Empowering Young Persons During the Transition to Adulthood

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2.1 Introduction

In the past years, it has been suggested that in order to increase patient participation and move toward more collaborative models of care, healthcare providers should aim at increasing patient empowerment (Bravo et al. 2015). This concept is understood as an enabling process or outcome that involves a shift in power that leads to patients being more involved in care and decision-making. Patient empowerment aims at increasing autonomy, patient participation, increased awareness, and consciousness, as well as the development of relevant psychosocial skills (Castro et al. 2016). Previous

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research has found that a higher level of patient empowerment is associated with improved quality of life, well-being, and clinical outcomes (Bravo et al. 2015).

Research on the application of patient empowerment in adolescent health and transitional care is limited (Úcar Martínez et al. 2017). During the transition to adulthood, there is a window of opportunity to support the young person. This support should involve among other things, the fostering of development of psychosocial skills that help the young person during the transition to adulthood and the transfer to adult care, as well as sufficient knowledge that leads to adequate self-care. Keeping this in mind, patient empowerment is a construct that is of value within adolescent health and transitional care.

Empowered young persons are the ones who will actively participate in care, which entails seeking information, participating in the decision-making process and making themselves heard. Furthermore, they are aware of the different influencing factors in the transition process, can prioritize the required actions to improve their quality of life and well-being, and acknowledge the need for assistance from others (e.g., healthcare professionals, relatives, or friends). Empowered young persons can also be considered a force of change since they gain the confidence to help others by sharing their experiences, resources, and coping mechanisms (Úcar Martínez et al. 2017). As previously mentioned, a higher level of patient empowerment has been associated with better patient-reported and clinical outcomes, enabling young persons to benefit from these effects, not only in the near future but also throughout their life course (Bravo et al. 2015).

This chapter focuses on patient empowerment, its origin and relevance, conceptualizations, and available measurements. Furthermore, the associations between patient empowerment and nursing are discussed including an exploration of the relationship between the nurse and the young person needed to foster empowerment and based on a person-centered care perspective. A deeper reasoning of why it is important to empower young persons during the transition to adulthood and exemplifications of how young persons can be empowered in clinical practice are provided.

2.2 Patient Empowerment: Relevant Theoretical Grounds

Prior to explaining how nurses and other healthcare professionals can improve patient empowerment in adolescents, it is important to understand the different conceptualizations available, the implications associated with this construct, and the associated benefits of a higher level of patient empowerment. Hence, this first section in the chapter provides important theoretical underpinnings that will help build the rationale for the following sections that discuss specifically the empowerment of adolescents with chronic conditions.

2.2.1 Patient Empowerment: Origin and Conceptualizations

Empowerment is a concept that arose from social sciences, initially associated with movements trying to fight social injustices. However, before that, empowerment was related with Paulo Freire, an educator who developed a way of involving students in the learning process in order to achieve better outcomes (Wallerstein and Bernstein 1988). He suggested a learning approach that encourages students to question critical issues and participate in the decision-making process. Furthermore, according to Freire, group dialogue is imperative, so participants can uncover their place in society and ways of moving forward (Wallerstein 2006). This approach toward education has had a considerable influence in how individuals can become empowered.

Within healthcare, the concept was introduced in the field of health promotion as patient empowerment, with the aim of increasing patient participation. From there, the concept has been adopted within other healthcare sectors, and currently it is suggested as a relevant approach when caring for persons with chronic conditions.

Before discussing the benefits of empowering patients, it is important to review some of the conceptualizations of empowerment and its attributes to its implementation within healthcare. Overall, empowerment has been better understood by its absence (e.g., powerlessness, helplessness, oppression, or subordination), rather than by characteristics indicating its presence. Empowerment has been conceptualized by several experts. Gibson (1991) defines it as the “social process of recognizing, promoting, and enhancing people’s abilities to meet their own needs, solve their own problems, and mobilize necessary resources to take control of their own lives.” However, empowerment has also been considered as a way of “enabling people to recognize their strengths, abilities and personal power and includes power sharing, respect for self and others as part of the process” (Rodwell 1996).

The aforementioned definitions are only two examples of an array of conceptualizations available. The different definitions described in the literature share three main attributes associated with empowerment. First, it is a transactional concept because it involves having a relationship with others. Second, it is a dynamic and developmental concept, due to the changes in power and control that occur and because the individuals and the community’s potential are improved. Third, it is a democratic concept because it suggests a redistribution of power that should lead to social justice (Gibson 1991).

An important attribute of empowerment that adds another layer of complexity when defining this concept is that it can be understood as both a process and an outcome. This is due to the fact that its translation from Latin can be interpreted as “to be able” or “to enable.” Both translations imply different ways of interpreting this concept. When understood as a process, it has to do with the professional relinquishing power and assisting persons to find solutions for themselves. However, this construct does not imply that persons are entirely responsible for their problems, or that healthcare professionals should adopt a passive role in helping the person achieving change. As an outcome, empowerment refers to taking over control, become autonomous, having the capacity of identifying the particular situation the person is in, and the factors that influence the specific situation (consciousness raising) (Gibson 1991).

If we try to define empowerment within healthcare, there is also a large number of definitions (Box 2.1). In a literature review undertaken by Cerezo et al. (2016), several definitions of empowerment were identified, some of them defining it as a process and others as an outcome. For instance, Aujoulat et al. (2007a) consider patient empowerment as “a process of communication and education between professionals and patients, in which knowledge, values and power are shared, which is seen as a process of personal transformation." Fumagalli et al. cited in Cerezo et al. (2016) conceptualizes it as: "gaining the motivation and capacity (skills and knowledge) that patients can use to participate in decision-making, thus creating the opportunity to shift the balance of power in their relationship with health professionals." Both of these definitions exemplify patient empowerment as a process or an outcome, respectively. Furthermore, they include attributes of empowerment and contextualize it within the healthcare setting, by highlighting the role of the healthcare provider and some of the benefits obtained by the patients. Patient empowerment implies collaboration between the healthcare professional and the patient, whereas both parties have equal power and work together toward achieving common goals, which eventually enhance the patient's skills on self-care and autonomy.

