with the purpose of better meeting the identified needs.

Background

Adolescence is a transitional phase between childhood and adulthood that is marked by major changes and transitions, thus it is natural that special attention be given to health among this age group.

Adolescents are considered a healthy population, whose morbidity and mortality rates are especially dependent on external factors and risk behaviours influenced by the environment. Some health determinants related to lifestyles begin at this age and are associated with worrying current and future health problems. Examples include accidents with risk of death and disability, use of harmful substances, violence, suicide and suicidal behaviours, unprotected sex, early parenthood, eating disorders, and lack of physical exercise (Guerreiro, Cruz, & Figueira, 2014; Machado, Alves, & Couceiro, 2011; Ministério da Saúde, 2012; Sawyer et al., 2005). Chronic diseases and acute episodes are often also causes of morbidity. This is a critical phase of development for the adoption of relevant health behaviours which will have repercussions over time, thus the health professionals and the community must prioritise actions aimed at the prevention and promotion of healthy lifestyles (Calheiros, Patrício, & Bernardes, 2014; Fonseca & Tavares, 2009).

During hospitalisation, adolescents interrupt their normal activities and their interaction with peers. They become isolated from what is familiar to them, and are subjected to rules, routines, schedules, treatments, and invasive procedures in a strange environment. The situation is often unexpected, since adolescence, as it was already mentioned, is considered one of most healthy phases of the lifecycle.

According to Maas & Zagonel (2005), a hospitalised adolescent experiences multiple transitions at the same time: *developmental, health-illness and situational transitions*, requiring particular attention by the nursing team who should have knowledge about transitions, as well as the necessary communication skills and sensitivity to understand what these experiences really mean.

These and other specific skills of nurses apply to every area of adolescent care, as it is recommended for child and youth health specialist nurses by the Portuguese Nurses' Association (2010), namely: maximisation of the potential for development, management of well-being, early detection and referral of behaviours

that interfere with the quality of life, and being progressively held responsible for health choices.

The Paediatrics & Child Health Division of the Royal Australasian College of Physicians believes that “Ideally, adolescents should only be admitted to a designated adolescent area” (Sawyer et al., 2010, p. 215). According to these authors, adolescent wards should include: therapeutic activities and programs such as art and music therapy; peer groups, collaboration with previously hospitalised *healthy adolescents*; professionals with adequate knowledge to care for adolescents; systems that encourage the timely transfer of these adolescents to adult services; and strategies that motivate them to use health care services, such as the *Youth Advisory Committees*.

Fonseca and Tavares (2009) also mention the necessary characteristics of these services, emphasising practical aspects such as academic monitoring, which is important in these stage of life, and professionals’ training.

In Portugal, the provision of care to young people in paediatric wards has been very heterogeneous, varying from hospital to hospital and service to service. However, Order no. 9871/2010 established that this extension would reach all areas of hospital care, although it could be done in a gradual and progressive manner to be defined by each institution in collaboration with the Regional Health Administration. Countries such as the USA, Canada, England, New Zealand, and Australia have different experiences regarding adolescent inpatient units (Sawyer et al., 2010; Abreu & Azevedo, 2012). However, Viner (2007) believes that there is little evidence to support its effectiveness, and, together with Payne et al. (2012), they believe that these units contribute to improve the quality of care.

The creation of Adolescent Units offers an excellent opportunity to change the organisation and provision of care to this specific group. “In the meantime, there is much we can do to make all hospitals more adolescent-friendly. Just ask any young person.” (Sawyer et al., 2010, p. 215).

Research question

The research question posed was *What are the experiences and needs of adolescents during hospitalisation in the inpatient unit?* However,

other questions were also formulated that allowed structuring this study: What were the feelings towards hospitalisation? What was the most complicated situation experienced during hospitalisation? What were the strategies used to overcome the most complicated situations? How did they feel in a paediatric unit?