Box 2.1 Frequently Found Definitions of Patient Empowerment in the Literature

Definition of patient empowerment	Author (s)
Process in which the person receives more control over decisions and actions that affect their own life and health	Nutbeam (1998)
Helping patients discover and develop the inherent capacity to be responsible for one's own life	Funnell and Anderson (2004)
It is the capacity shown by patients with chronic disease to accept their illness and to develop and use specific coping strategies in order to regain a sense of control	Bulsara et al. (2006)
An increase in the person's control over the determinants of his/her quality of life, through an increase in either health (e.g., self-confidence, self-esteem, self-efficacy, and autonomy), or knowledge (self-knowledge, consciousness raising, skills development, competence), or freedom (negative or positive)	Tengland (2008)
The degree of choice, influence, and control held by patients over treatment, the disease and their relationship with health professionals	Anderson and Funnell (2010)
Process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important	Castro et al. (2016)

Even when existing definitions of patient empowerment share its attributes, their origins are uncertain or can be misunderstood with other concepts (e.g., self-efficacy and autonomy). Nonetheless, Small et al. (2013) have proposed a definition of patient empowerment that emphasizes it, both as an outcome and a process, and takes into consideration the transactional and dynamic nature of the concept. According to them, patient empowerment is "an enabling process or outcome arising from communication with the healthcare professional and a mutual sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities and ability to achieve change over their condition" (Small et al. 2013, p. 2). Furthermore, based on in-depth qualitative work, they propose five dimensions that can facilitate the development of instruments to measure this construct:

- Knowledge and understanding: the level of disease-related knowledge that the patients need in order to feel in control of their health and their lives.
- Personal control: patients should have the capacity to handle their disease outside of the clinical practice. Personal control entails having personal strategies to stay in control and being able to continue with daily life.
- Identity: this entails how patients manage to keep their illness as a minor part of their lives and on their sense of self.
- Shared decision-making: feeling able to make personal decisions along with the healthcare professional and having the choice to participate in the decision-making process.
- Enabling others: the ability to share experiences and motivate others who are going through a similar situation (community empowerment). Moreover, by sharing with others they also have the opportunity to become organized and influence the healthcare system in situations that promote an unequal access to services or unmet needs (Úcar Martínez et al. 2017).

Patients who have a high level of empowerment demonstrate the five dimensions through their capacity of making personal decisions in relation to their health, managing their condition, being sensitive to others, and having sufficient knowledge to be in control. The aforementioned tasks reflect individuals who are engaged in managing their health in order to improve their quality of life and well-being.

2.2.2 Benefits of Improving Patient Empowerment

The literature suggests that outcomes of improved patient empowerment are related to three different changes: changes in self, changes in behaviors, and changes in relationships (Falk-Rafael 2001). Changes in self are associated with altering one's self-image or self-evaluation and can be interpreted as achieving higher levels of self-esteem, self-efficacy, and increased autonomy. Changes in behaviors are associated with increased knowledge and skills that result in informed decisions that eventually lead to healthier choices. Changes in relationships occur from patients becoming more involved in their care, and, therefore, being able to express their needs, concerns, and expectations during care planning (Falk-Rafael 2001).

Changes in self, behaviors, and relationships are important outcomes of a higher level of patient empowerment. However, these changes are the precursors to better patient-reported and clinical outcomes. These benefits take place by improving the individual skills for decision-making, disease management, and more responsibility for health behaviors. Indirect benefits can be achieved by involving peers or caregivers since they can provide assistance to the young person when needed and increase their knowledge based on an experience exchange (Oris et al. 2016). Additional indirect benefits are possible by having better healthcare access and services

(Wallerstein 2006). Studies assessing the effects of higher levels of patient empowerment in adults found improved quality of life, well-being, independence from healthcare, better adaptation to chronic illness and disease and pain management (Altshuler et al. 2016; Bravo et al. 2015; Cheng et al. 2018; Groen et al. 2015; Wallerstein 2006). Preliminary research has also found clinically significant changes and associations between patient empowerment and specific disease markers, such as HbA1c (Cheng et al. 2018; Wong et al. 2014).

Empowered individuals are also more assertive and feel more confidence to speak up for themselves, especially for those experiencing unfair treatment (Falk-Rafael 2001). They can control or change aspects in their environment that have negative effects over their health and lives, by gaining mastery over one's life (able to control work, family and society). Being empowered results in young adults who are more goal-oriented and purposeful, rather than being reactive to different situations. Indeed, they become proactive (Wallerstein 2006).

Knowledge is an important aspect of empowerment because it helps patients to make informed decisions and take responsibility for their choices. Empowered patients also develop critical thinking skills, and they are able to set their own goals. By having sufficient knowledge, patients are able to have better self-management skills and are capable of taking care of themselves with more confidence. Increased knowledge can be considered an outcome of patient empowerment, but it is also a prerequisite to achieving behavioral changes. However, such changes require intrinsic motivation that only results from an empowering process (Booker et al. 2008).

Empowerment is also associated with economic benefits for the healthcare system. A previous study suggested that empowering interventions are cost-effective (Johnsen et al. 2017). This could be associated with the idea that better-informed patients are capable of making healthier choices and have improving adherence, and hence resulting in reduced healthcare costs (Cerezo et al. 2016). However, further research assessing the benefits of patient empowerment in healthcare organizations is warranted.

2.3 Patient Empowerment During the Transition to Adulthood

Patient empowerment has been associated with improvements of both patient-reported and clinical outcomes. While these benefits might be sufficient to understand the need to empower young persons, in this section the need to empower young persons in light not only of their chronic condition but also of their developmental needs is explained.

2.3.1 Youth Empowerment and the Transition to Adulthood

Adolescence is an important period in life, involving a series of physical and psychosocial developmental changes, which will have an impact on life in the upcoming years and in adulthood. Successful achievement of the developmental tasks of the developmental stage of adolescence is essential for advancement to adulthood. Additionally, adolescence is considered as a preparatory stage for adulthood. This developmental stage and the eventual outcome of becoming an adult is a transition process. Meleis (2010) defines a transition as "a passage from one life phase, condition, or status to another, is a multiple concept embracing the elements of process, time span and perception." According to her, there are four types of transition: (1) developmental; (2) health/illness; (3) organizational; and (4) situational. Young persons with chronic conditions will simultaneously go through all four types of transitions since they are faced with becoming an adult, go from pediatric to adult care, change environments (e.g. college, work, and hospital), and include/remove other people from their lives (Acuña Mora et al. 2016; Fegran et al. 2014).