Methodology

With the purpose of understanding the experiences of adolescents during hospitalisation in an inpatient unit and identifying their needs in that context, we designed a qualitative, exploratory and descriptive study, with content analysis according to Bardin (2009).

The study was carried out in the Medical Paediatric Unit of the Paediatric Hospital of the Coimbra Hospital and University Centre. The participants were 12 boys and girls aged between 12 and 17 years, admitted for more than 72 hours. The sample was selected by convenience.

The exclusion criterion was young people with impaired verbal communication. Data were collected through interviews. To prevent the possibility of any stressful situation influencing their reports, the interviews were conducted in periods when the adolescent expressed feeling no pain or did not have to undergo invasive procedures. As response content became repetitive after the 12th interview, we decided to stop data collection.

The Unit assists children aged between 28 days and 17 years and 364 days and has a priority inpatient wing for young people of all medical specialties. For logistic reasons, this wing may occasionally assist smaller children. In terms of space, the unit provides some of the conditions recommended by authors such as Fonseca and Tavares (2009) and Stheneur et al. (2010) for adolescent care in paediatric wards: suitable beds, individual bathrooms, single rooms and wards with two beds and individualised spaces.

At the time of admission, adolescents are explained the hospitalisation rules and given a brochure that validates the information. Their parents or carers are also explained these rules and given an explanatory brochure.

Adolescents are not allowed to move outside the service area. At night, one of the parents or carers is allowed to stay in the room, provided that this person

is over 18 years of age. Visits from friends and relatives are allowed.

The data collection technique used was the semi-structured interview, based on an interview script previously applied by Azevedo (2010).

The first questions were used to obtain data on the participants' sociodemographic characterisation and hospitalisation; the remaining questions were open-ended questions aimed to understand the experiences and needs of adolescents. The interviews were carried out in person during the period of hospitalisation. The parents could be present if the adolescents found it to be more comfortable for them. The interviews were audio recorded and transcribed in full.

In order to respect the ethical and legal procedures, permission was requested to the institution for the conduction of this study. Authorisation from the participants and their parents or legal representatives was also obtained. Therefore, after being selected, each participant was informed of the ongoing research and questioned about their interest and willingness to collaborate. Before the interview, this information was also provided to the legal representative(s), together with the free and informed consent, which they subsequently signed. Despite being minors, all

participants signed the consent, in order to make them feel that they had decision-making power.

In the first phase, a floating reading was conducted to identify the content of the interviews, looking for the feelings and needs of adolescents during hospitalisation. For the encoding process, we selected the theme as our unit of record. To understand the meaning of the unit of record, we presented the units of context. The categories were subsequently elaborated.

We interpreted the data based on the themes emerging from the analysis of the interviews and on our theoretical framework.

Analysis and discussion of results

Young people were aged between 12 and 17 years, mostly boys, who lived in the municipality/district of Coimbra, lived with their parents, and socialised with friends of similar ages. They like video games, watch TV, movies and series, listen to music, play football, ride a bike, and all of them attend school.

The remaining open-ended questions aimed to answer the research questions, addressing aspects related to hospitalisation.

Table 1
Adolescents' feelings towards hospitalisation

Dimension	Category	Subcategories	Units of record
Feelings towards hospitalisation	More positive feelings	Relationship with professionals	"The nurses are nice, and so are the doctors. . ." "people are nice" "being here is also not bad. . ." "I feel good, comfortable . . ." "I feel good . . ."
		Environmental conditions	"I like the environment" "it's big, spacious . . . it's calm" "Good. I like the hospital."
	Less positive feelings	Social isolation	"I enjoy being here. . ." "The problem is that I'm stuck here. . . I can't go for a walk. . ." "I miss going for a walk . . ."
		Ambivalent feelings	"I feel good . . . but it's a bit boring sometimes . . ."
		Routine changes	"I can't do my things, the ones I do at home . . ."
	Neutral feelings		"I feel normal"

Three categories emerged from the reports of the adolescents: more positive feelings, less positive feelings, and neutral feelings.