Going through adolescence is for some young persons a challenge. For adolescents with a chronic condition, it can pose additional challenges since they need to balance this developmental stage along with specific healthcare needs (Sawyer et al. 2007). The effect that a chronic condition has on the adolescent varies according to its severity, available resources, and individual characteristics. However, effects on well-being, education, growth, and family and peer relations are usually part of the challenges that these persons have to handle.

Three elements have been identified which facilitate a successful transition process to adulthood: (1) a healthcare system that ensures the implementation of an effective transition program; (2) a shift in staff attitudes toward more youth-friendly environments; and (3) a young person who works on achieving the competencies (e.g., achieving autonomy, better self-management, identity formation, balance family, and peer influence, adapt to intellectual abilities (Sansom-Daly et al. 2012)) associated with adulthood together with the feelings of empowerment (Viner 2008). This latter point suggests that empowerment can be a possible outcome for the transition process. Moreover, the process of empowerment starts with an awareness phase associated with a contextual change, which in this particular situation are the transitions to adulthood experienced by the young person.

Youth empowerment or adolescent empowerment has been understood as "achieving efficient growth by overcoming specific situations through the acquisition of competences" (Úcar Martínez et al. 2017). While this book is focused on adolescents with chronic conditions, the concept of empowerment has been associated with healthy peers as well. It is an approach by which young people gain authority and confidence to make decisions and change their lives and those of others within their social networks (Úcar Martínez et al. 2017). Hence, this construct has benefits beyond those related to a chronic condition and provides skills that are necessary in order to become a functioning adult.

2.3.2 Social Support and Empowerment During Transition

During transition, adolescents face significant changes in relationships. These changes involve significant others, whether they are nurses, physicians, relatives, or peers (Fegran et al. 2014). They are the social support that should help the adolescent become responsible and achieve independence. Additionally, recalling that patient empowerment is a transactional and dynamic concept, these relationships will have a considerable impact on the level of empowerment of the adolescent and on the other outcomes associated with this construct. Hence, an understanding of these relationships during transition is needed in order to have a clearer view of all the power roles and their effects on the level of empowerment of the young person.

Research on transition has found that parents of adolescents with chronic conditions are overly involved, which can inhibit the acquisition of the developmental tasks needed for adulthood (While et al. 2017). Research has also found a correlation between low parental involvement and better adolescent transition readiness and self-management (Stewart et al. 2017). Moreover, parental perceptions of their adolescent's skills have a considerable impact on their road toward autonomy (Heath et al. 2017). It is worth highlighting that parents of adolescents with chronic conditions experience their own transition in the process of letting their child take the role as primary caregiver. Parents can be facilitators as long as they are reminded of their role, as well as having their needs and concerns acknowledged and discussed. Otherwise, they could become reluctant to assist the adolescent and struggle when the young person demands autonomy.

The healthcare providers' role during transition is that of enablers and collaborators. They need to be aware of their own expectations for adolescent self-management, so the demands they place on the young person are not based on their own perceptions (Nguyen et al. 2016). Healthcare professionals also know that the role of the parents needs to evolve in order to encourage the adolescent to develop self-management skills. Healthcare workers' approach during clinic encounters need to change, such that they are talking to the adolescent directly, rather than to the parents.

Of course, parents should be kept involved and used as "safety net" for the adolescent. The responsibility shift can happen only gradually (Huang et al. 2011).

Research on peers during transition is not greatly available. However, adolescents have expressed that having other adolescents with a chronic illness around was crucial support during transition to adulthood (Fegran et al. 2014). Social support from peers also has been found to have positive effects on the results on psychological functioning (Oris et al. 2016).

2.3.3 Associations Between Patient Empowerment and Other Transition Outcomes

In transition literature, patient empowerment was initially mentioned as a way of increasing responsibility, accountability, and self-determination (Betz 1998). Since then, the literature has linked empowerment with a process that improves other transition outcomes, such as self-efficacy and as a way to achieve a more active role as an independent individual in the adult healthcare system (Freyer and Brugieres 2008; Rosen 2004). Moreover, a recent review identified "the need for young adults to become empowered to self-manage their own condition independently and confidently" as a recurrent theme in the transition literature (Burke et al. 2018). On the other hand, empowerment also has been understood as an outcome of transition, as proposed by Viner (2008). According to these authors, transition is a collaborative process that should focus on empowering young persons (Christie and Viner 2009). This was further supported by Hait et al. (2006), who considered the traits (i.e., outcomes) of a successful transition to be increased empowerment, self-efficacy, and self-determination.

Patient empowerment, when applied to the care of young persons with long-term conditions, may lead to increased autonomy and patient participation and a path by which persons with chronic conditions can become managers of their lives. These skills can help to turn around the negative outcomes that have been found in this group, such as lower health-related quality of life (While et al. 2017), lower levels of self-care (Sansom-Daly et al. 2016), higher probabilities of engaging in risky health behaviors (Surís et al. 2008), and lower levels of treatment adherence (Robertson et al. 2015). Additionally, adolescents with chronic conditions have reported fewer protective factors (i.e., conditions that lead to a better resistance of risk factors and negative health outcomes) (Nylander et al. 2014).

Youth empowerment is associated with individual developmental outcomes that include "increased self-efficacy and self-awareness as well as positive identity development, positive social bonding, awareness of organizational operations and interpersonal relations, and a sense of purpose" (Jennings et al. 2006). By incorporating empowerment in care, young persons can be assisted with developing important psychosocial skills (e.g., self-management and decision-making) that can be of use during the transition process and in adult life. Studies have found that during transition, adolescents can feel uncertain about their skills and have expressed their need for a better transition preparation that enables them to manage their disease better (Heery et al. 2015; Chen et al. 2017).

Empowerment entails a transfer of power and an increase of knowledge and skills (e.g., coping strategies, self-efficacy, sense of control, and illness acceptance) both of which are needed when becoming an adult and preparing to assume more responsibility. Empowered young persons show higher levels of self-esteem, awareness of one's strengths and needs, active participation in care, well-informed decision-making, developing relationships that provide social support and taking action toward improving one's life's conditions (St-Cyr Tribble et al. 2008). All these factors can be considered as indicators of empowerment.

Working toward increasing empowerment is a developmental process enabling the young person with increasing comfort, skills, and practice to ask questions, express opinions, and make informed decisions, which may eventually lead to improved outcomes as a result of the transition from adolescence to adulthood. Furthermore, feeling empowered allows them to drive their own transition and become aware of all the interacting factors that affect this process and possible ways to handle situations that arise during this period of change.

Studies found that adolescents with chronic diseases had low health literacy, which can have a negative impact on health behaviors and health outcomes

(Sansom-Daly et al. 2016; Heery et al. 2015). Empowered young persons are also informed young persons. Knowledgeable patients are then expected to develop healthier behaviors, improve health outcomes, and are capable of navigating the healthcare system better (Heery et al. 2015; Schulz and Nakamoto 2013). Such health effects, if maintained throughout the years, can have beneficial long-term effects throughout the life course. Furthermore, better knowledge has been associated with better transition readiness (Stewart et al. 2017).

2.4 The Road Toward Adolescent Empowerment

In the following section, some practical suggestions are discussed that will enable nurses and healthcare professionals to empower adolescents with chronic conditions. The information provided in this section can help nurses and other healthcare professionals understand their role in the empowerment process by questioning their own care philosophy, gain insight into certain considerations that are of relevance especially during the transition process, learn some relevant ethical standpoints and become acquainted with previous research on this subject.

2.4.1 Nurses' Role in Empowering Patients

In order to empower patients, nurses need to reflect upon their own assumptions and try to understand which philosophy of care they use and how this affects their interactions with patients (Anderson and Funnell 2005). As Gilbert (1995) states "for nursing practice to be empowering the nurse needs to be able to identify the discursive practices through which they as nurses are formed. For it is these, and their associated norms and values, which nurses then carry with them into their everyday roles."

For many nurses, empowering patients entails a paradigm shift. However, to provide adequate care, nurses need to be aware that adolescents are responsible for their own care and they should be involved in the decision-making process. This can be better understood when comparing the number of hours that a patient dedicates for self-care and the number of hours that are provided by healthcare professionals. The latter is considerably less. In addition, while nurses and healthcare professionals have extensive knowledge pertaining to the provision of specialized care, adolescents have varying levels of knowledge of and coping with their long-term chronic conditions. This makes them experts as well. Thus, ideally, the power in a nurse–patient relationship needs to be balanced.

Achieving such a balance is not an easy task. In order to empower adolescents, nurses need to understand and reflect on several assumptions. First, health belongs to the individual. Hence, patients are responsible for their own health. Second, every adolescent has the capacity for growth and self-determination. This means that while they can make decisions by themselves, they also need information and guidance during the process. Third, nurses can promote a sense of control in adolescents, but only they can empower themselves. Fourth, nurses need to surrender the need for control and value adolescents' participation. Fifth, cooperation is essential in the process of empowering patients, which requires mutual respect and communication. Lastly, trust needs to be built (Gibson 1991).

Anderson and Funnell (2005) have suggested a series of questions that nurses can ask themselves in order to determine/understand which philosophy of care guides their practice. Among those questions are as follows: Do I have the right to expect patients to have a different judgment? Am I often trying to persuade patients to follow my advice? Does the non-compliance of patients affects my effectiveness? and Do I feel frustrated when patients do not follow a care plan?

"The empowerment approach requires change from feeling responsible for patients to feeling responsible to patients" (Anderson and Funnell 2005). This means that nurses are collaborators by providing the patients with information and support enabling them to identify their problems and the options to solve them. In order for the nurse and the patient to collaborate in care and achieve patient empowerment, a person-centered approach is a prerequisite. Indeed, it is suggested that the overall purpose of person-centered care is to empower and emancipate the person, by facilitating the person's agency and nurses being in less control (El-Alti et al. 2017).

Achieving a person-centered care philosophy entails three relevant stages (Ekman et al. 2011). First, establishing a partnership with the patient by becoming familiar with their personal story. This allows identifying barriers and resources to care that are relevant or have an effect on the person's health. Second, developing a partnership through constant communication. It is important that the person feels comfortable with the nurse, so he/she can feel free to share and discuss without the risk of being judged. The partnership allows building common trust and establishing goals along with the person. Third, safeguarding the partnership by documenting decisions made is needed. Any care plan agreed upon between the nurse and the person is meant to be documented, and also revised with time. This approach allows determining if there is the need to modify or add goals according to the improvements made and the resources available (Ekman et al. 2011).

Nurses who work toward empowering their patients are able to facilitate individual learning that is appealing to the adolescent. This is achieved by implementing various learning techniques and use of different resources (e.g., leaflets, videos, computer programs, mobile devices, mobile apps, web sites, and group meetings). By doing so, they meet the needs of the patients by considering the patients' knowledge, attitudes, and values. It is important to remember that as Freire used to work with his students, the nurse should aim to facilitate the critical thinking of the patients so that they can be assisted as needed to identify their skills, resources, and possible solutions, and not solely focused on improving compliance (Aujoulat et al. 2007b).

Nurses can establish an empowering caring relationship by dedicating enough time to work with the person. They need to create a positive environment, by demonstrating interest in the person's opinions and not present themselves as judgmental. It is important to realize that learning to become autonomous or even more involved in care is a process. Therefore, the adolescent needs time to learn. This is reinforced by what St-Cyr Tribble et al. (2008) states “empowerment is a long-term process of change… usually the process starts with an awareness phase and ends with an action phase, be it individual or collective in nature. The awareness phase is often generated by a crisis or contextual change.”

While empowering patients, it is important to respect the patients’ self-determination and autonomy. This can also be achieved by nurses using motivational interviewing as a tool to initiate behavior change. This technique is a counseling approach wherein the role of the healthcare professional is to help the patient become aware of the decision-making implications of whether to undertake a change (Lundahl et al. 2010). As stated by McCarley (2009) by using motivational interviewing, it is possible to engage patients and empower them, which ultimately leads to patients achieving their personal goals. Through motivational interviewing, the nurse can express empathy for the patient’s situation, identify discrepancies between current behavior and established goals, work around resistance and support self-efficacy (McCarley 2009).

Enabling adolescents to becoming empowered during their transition to adulthood is a bidirectional process. If nurses want to empower patients, then there is an additional aspect that has to be considered. The literature suggests that nurses are only able of empowering patients when they work within an organization that supports them to feel in control as well with their nursing practice (Gibson 1991). This particular point is associated with a wider view of empowerment, which relates to the social and political contexts. As Gilbert (1995) mentions, “nursing, nursing knowledge and nurses themselves have to be aware that they, and the environment in which they practice, are as much the product of power as are those they claim to support.” Studies that have assessed organizational empowerment found that it leads to nurses having a higher psychological empowerment Kuokkanen (2002). It is evident that power structures outside of the nurse–patient relationship will have an impact on the nurse’s intervention approach (see Fig. 2.1).