The adolescents gave more importance to the people and the environment, which are essential for the

provision of care as recommended by Sawyer et al. (2005), Fonseca and Tavares (2009), and Stheneur et al. (2010).

Both the fact that they have to stay in the unit (to comply with the internal rules) and the changes

in their routines generated less positive feelings. The feeling of being imprisoned/confined was also found by Azevedo (2010), revealing that hospitals'

rules and regulations, for safety reasons or others, are not flexible to the adolescents' needs.

Table 2
Adolescents' needs during hospitalisation

Dimension	Categories	Subcategories	Units of record
Needs felt during hospitalisation	Daily life		"going for a walk . . ."
			"having a coffee with my friends . . the school, as strange as it may seem"
	Personal objects		"leaving the unit, . . . but we can't"
			"dressing like a normal person, doing my hair, my makeup, it's complicated here."
			"going out with my friends. . . hanging out with my friends"
			"going for a walk . . ."
	Pets		"my bed, my things"
			"I miss my clothes . . ."
	Family		"I miss watching my favourite series; they have TV here but no cable. . ."
			"my electric guitar".
	Does not know		"my dog . . . If I could I would bring her to the hospital to be here with me"
			"and I miss my parents and my siblings . . ."
			"Honestly, I don't miss a thing, . . . I feel good, I'm very comfortable here in the room"
			"I don't know . . . I have a TV, a computer . . ."

Several categories emerged in this dimension. The social isolation felt by the adolescents during hospitalisation seems to have the most influence over their answers. Indeed, hospitalisation interrupts the daily and important activities of adolescents, such as going out into the street, going for a walk, being with friends, going to school, and taking care of their personal image. As pointed out by Matos (2008), family, friends, school, leisure and community are the most important contexts for adolescents while building their identity.

They miss their home environment, their personal belongings, their pets. Although the family may be present during hospitalisation, some adolescents also mentioned missing their families. Even in a stage of life characterised by the development and affirmation of identity and autonomy in which the relationship with the peers becomes significant, the family continues to be a source of affection and security. Some young people feel very comfortable at the hospital, which could indicate a feeling of balance and acceptance of the new situation.

Table 3

Most complicated situation experienced by the adolescents during hospitalisation.

Dimension	Category	Subcategory	Units of record
Most complicated situation during hospitalisation	Health/illness transition	Disease manifestations	"It was really the pain. . . That was it, nothing else. . . But then, having to have surgery again, it was even worse. . ." "When my temperature reached 39.9 °C". "when I had a lot of pain . . ." "the pain . . ."
		Therapeutic interventions	"when I had surgery, because then I had all these tubes around me . . ." "it was just inserting the catheter." "it is always inserting the catheter . . . I really panic around needles"
	Situational transition	Interruption of activities	"it was losing things from outside . . . I'm a model so I lost a lot of jobs . . . and that was really hard."
		Hospitalisation conditions	"The most complicated moment was when I got here and I had no company at all . . . I was alone in my room, I had no TV . . .") "the food"
	None		"there was really nothing . . ."

Invasive procedures are highly frequent in healthcare services. The pain associated with the disease symptoms or the therapeutic interventions was the most complicated situation experienced by the adolescents, thus pain management and treatment should be a priority among healthcare professionals. The Directorate-General of Health has issued several guidelines on pain assessment and management, more specifically for children and adolescents. Nurses in particular should regularly assess and manage pain through autonomous and interdependent interventions, such as information about the procedures, planning them, teaching

self-control techniques, using assessment scales, and systematically using pharmacological and non-pharmacological strategies (Direção-Geral da Saúde, 2012).

The interruption of an important activity was another situation mentioned by the adolescents. As previously mentioned, hospitalisation deprives adolescents from the development of their daily activities, their hobbies and leisure activities. In a phase of affirmation, this situation is very significant.

The disease manifestations and the therapeutic attitudes were identified as one of the most complicated situations in other studies (Azevedo, 2010).

Table 4

Strategies used by the adolescents to overcome the less positive moments

Dimension	Category	Subcategory	Units of record
Strategies to overcome the less positive moments	Focus on problem-solving		"caring for myself psychologically and gaining strength through something that excites me" "taking a bath was the best idea to control pain . . ." "I always try to take a deep breath, think about positive things . . ." "I always thought I was normal and now I had to handle the pain for a while. . ." "I try to be in a good mood, not to think a lot about it. . ."
		Leisure activities	"I listen to music . . . I'm usually in my computer, online, and from time to time I make some drawings." "I listen to music in my computer and I forget about the needle stick, the pain . . ." "the ladies in the living room ask me to do some things for them and I do it . . ."

Support from the unit's professionals/healthcare professionals	"I talk like this with the nurses who understand me. . . and then I get distracted . . ." "with the support of all doctors and nurses"
Family support	"and my mom comes here every day. . ." "talking to my closest relatives who give me more strength." "I always hold my mother's hand. . ."
Not dealing with the problem	"I thought about something else. . . I tried not to think" ". . . I can't do anything" "I usually let it happen, I let it go away . . ."

At a stage of the lifecycle in which adolescents are confronted with developmental challenges, the experience of the illness and the hospitalisation can be particularly critical given the threat to their physical and emotional integrity, the treatments, and the suffering. Coping, which is considered by Guerreiro et al. (2014) as a stabilizing factor that facilitates adaptation or adjustment to stressful events, was used by young people in their various strategies and styles. They used strategies *focused on problem-solving*, and strived to be well, think positive, use strategies to

reduce pain, and be in a good mood. They also asked for the support of the professionals (*the nurses that understand them*, which reinforces the importance of the team intervention strategies as a therapeutic action) and for the presence and support of their family (the emotional support was greatly appreciated, despite the fact that young people were in a stage of personal affirmation and search for autonomy). They also used strategies for avoiding or not dealing with the problem, such as doing nothing about the situation, letting it go away, trying not to think about it.

Table 5

Relationship between the adolescents and the healthcare professionals

Dimension	Category	Subcategories	Units of record
Relationship with different healthcare professionals	Good relationship		"Good" "Very good" "I like all of them" "Even auxiliary staff and catering staff . . ." "I have no reason to complain."
			"they are nice and when we need help they help us . . ." "Excellent, super nice . . ." "they are always vigilant and available". "they gave me strength to overcome things as quick as possible . . .". "the doctors are looking out for me, and so are the nurses . . . I always try to talk to the nurses whenever something is not right to come to an agreement . . . auxiliaries also treat me nicely" "I think they are all nice." "They are kind, efficient . . . They are nice . . ."
	Relational and professional skills		
	Personal characteristics		"Some nurses and auxiliaries are very grumpy"

These reports confirm the importance of a qualified, empowered and prepared team to deal with the adolescents and provide sensitive care to the individuals in this age group. The reports of the adolescents show how they perceive and value the availability of nurses and other professionals: attention, care, emotional support, communication, friendship, and kindness.

These opinions corroborate those expressed by several authors who underline, in addition to age and the service where care is provided, the importance of multidisciplinary teams with training in adolescent care, who are capable of meeting the specific needs related to the disease and the development (Fonseca & Tavares, 2009; Sawyer et al., 2010; Ordem dos Enfermeiros, 2010).

Table 6
Hospitalisation in a paediatric unit

Dimension	Category	Subcategory	Units of record
Adolescents' feelings towards sharing the unit with younger children	Feeling good in a paediatric unit		"I feel good" "I feel good. . . There are younger children, but there are also others who are older than me . . . And I like all of them. . . I like to visit the babies in their rooms, I like to caress them while they are in the hallway. . ." "I feel good . . . I've nothing against them. I even like children." "I feel good. I'm entertained with my things. . ." "young people socialise more. . . I've already been in an adult unit but it's better here for young people of my age . . . it's easier to get along with a child than with an adult . . ." "I think it's very good for us to have contact with everyone . . . to make more friends . . . to support each other . . . I've been in an adult unit . . . I rather be with kids than with older people." "Sometimes we have nothing to talk about. It was different with a colleague with the same age as me. . . it was good, but today a younger one was admitted" "It is strange and funny at the same time . . ."
	Feeling better than in an adult unit		
	Prefer being with peers		
	Feeling odd		