Research on nurses’ empowerment has highlighted that the benefits of empowering nurses are higher job satisfaction, feeling respected and having better professional relations and mental and physical health. Empowered nurses are capable of assuming responsibility, influence the development and implementation of care plans, and contribute to organizational decisions (Casey et al. 2010). The benefits of empowering nurses extend to the patients since research has found patients have a higher satisfaction with care (Copanitsanou et al. 2017). This has been theoretically associated with the implementation of patient empowering strategies that lead to higher patient empowerment and better patient outcomes (Spence Laschinger et al. 2010).

2.4.2 Transition and Patient Empowerment: Fundamental Considerations

As it has been mentioned previously, patient empowerment is associated with selected core competencies. Before trying to empower young persons with chronic conditions, it is important to examine certain considerations that are of relevance especially during the transition process.

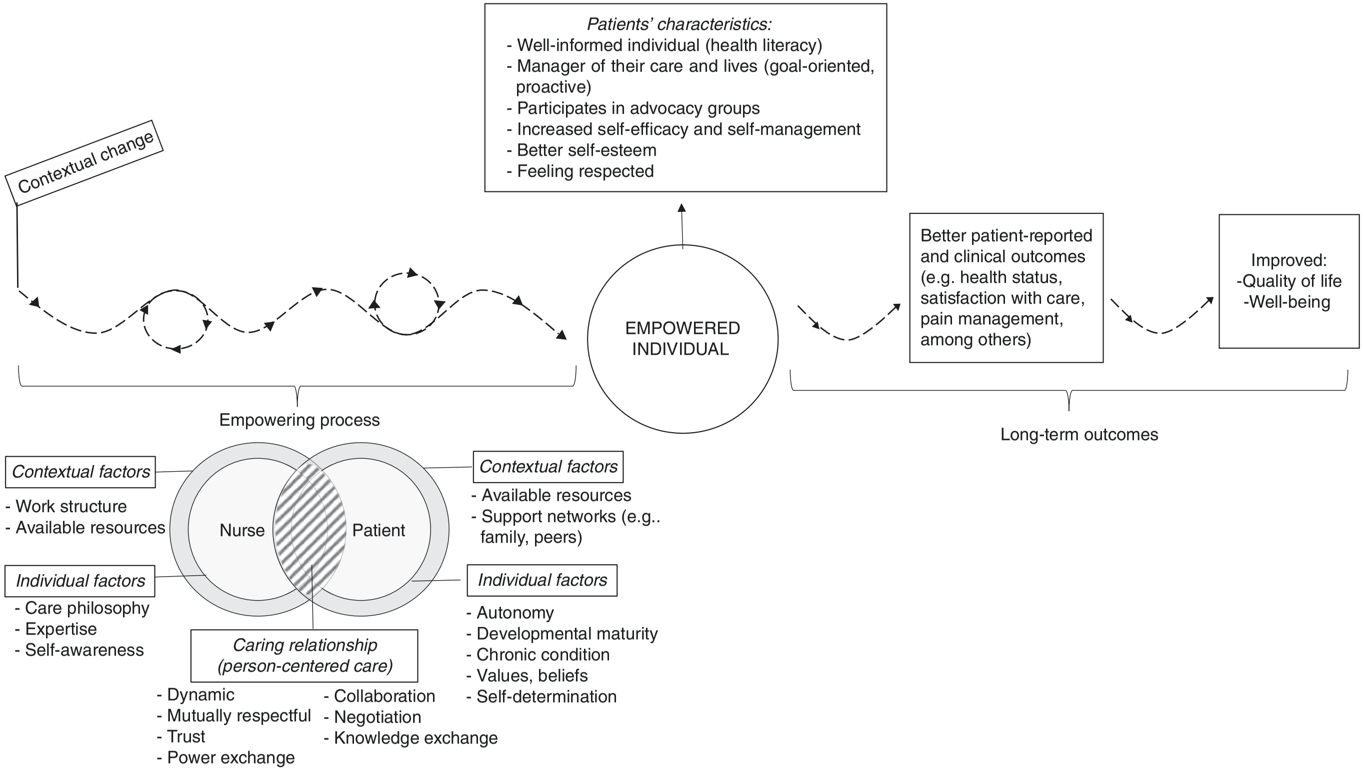

Fig. 2.1 Empowerment model: understanding empowerment as a process and outcome

First and most importantly, incorporating patient empowerment into practice requires an understanding of the concept of patient empowerment and its implications. This understanding entails being aware of the different conceptualizations available, the difference between empowerment and other constructs (e.g., self-management, self-efficacy, and sense of coherence) and its core characteristics. Across the literature, there are a number of issues regarding the use of patient empowerment. For instance, studies that have attempted to increase patient empowerment, instead of measuring such construct, decide to measure associated constructs that do not capture the entire spectrum of effects that empowerment has on a person. Self-efficacy is one of the concepts that is commonly considered as a synonym of patient empowerment. This issue may be associated with the array of conceptualizations of the construct (Cerezo et al. 2016), due to a lack of thorough assessment that needs to be done in order to comprehend how different constructs relate and differentiate from each other.

Second, in the context of adolescents with chronic conditions, parents are usually involved in their care. Therefore, any empowering intervention should take into consideration the different power relations involving the young person (Viklund et al. 2007). Ideally, parents are meant to relinquish the responsibility they have over the young person's condition and life and let the young person assume a more participatory role. This responsibility shift is not easy and parents as well as adolescents can struggle with it. For the parents, the balance between overprotection and assigning more responsibility carries moments of anxiety and uncertainty (Akre and Suris 2014). Nurses are in a position in which they can guide the parents in this power exchange process so that parental involvement leads to facilitating the young persons' decision-making and promote their engagement in care.

Third, most of the focus on empowerment so far has been on how to accomplish empowering relationships among the nurse, parents, adult authority figures, and the young person. However, there is an additional aspect to consider when discussing empowerment, which are the interactions with peers. As Freire pointed out, an important aspect of empowerment is having the opportunity to interact with peers in order to identify strengths, barriers, and solutions together (Wallerstein 2006). Young persons should have the opportunity to share their experiences with peers since this allows them to enhance their knowledge, life skills, and broaden their perspective (Bartlett and Coulson 2011).