Based on the answers obtained, we found that the adolescents agree with this organisational model of being assisted in a paediatric unit. Although there is a specific wing for older children in the unit, they still share the hallways and activity rooms with younger children.

Some of them enjoy being with younger children and even with babies. Others, who have had experiences in adult units, prefer to stay in a unit like the one analysed in this study, reporting that they can more easily socialise with children than with adults or *older people*.

Even when it seemed awkward, it was not unpleasant to share the same space. The need to be together with other adolescents of similar ages was also mentioned as important and this is a useful indication that can be used by the services to organise the hospital areas and inpatient units.

Payne et al. (2012) mentioned that there has been a growing interest in the discussion and implementation of units for adolescents and that this is already a reality in countries such as England and Australia. They also mentioned that there is evidence of improved quality of care in these units. Viner (2007) reported that the units for adolescents improve aspects of quality when compared with paediatric or adult units.

Another aspect that we wanted to ask them about was the type of company that they prefer next to them. Adolescents mentioned that they prefer the family, the parents, the grandparents and even their best

friend to accompany them. As they are in a phase of acquiring and developing their autonomy, the need for no systematic supervision was also mentioned.

With regard to the *Friends' reaction to hospitalisation*, the reports of the adolescents show that most of them felt supported by their friends and that their reaction did not come as a surprise to them.

Adolescents gave several suggestions when answering the open-ended question *Mention other aspects that you were not asked about*, such as having more movies and TVs, a balcony to get fresh air, to go outside with a security guard if necessary, to go out momentarily alone or with an operational assistant, a library with age-appropriate books, newspapers and fashion magazines, a park, be able to go out with the father or with the mother given that this is a more complicated phase, Internet and more computers, a teacher in the activity room for longer periods of time.

Conclusion

Adolescents are seen as individuals with very specific characteristics, thus research on adolescence has acquired a growing interest. This stage is characterised by important physical, psychosocial and behavioural changes, which are strongly influenced by the contexts where they live and integrate themselves. The adolescents in this study provided similar answers to the questions, which is in line with other studies.

The data collected and the feelings experienced by hospitalised adolescents underline their positive opinion about the team, the space and the physical conditions, but also the less positive aspects of feeling confined, bored, and unable to leave the unit. They miss their friends, their daily activities, their extended family, their personal belongings, their home, their pets.

The situations that can cause pain and suffering were those most often mentioned as «the most complicated situation», but also the fact that they have interrupted important activities and are in an unfriendly environment. In view of these experiences, they were able to use problem-solving and emotional strategies to overcome them. They mobilised personal resources, reached out to family members and professionals for support and/or let it go away. The relationship with the professionals was seen as positive or very positive in almost all of the reports, and the technical and relational qualities and skills were underlined. They enjoy being in a paediatric unit.

The rule of not allowing adolescents to leave the unit, not even to go to one of the food machines with their parents, or to walk around the hospital hallways, should be reviewed since adolescence is a phase of exploration, search for autonomy and freedom, which is interrupted by hospitalisation and inflexible rules. In view of the abovementioned reasons and given the adolescents' growing need for specialised care to increase their ability to adapt, it is essential to continue to study these issues. We acknowledge the small sample size and the fact that the study was only conducted in one unit as weaknesses and limitations of this study. Data cannot be generalised. Even so, it was important for the consolidation of more information in this area. Further studies should be conducted on this topic, with more representative samples and other methodologies.

The existence of research in nursing is an indicator of the desire to provide better nursing care, and we expect that this study has contributed to accomplishing this goal.

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