Fourth, the nurses' level of expertise impacts the type of strategies they implement to empower young persons. As stated by Falk-Rafael (2001), "the nurse's expertise also was essential to increasing clients' knowledge and skills so they could make more informed choices and take more effective actions in pursuing their health goals. Nurses reported that they used multiple strategies to teach, from providing oral and written information to role modeling and providing situations in which clients could practice new skills safely." Therefore, nurses need to have sufficient knowledge about different teaching and learning techniques that are developmentally appropriate to foster empowerment for young persons.

Fifth, any intervention should always make use of information channels that are relevant for the intended group. When working with young persons, nurses can access technology, such as social networks, mobile applications, or online information resources. A previous study highlighted the importance of healthcare professionals becoming more "net friendly" and identified empowering outcomes of online support groups, concluding this tool can help achieve a more balance power relationship between the healthcare provider and the patient (Bartlett and Coulson 2011).

Moreover, any intervention directed to young persons should follow the quality of care youth friendly framework established by the World Health Organization (World Health Organization, Department of Maternal Newborn, Child and Adolescent Health 2012), meaning, these services need to be acceptable, equitable, appropriate, and effective. This framework of care ensures health services are meeting the needs of this group and making a positive impact on their health (World Health Organization, Department of Maternal Newborn, Child and Adolescent Health 2012).

Sixth and lastly, throughout the chapter, in several sections it has been mentioned that empowerment aims at making the adolescent the manager of his/her health. However, this is not possible to achieve if the person lacks knowledge and skills that build upon the prerequisite competencies the adolescent has achieved. Any type of empowering strategy should always involve increasing the patient's knowledge. This involves knowledge related to not only their chronic condition but also their developmental competencies, their self-awareness about themselves as individuals (e.g., skills and weaknesses), and about the means available to achieve change (Tengland 2008).

2.4.3 Ethical Issues Associated with Patient Empowerment

When evaluating ethical aspects surrounding empowerment, two questions deserve to be discussed: "How unethical is it not to empower young persons?" and "Should persons who refuse to be empower go through this process?"

As Griffiths et al. (2007) have stated, "it is unethical for patients not to be involved in decisions about their health and, by extension, for the public not to be involved in how care is organized." Young persons' participation assures that the care provided is based on their needs, resources, understandings, and barriers. Otherwise, the nurse will be assuming what is "best" for the young persons, which is not based on their needs, interests, and preferences, that fall short of their intended goals, without considering their health meanings and not achieving positive and relevant outcomes (Spencer 2014).

Even when healthcare providers may consider to include the young person in the care process, they may be imposing normative ideas of what young person needs to do. This is understood as "impositional empowerment." As Spencer (2014) states, impositional empowerment "downplays evidence of young people's power to act according to their own understandings of health, which are often different to the more top-down, imposed meanings found in official health discourses."

The second question takes the stand from the young person's perspective. So far, it has been assumed that young persons want to be empowered. However, there might be cases in which it is not possible to empower young persons because they refuse to or in certain circumstances this is not feasible. It is not possible to promote empowerment if all parties involved (i.e., nurse, young person, and parents) are not willing and engaged in the process. The responsibility shift is an iterative process and young persons need to feel confident in their skills to care for themselves. In some cases, patient' perceptions of personal control and responsibility are influenced by environmental aspects (e.g., political liberties and access to services) or personal characteristics (e.g., cultural beliefs, educational level, religion, developmental status, and type of chronic condition) (Fegran et al. 2014). These perceptions can lead the adolescent to have a negative view on empowerment. Moreover, the adolescents' lack of desire to become autonomous can be the result of a lack of preparation for self-care, overprotective parenting styles or healthcare providers who do not assist the young person in becoming autonomous (Lugasi et al. 2011).

The nurse has to reconsider the best approach toward involving these young persons in care. "A helping professional's insistence on her or his goal, when it differs from the client's, would not facilitate the client's empowerment process" (Cattaneo and Chapman 2010). The aforementioned quote highlights the need for collaboration from the young person in order to empower them. Their collaboration could be limited by inadequate knowledge about their long-term conditions or have misunderstandings about their capacities. This could be the result of having their parents or healthcare providers keeping information from them as a way of protecting them or as a result of their parents' child-rearing practices. However, adolescents' participation needs to be considered a priority since this is their right (Convention on the Rights of the Child 1989).

2.4.4 Transition Programs Aiming to Empower Adolescents

To date, few experimental studies have developed and evaluated transition programs addressing patient empowerment. One study from Germany assessed the effect of a generic transition-oriented patient education program on adolescent's health service participation and quality of life (Schmidt et al. 2016). The intervention was developed following the conceptualization of empowerment proposed by Zimmermann (1995), which entails interpersonal (capability to influence a given context), interactional (understanding how the system works), and behavioral components (exerting control) (Schmidt et al. 2016; Zimmerman 1995).

The intervention was based on a qualitative study finding that involved adolescents with chronic conditions (Bomba et al. 2017). The program included eight intervention modules: (1) let us go; (2) transfer to adult medicine; (3) the new doctor–patient relationship; (4) health insurance and related topics; (5) future and employment; (6) people around me; (7) my resources; and (8) close (i.e., setting personal goals and experience exchange) (Schmidt et al. 2016). The curriculum of the modules was based on current guidelines and recommendations of methods and strategies frequently used in empowerment-based educational interventions. The content was largely generic, but some of the modules included disease-specific aspects.

In order to assess the effectiveness of the modules, the study included patients with cystic fibrosis, Type 1 diabetes mellitus, and inflammatory bowel disease from 12 outpatient clinics and rehabilitation centers. Patients in the clinics followed the modules or usual care. The modules were implemented in 2-day workshops in groups with a minimum of four participants and a duration of 60–90 min. The workshop facilitators were a psychologist and a pediatrician, and in some occasions a young adult with a chronic condition and a physician from adult healthcare were included.

During the implementation of the modules, various interactive group methods and learning processes were used (not specified in the paper). The primary outcomes in this study were health-related transition competence, self-efficacy, patient activation, satisfaction with healthcare, and quality of life. This study found significant improvements in transition competence and self-efficacy of patients with type I diabetes mellitus and inflammatory bowel disease (Schmidt et al. 2016).

This study provides relevant evidence for a broad range of chronic conditions and describes an intervention that was developed based on the expressed needs of a group of young persons with chronic conditions. However, there are some limitations to it. First, it is unclear how the modules relate to Zimmerman's understanding of empowerment. It can be interpreted from the article that empowerment is understood as a process rather than an outcome and therefore associated constructs are measured (e.g., self-efficacy). Nonetheless, further information is needed in order to understand the connection between the theoretical foundation and the practical strategies of the intervention. Second, a more detailed description of the intervention components is needed in order to replicate the intervention. Third, there were no nurses involved in the development or evaluation of the intervention.

Another study aimed to evaluate a person-centered transition program for young persons with congenital heart disease in Sweden (Acuña Mora et al. 2017). The transition program was developed based on a series of qualitative and quantitative studies involving young persons with congenital heart defects, their parents, and healthcare providers (Burström et al. 2015, 2017, 2018, 2019; Bratt et al. 2018; Sparud-Lundin et al. 2017; Asp et al. 2015). These preparatory studies assessed the needs of these groups, the current state of transition practices, as well as possible areas of improvement.

The intervention was developed by nurses, and it comprised eight key components: (1) transition coordinator; (2) written person-centered transition plan; (3) provision of information and education about the condition, treatment, health behaviors, education, job, and relationships; (4) high availability by telephone and email; (5) information about and contact with the Grown-Up Congenital Heart Disease (GUCH) clinic; (6) guidance of parents; (7) meeting with peers; and (8) actual transfer to adult care (Acuña Mora et al. 2017).

The transition coordinator was a nurse specialist who received training in adolescent health, person-centered care, and adolescent health interview techniques. This transition coordinator was responsible for the implementation of the different components. Throughout the program, the transition coordinator followed a person-centered care philosophy (as explained in the previous section). Young persons met the transition coordinator on three occasions. During these meetings, they discussed the young persons' knowledge needs, available resources, set goals for the upcoming meetings, and evaluated the information received (Further information on the strategies used by the transition coordinator are provided under Sect. 5.1).

The primary outcome of this study was patient empowerment. Secondary outcomes included disease-related knowledge, health behaviors, patient-reported health, quality of life, and transition readiness. At the moment, data collection and analysis for this study was ongoing, so preliminary results were not available.

Based upon this second intervention, certain aspects can be mentioned. First, a thorough needs assessment was done in order to develop the intervention. Second, whereas the intervention is being conducted with young persons with congenital heart defects, the authors have stated that the intervention components are generic, and it would be possible to implement it in other groups. Indeed, several of these components have been implemented and tested in young persons with juvenile idiopathic arthritis (Hilderson et al. 2013). However, the effectiveness of the transition program to increase the level of empowerment has to be tested first. Third, parents are included in the intervention, which highlights the role they have in the transition process.

2.4.5 Empowerment as an Outcome: Available Measurements

To date, there are several instruments available to measure patient empowerment, among them are the Healthcare Empowerment Inventory, the Diabetes Empowerment Scale, and the Patient Empowerment in Long-Term Conditions instrument (Barr et al. 2015). In 2015, Barr et al. (2015) undertook a systematic review that aimed at identifying available instruments that measured patient empowerment. At that time, they included 19 instruments, of which six were generic, 13 disease or specialty-specific (Barr et al. 2015). From the review, they concluded that there was limited evidence that supports the validity and reliability of available tools. Furthermore, they highlighted that existing instruments have several shortcomings: many of them lack a theoretical foundation; some are disease- and context-specific instruments; none have been developed for young persons; and most of the instruments have inadequate psychometric properties (Barr et al. 2015).

As mentioned before, one of the most common shortcomings of available measurements is the lack of a clear theoretical foundation. Since there is no consensus on a definition of empowerment, it is not surprising to find that different measurements use different definitions. Furthermore, there are instruments that do not provide a clear background on which definition and dimensions/attributes are used when developed. In section 1, the definition provided by Small et al. (2013) can be considered as one of the most complete conceptualizations of patient empowerment. Their definition is grounded on a review of the literature, and the dimensions are based on a qualitative study that involved adults with chronic conditions. This definition and the proposed dimensions have been used as the basis for the development of two instruments.

The first instrument was developed by Small et al., named *Patient Empowerment in Long-Term Conditions* (Small et al. 2013). It included 51 items across the five dimensions. The scale's structure was measured through exploratory factor analysis, reliability was assessed with Cronbach's alpha, and construct validity was evaluated by comparing to other scales that measure self-efficacy, quality of care, patient enablement, among others. Results from the aforementioned psychometric properties did not support the five-dimension structure, only three factors were identified. From the results, it was concluded that further instrument refinement was needed in order to use the scale in longitudinal or randomized controlled trials (Small et al. 2013). This scale is currently undergoing additional psychometric testing by a group of researchers who have translated the instrument to Spanish (Garcimartin et al. 2017).

The second instrument *Gothenburg Young Persons Empowerment Scale* (GYPES) was developed by Acuna Mora et al. (2018). This instrument is specifically developed to be used in young persons with chronic conditions. GYPES comprises 15 items (three items per dimension) that are measured on a five-point Likert scale (strongly agree to strongly disagree). GYPES was developed following the definition and dimensions proposed by Small et al. (2013). The scale produces an overall score, but it also provides a score for each dimension, with a higher score denoting a higher level of empowerment (Acuña Mora et al. 2018).

GYPES was evaluated in three consecutive studies that involved young persons with congenital heart defects and type I diabetes. The results from these studies provide preliminary evidence on the validity and reliability of GYPES. The scale can be used in descriptive studies to depict the level of empowerment or in intervention studies that evaluate the impact of healthcare interventions aiming to increase patient empowerment (Acuña Mora et al. 2018). So far, the scale is available in three languages: Swedish, English, and Dutch.

2.5 Application to Practice, Education, and Research

2.5.1 Application to Practice

The previous section included practical suggestions regarding what nurses and other healthcare professionals need to consider when aiming to empower adolescents. In this section, we provide clearer strategies based on the transition program designed by Acuña Mora et al. (2017). In that study, the transition coordinator used different strategies, such as the following:

- Identifying suitable learning techniques for the young person. Based upon learning needs, the type of resources needed were selected (e.g., heart anatomic model, pictures, videos, and pamphlets), in order to provide relevant information.
- Supporting the young persons in identifying strengths, resources, challenges, and barriers by utilizing HEADSS psychosocial interviewing (Home, Education, Activities, Drugs, Sexuality, Suicide). HEADSS assessment identifies areas of

need by enabling the healthcare providers to conduct a developmentally appropriate psychosocial history (Cohen et al. 1991).
- Encouraging the young person to actively participate in discussions and assume more responsibility in care, by using the shared management model (Kieckhefer and Trahms 2000).
- Assisting the young person to establish care goals that are documented in a transition plan and evaluated continuously during the transition process.
- Assessing the young person's understanding of information provided by asking them to provide a summary of the information they received.
- Promoting communication skills and sharing/learning coping strategies by planning activities wherein the young persons can share experiences related to their condition with others.
- Discussing with the parents their concerns about the responsibility shift and the eventual transfer to adult care.
- Exploring the parents' understanding on how to support the young person and provide them with examples on how to become a support in the young persons' developmental process.

Overall, as stated by St-Cyr Tribble et al. (2008) any empowering intervention should comprise five key aspects: (1) develop and maintain a therapeutic relationship; (2) create a care plan based on the young person's point of view and strengths; (3) encourage and support the decision-making process; (4) help broaden possibilities; and (5) facilitate the learning process.

2.5.2 Application to Education

In order to empower young persons during the transition to adulthood, nurses need to be familiarized with different theoretical aspects, such as patient empowerment and person-centered care. Indeed, if we intend to empower adolescents and young adults, then it is important to comprehend the implications of this construct and what are the responsibilities of the nurses. Although patient empowerment is associated with a balance of power, this interpretation can lead to misconceptions about the role and responsibilities nurses have in care, and may create resistance toward empowering patients. Nonetheless, it is important to acknowledge that part of the nurses' responsibilities is to help adolescents develop skills that can help them to cope with their illness and their daily life and eventually become autonomous. To achieve such goals during training, nurses need to become familiarized with different pedagogical techniques, motivational interviewing, and youth friendly approaches.

Provision of information, such as giving the young person a brochure, is not sufficient since this does not ensure they have understood the information received. If adolescents do not understand the information received, they cannot apply it to their health behaviors (healthy literacy) and achieve better health outcomes (Fleary et al. 2018). Familiarity with different pedagogical approaches and learning techniques enables adolescents to receive information that is person-centered that has a more measurable effect on their daily lives. Information provided based upon different learning techniques and that is developmentally appropriate increases the probability that the young person will understand the information and be able to use it in a better way.

Additionally, since a person-centered approach is seen as the ideal way to empower our patients, a deeper understanding of the implications of this philosophy and its application in daily practice is necessary. Training in person-centered care should involve different ways of planning and implementing person-centered care and approaches toward establishing a partnership and effective care plans, among others.

2.5.3 Application to Research

The aspects of the transition program described in Sect. 5.1 is currently being evaluated in young persons with congenital heart defects and Type 1 diabetes. The results of this study and process evaluation will provide information on the effectiveness of the transition program and the components that were effective. If shown to be effective, further research could replicate the model to evaluate its transferability to other chronic conditions.

In order to assist young persons in dealing with their chronic conditions, to help them preparing to adulthood and adult care, transitional care research should focus on identifying the clinical and developmental needs of young people. Most research on transition has used disease-specific measures, as well as measures that focus on transition readiness, quality of life, uninterrupted access of care, follow-up, and healthcare utilization (Campbell et al. 2016; Crowley et al. 2011). However, few of these outcomes address developmental and psychosocial needs associated with the transition to adulthood. Moreover, it would be of interest to assess long-term clinical outcomes associated with patient empowerment. Indeed, empowerment can be seen as a proximal or “intermediate” outcome that is individualized. If we are able to identify long-term outcomes in young persons with chronic conditions, it could help us to tailor transition programs even more.

Assessing the perspectives of healthcare providers who facilitate the empowerment of young persons would also be of interest. It has been suggested that the healthcare providers’ own level of empowerment could affect the patient–healthcare provider relationship. Hence, evaluating the work environment of those responsible for the transition process could be a way of indirectly increasing the level of empowerment of young persons.

2.6 Key Advice/Points

- Goal setting and the shared management model are some of the strategies that nurses can use to empower young persons.

- Nurses need to feel empowered themselves in order to promote young persons to have a more active role with the management of their long-term conditions.
- The parents' role needs to be acknowledged and they have to be supported in relinquishing responsibility and assuming a supportive role.
- Knowledge and skills are essential components of any empowering intervention, without which young persons cannot assume more responsibility.
- Person-centered care is a philosophy that places the patients and their lived experiences in the center of the care process.

2.7 Conclusion

Evidence on patient empowerment shows it is an outcome leading to actively engaged patients in the care process. Moreover, it has been associated with relevant clinical outcomes, which entails that its effects can have long-term benefits in health. During transition, empowerment assists with the acquisition of developmental competencies that young persons need to manage adulthood and feel capable of navigating the adult healthcare system. These achievements facilitate young persons with developing self-management skills, autonomy, and self-awareness. These skills eventually may lead to behavioral changes that ultimately are expected to have effects on clinical outcomes and developmental outcomes of adulthood.

In order to achieve patient empowerment, nurses need to be aware of the empowerment process. This entails nurses being acquainted with the attributes and assumptions associated with this construct. Nurses need to be aware of their care philosophy, the role they assign patients during care and their teaching and learning capacities. In the process of empowering young persons, it is important to remember that this is an iterative process, which means that young persons may go back and forth, while adjusting to their new role and tasks that are required from them. Furthermore, throughout the transition process, parents have a fundamental role and their own specific needs should be acknowledged in order to facilitate the empowerment of their adolescents.

2.8 Useful Resources

- https://www.canchild.ca/en/research-in-practice/transitions
  - Research on the transition of adolescents with disabilities can be found in this website.
- https://www.gottransition.org/
  - This website is a collaboration between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. They aim to improve transition through the use of innovative strategies for health professionals and youth and families. Among the resources found here are the six core elements of healthcare transition and associated tools with every element.

- http://www.sickkids.ca/Good2Go/index.html
  - Different transition tools such as information sheets and other transition-related websites can be found here. One of the tools describe in the website includes the “My Health 3 Sentence Summary” that provides practical approaches that adolescents can use during transition.
- http://www.stepstones-project.org/en/
  - Information regarding the STEPSTONES (Swedish Transition Effects Project Supporting Teeangers with chrONic mEdical conditionS) project is provided in this website. This project aims to develop and evaluate the effectiveness of transition programs to support teenagers with medical conditions in their transition to adulthood, and their transfer to adult care in Sweden.
- http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx
  - This website describes the “Ready Steady Go” transition program implemented in some hospitals in the United Kingdom.

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